HOME-BASED AND LONG-TERM CARE

Home Care Issues at the Approach of the 21st Century from a World Health Organization Perspective

An Annotated Bibliography
Home Care Issues at the Approach of the 21\textsuperscript{st} Century from a World Health Organization Perspective

- A LITERATURE REVIEW

WORLD HEALTH ORGANIZATION
1999
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Preface:

The next two decades will see dramatic changes in the health needs of the world’s populations with non-communicable diseases as the leading causes of disability. Increases in the older population by up to 300% are expected in many developing countries. In addition, HIV/AIDS, TB and lymphatic filariasis continue to be a major cause of disability (and death). Everywhere there is a steep increase in the need for long-term care.

These changes require a very different approach to health sector policy and health care services since a disease-specific approach, alone, is no longer appropriate. The one common denominator resulting from these demographic and epidemiological changes is functional dependency and the growing need for care to manage everyday living. Rising health care use and spiralling costs have everywhere led to a trend and the necessity to treat patients in the home. Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person’s maximal level of comfort, function and health including care toward a dignified death. Home care services can be classified into preventive-promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories. This paper primarily addresses long-term home care.

In all WHO regions there is strong interest in this subject. But while the need for home care is growing rapidly everywhere, so is the danger that the label “home care” will be used to forego public and government responsibility with dire consequences for the quality of care. In particular there needs to be concern for the health and lives of women who are the main caregivers not only for their own families and communities, but also in the formal health sector. Well-managed and supported home care, however, can improve the quality of life of patients of all ages and caregivers alike. An optimal balance between family and public responsibility must be sought.

Home and family caregiving has implications for many sectors (e.g., education, labour, transport, etc.) and is an integral part of the health and social care systems pertinent to all age groups. It must be integrated with other public health, clinical and social care. Concerns of equity, quality, and sustainability and a life-course approach must guide its development. All aspects of home care (policy, financing, legislation/regulation, its human and physical resources, continuity and support of care, etc.) need to be addressed. A major concern is women’s access to and control of the resources needed to assume this responsibility.

The objective of the World Health Organization is to put this important area on the agenda of its Member States and to raise the awareness of civil society. As a first step, we have tried to take stock of the available knowledge and experience in home-based and long-term care by reviewing the published literature, following an old Maori saying “Move into the future backwards using the strengths of the past to guide us forward”.

This review is the result of a series of electronic literature and citation searches accessing 35 major bibliographic databases and over 1,300 journals,
monographs, books and government documents in 12 languages. These originating searches yielded a total or 20,000 potential sources. As the search strategy was narrowed and became increasingly targeted, it was possible to eliminate duplicates, including those sources in multiple publications and in multiple languages. Over 8,000 were eliminated by removing all the long-term care citations that addressed institutional care only. The primary search term throughout this entire process was home care, which was initially placed in the broadest context possible and then narrowed in stages to yield the final product. Abstract reading eliminated another 7,000 that were site or jurisdiction-specific; that is, those that would not be transferable to other locations. Inspection of about 3,000 more abstracts enabled removal of other sources that might be transferable within the developed world, but that held no promise of being adapted to the developing world or to rural areas, in general.\footnote{This reference is used to identify programs that could not be applied in the aboriginal communities in isolated northern areas of Manitoba.} A search of articles led to the elimination of another 1,500 that were similarly lacking in transferability. In the final version, 350 sources were retained.

The literature review is organized under six broad areas. These are home care policy, home care services, policy and service issues related to formal and informal caregiving, home care in cases of specific diseases, home care staffing and home care as a component of some other part of the health care system. The detailed Table of Contents includes the six section and multiple subsection headings to assist the reader in finding information.

As is the case with any bibliographic exercise, there are many sources that might be placed in multiple groupings. Every attempt has been made to restrict entries to only one group, however, a few sources will be found in more than one group. On the other hand, no cross-referencing has been attempted, as this often makes the product unnecessarily complex and lengthy.

\textbf{Acknowledgements:}

As with any major undertaking, this project would not have been completed without the assistance of many people. First and foremost, I would like to acknowledge Betty Havens without whose vast knowledge and expertise, none of this would have been possible. Betty Havens has worked in the area of home-based and long-term care over the last 30 years in Canada focusing on policy and service development as well as on research. Betty Havens was the first woman ever to chair a World Health Organization Expert Committee in 1988, (Expert Committee on Ageing). She also has broad international experience and many of us from developing and developed countries alike, know her as an inspiring mentor, teacher, researcher, advocate and friend.

In preparing this work, Betty Havens, as the author, had the assistance of many people. We want to acknowledge their contribution to the project.

Bill Poluha, librarian at the Neil John Maclean Health Sciences Library of the University of Manitoba was instrumental in all aspects of searching the relevant
electronic databases. His assistance was invaluable in securing access to Embase and the Web of Sciences which substantially increased OUR ability to include non-English language sources and sources from less traditional journals. A wide variety of other library staff at Neil John Maclean and Dafoe libraries also assisted in the process of securing text materials.

Dr Janice Keefe from Mount Saint Vincent University has shared her work on caregiver compensation, including substantially reducing the time spent searching for the relevant non-Canadian literature. She gave unstintingly of her time and expertise in accessing these sources.

David Moher from Children’s Hospital of Eastern Ontario made later searches with Embase and the Web of Science much more efficient and without his work, the literature related to HIV/AIDS would not have been as complete.

I would also like to acknowledge Ms Linda Burgess for her painstaking work of language editing and formatting this document and the final preparation for publication and distribution.

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SYNOPSIS
Home-Based and Long-Term Care Issues

Introduction:

Home care is generally envisioned as care provided in the home that has one of three objectives: to substitute for acute care hospitalization; to substitute for long-term care institutionalization; or to prevent the need for institutionalization and maintain individuals in their own home and community. The overall goal is to provide high quality, appropriate and cost-effective care to individuals that will enable them to maintain their independence and the highest quality of life. Virtually all studies have found home care to be associated with higher quality of life, and some studies have also found it to be cost-effective. Cost-effectiveness has been found most frequently in home care that substitutes for long-term care institutionalization. Cost-effectiveness is more difficult to demonstrate in home-care programs that maintain individuals in their own homes when they need care but are not candidates for institutional care. In this paper, the major emphasis is on home care that is designed to enable recipients to live in their familiar communities, in the company of their families and friends, and to continue to enjoy the best possible quality in their lives.

Several issues must be resolved if home care is to become, or continue to be, a viable community care program. Two of these issues are closely inter-related; they are the potential for exhaustion or “burnout” of caregivers in the informal sector and the potential for burnout of formal caregivers.

The available evidence suggests that families and informal network members want to continue to care for their members who require care. Further, persons who require care want to remain in their own homes and communities.

However, the level of care required by home care users has increased and is likely to continue to do so in the foreseeable future; therefore, both the amount and intensity of care provided by informal and formal caregivers are also increasing. The question is whether caregivers can continue to provide the care required without themselves becoming consumers of health care. There is little point in straining the capacity of caregivers to such an extent that we wind up with two users of the health system rather than one (Haug, 1985). This makes provision of support to informal caregivers by both the formal and informal sectors even more important. However it should also serve as a warning that the stress of caregiving by those in the formal sector can become so great that they become ineffective or unable to continue to perform their jobs. Thus, those in formal caregiving roles also require support to continue providing high quality care.

While many formal home care service delivery systems provide some relief and support to informal caregivers, the amount, frequency and duration of this
support vary widely. When support to the informal caregiver is not both an explicit goal and a legitimate function of the formal system, this support often begins too late and is too little to delay or prevent caregiver burnout.

Support to formal caregivers varies even more than with informal caregivers. Many service deliverers provide no support at all to their employees. The idea that those employed in the long term home care sector might require periodic relief leaves has received very little attention. Leave-time, with or without pay, is given occasionally, but it is not an expectation of either employers or formal caregivers. Use (and abuse) of sick time, requests for shift changes and high turnover rates, especially in times of high unemployment, may be indicators of inadequate or no support to formal caregivers. Lack of employment stability among formal caregivers reduces continuity of care and becomes a problem both for home care users and their informal caregivers, as well as the delivery system as a whole. Therefore, adequate attention to working conditions, in-service training and emotional support to staff who are providing care to difficult, rapidly deteriorating or terminally ill users of the system are preconditions for quality home care. High quality employment practices should be used to address stress indicators before formal caregivers cease to provide care, or worse, become clients or patients themselves.

The majority of both institutional and community long-term care users are women, as are the vast majority of both formal and informal caregivers. As a result, the issues surrounding long-term care are women's issues as well as health care issues. The lack of studies focusing on women who are formal caregivers or voluntarily care for non-family members and who are also informal caregivers to family members when they are not working is a serious deficit. We know almost nothing about these women and the burden of caregiving and nothing at all about the impact of their dual caregiving roles on their own health status. In countries with a high incidence of HIV/AIDS, young girls and old women are responsible for caring for the middle generation suffering and dying of AIDS. Nothing is known about the effects on the health and development of these girls, or the health and quality of life of these old women.

Other important issues within home care include the impact of new technologies, both low technology such as the use of appropriate body mechanics to enhance physical caregiving potential and “high” technology such as electronic aids. Terminal care has been touched on only briefly in the home care bibliography though a large body of literature deals with palliative care and care to the terminally ill, particularly in North America and northern Europe. Important issues beyond the boundaries of the health care system includes unemployment and changing amounts of poverty, which may increase the pool of personnel available to provide informal care or decrease the care user's ability to pay for un-insured or voluntary services.

The first section of this paper deals with home care policy; the second with home care services. The third section deals with policy and service issues related to
formal and informal caregiving; the fourth section with home care in cases of specific diseases. The final two sections deal with home care staffing and with home care as a component of some other part of the health care system.

The sources that form the basis for this paper, and are included in the Annotated Bibliography, describe “best practice” that could be either replicated or modified for many locations, regardless of the configurations of personnel and stages of development. This is not to suggest that any one programme may simply be transplanted to another site, rather, these descriptions should stimulate local decisions about how reported successes may be replicated while avoiding the failures of others. It is also true that new versions of these best practices will be endlessly variable and creative, and new examples that truly “fit” new settings will continue the progress in delivering care in the home and community. We urge that new examples be documented in order that others may learn from them and the field may advance.

**Home Care Policy**

The policy sources presented here reflect the state of the fields of policy analysis and home care and are largely descriptive. Though this descriptive material generally does not attempt to do more than present existing home care policies within a historical and cultural context, many evolving programs will find useful ideas that may be applied in new jurisdictions or modified to fit other programs. Not surprisingly, much of the policy material relates to caregiving, both formal and informal. The most important theme is the durability of informal caregivers in the home tempered by the warning that caregivers must be supported if they are to continue to provide care without becoming exhausted and ill themselves. This leads to the conclusion that formal care supports and complements, but does not replace informal caregiving. An important consideration here is that policy makers desire more information about home care than they are receiving and they are more willing to use this information in framing home care policies than is generally believed.

**Home Care Services**

The literature on home care services also tends to be descriptive. This literature primarily describes innovations in services and service delivery and is almost exclusively drawn from urban settings. Home care desperately needs more documentation, even though those involved in delivering services may rightfully claim that they are too busy. Nevertheless, the field must find better ways to ensure that best practices are documented. Most urgently, documentation of programmes in developing countries is needed and must be disseminated so that they are accessible to those who can learn from the experiences.
**Formal and Informal Caregiving:**

Much of the home care literature deals with caregiving, especially informal caregiving. The literature on formal caregiving concentrates on retention rates and ways to increase retention among these workers. Two key aspects of informal care are family structures and community or neighbourhood networks, both of which may support intergenerational caregiving regardless of the direction of the support. As suggested above, the support for informal caregiving is essential to all home care and therefore is a major topic in the caregiving literature. The issues of whether or not to pay informal caregivers, and if so, at what rate and in which form of compensation are closely related and, as yet unresolved in most countries. The finding that informal care is not “free” care has been seldom reported. It is probably worth noting here that the literature on caregiving to victims of dementia is almost never included in the general caregiving literature, and the dementia caregiving material usually does not deal with other kinds of caregiving. This separation in the literature underlines the perception that caregiving for dementia sufferers is different qualitatively from general caregiving.

**Issues with Specific Diseases**

The largest body of disease-specific home care literature relates to persons with HIV/AIDS. Most of the “best practice” examples reported are site-specific, but many hold promise for adaptation and adoption in other locations and two are generally appropriate to other diseases and forms of home care. For example, one article (Rossert, Defert, et al. 1994 ID: 16) reports success in delivering home care to patients who live alone, which is a persistent home care issue; this success should be replicable with other diseases in a wide variety of locations. The best examples of training indigenous, usually volunteer, caregivers are also found in the HIV/AIDS literature and, again, should be emulated by home care programs generally. The importance of intergenerational support in caregiving is highlighted by the naming of HIV/AIDS in Africa as the “grandmothers’ disease”. This label comes from the fact that the burden of care often rests with grandmothers, who are the only ones left to care for adult victims and their children, who may also suffer from the disease. The lack of knowledge about the disease combined with poverty, especially in rural areas means that its spread is extremely rapid. The lack of policy initiatives is distressing, since much more is known about HIV/AIDS than is being used either by potential victims or policy makers.

**Home Care Staffing**

Home care staffing issues are largely, though not exclusively, issues of training the personnel who deliver home care, including informal and other voluntary caregivers. In the case of formal caregiving staff, training is best undertaken as a
multidisciplinary process and should include paraprofessionals and informal caregivers. Training has been identified as one of the most successful ways to improve retention rates among home care workers; therefore it is particularly disappointing that training is done so infrequently. Given the high incidence of injuries among home care workers, largely as a result of lifting clients, it is especially regrettable that training in body mechanics and lifting is not uniformly provided to all caregivers. The limited amount of training related to establishing and maintaining positive interpersonal relationships—so essential to good quality care—is an equally serious concern which needs to be urgently addressed.

Adult day care and respite are home care program components that are essential to enable informal caregivers to continue to provide care. They are also the only congregate forms of care that are usually included in listings of home care services. Because these services are used intermittently and with highly individualized scheduling, they must be extremely flexible. Consequently, the services present more staffing challenges, although fewer delivery challenges than other home care services.

Nursing personnel, who are usually identified as the major resource in formal home care programs, perform a wide variety of tasks and assume many roles in home care. These roles include assessment, case management, preventive care, provision of needed services for chronic care and episodic acute care treatment, collaboration with physicians, monitoring of informal caregiving, complex care to the most severely compromised home care clients, and links to the broader health system.

The role of technology and especially “high” technology, including information technology, in home care is an emerging issue and one that will become more common. It is important to ensure that appropriate training precedes and accompanies the adoption of “high” technology. There are ethical issues and quality of care as well as quality of life issues that are relatively unique to “high” technology in home care. Policy makers as well as service personnel and the general public must address these issues if the inclusion of “high” technology is to be viable in home care.

**Component of the Health Care System**

It is noteworthy that when home care is viewed as a component of ambulatory care or community care, it is generally poorly integrated into its host system. On the other hand, when home care is viewed as a component of hospital care, it is so tightly integrated into the hospital system that it is virtually impossible to identify where one ends and the other begins. The integration of home care into a comprehensive health care system, primarily as represented by health care planning, is generally very rudimentary. Demonstrating the ability to increase or maintain the cost-effectiveness of home care tends to be the driving force behind this in the most industrialized nations. Most examples result from community needs assessment
surveys. In addition, other sources of planning exercises focus on components of needs assessments. In both cases research design assistance would enable greater returns to planners with less human and fiscal investment.

**Conclusion:**

There is a wealth of literature related to aspects of home care that is not included here. Much of this literature is from Europe and North America. It is hoped that the original sources cited here will be relatively easy for readers to access. Readers who have specific needs for information on selected aspects of home care are encouraged to search the electronic databases used to develop this paper and the Annotated Bibliography.

This summary makes it clear that policy development is required in several areas, most specifically in relation to:

- supporting informal caregivers, by design not by default;
- endorsing the multidisciplinary and multifaceted training of home care personnel, including informal caregivers and clients;
- deciding whether or not to compensate informal caregivers and if so, how to do this;
- ensuring that the most vulnerable groups in the population are explicitly included in health and home care policies;
- ensuring that rural and remote communities receive policy and program attention;
- encouraging the documentation of home care policy and experiences and the evaluation of home care programs;
- incorporating population health strategies based on health determinants in health policy development;
- addressing “high” technology in the home; and, while remaining flexible,
- basing decisions on the best available evidence.

A second and equally obvious result of this summary is that the training of home care personnel is largely inadequate and must be improved if home care is to remain viable in the face of increasing demands, increasing complexity of care and diminishing informal support networks. Training needs include:

- more training for home care clients and their informal support network members;
- integrated and multidisciplinary training of professional and paraprofessional home care personnel;
- greater use of the “train the trainer” model to expand the caregiver pool of indigenous home care personnel with monitoring of quality;
• training of formal home care workers that includes skills training and training in establishing positive interpersonal relationships;
• training in the use of “high” technology, including information technology;
• explicit incorporation of the importance of providing culturally sensitive and appropriate services, including particular attention to rural communities; and
• training in policy analysis, secondary data analysis and research methods.

The third obvious need that this summary identifies is the need for more or better research in a number of areas related to home care. As suggested in the Introduction, the lack of epidemiological data on women of all ages is a serious problem, and more specifically, dual caregivers require attention. In addition, research needs to be undertaken:

• in home care policy analysis;
• in home care program and service evaluations;
• in the impact of “high” technology on home care clients, their informal caregivers, and formal caregivers and the potential “medicalization of the home”;
• on the long-term health and economic impacts of caregiving;
• with service modelling to increase the cost-effectiveness of home care; and
• using secondary analysis of available data.

Developing greater uniformity in community needs assessments can increase transferability of programs and further comparative analyses across multiple jurisdictions.

The goal of all home care is to provide high quality and appropriate care to individuals in the community and their caregivers, to enable them to maintain their independence and the best possible quality of life. This paper points out what has been accomplished in home care around the world and suggests what still needs to be accomplished to make this goal of home care a reality, regardless of location, level of development or specific reason for home care.

Reference:

PART I
ANNOTATED BIBLIOGRAPHY
Overview

Introduction:

This annotated bibliography presents six groups of citations. The first section deals with home care policy, the second with home care services, the third section deals with policy and service issues related to formal and informal caregiving and the fourth section with home care in cases of specific diseases. The final two sections deal with home care staffing, and finally, with home care as a component of some other part of the health care system. Most of these sections have multiple subsections.

Part 1 of this document contains a brief discussion of each topic area, including citations for the relevant references, in normal citation style. These six sections are followed by a repeat listing, in Part 2, of all the citations presented section by section, identified by title, date, author(s), publication information, full keyword lists and includes the abstracts or notes for each reference. A complete list of all references and a Glossary occurs at the very end of this annotated bibliography.

Home Care Policy:

This first group of references is primarily concerned with policy issues although service delivery issues are included in some of these sources. Many of these sources deal with policies that are broader than home care, but in most cases, home care policy is the major focus of this material. This section is organized primarily by geography to enable the reader either to immediately move to a particular subsection or to discard one or more subsections. Most of these articles are not based on research as they are more often developed from programme or service experiences; that is, “best practice” material. Some sources are policy documents with a minimum of interpretation. However, they are reflective of the state of knowledge in the field of home care policy and tend to have a forward-looking perspective.

Policy Overview

Being able to develop an overview of home care policies around the world, is a daunting task and no source was found that really accomplished this task. However, one article was found that addressed policies relative to disabilities from
a global perspective (Bowe, 1990) that provides a useful framework for considering home care policies. Bowe identifies the necessity of bringing together integration, normalisation, accessibility and adaptability to solve disability-related problems. A second article deals more specifically with home care policies in multiple western jurisdictions (Scharf et al., 1995) although even these policy issues are not addressed from as global a perspective as Bowe views disabilities. The only other overview article is also specific to home care policies (Hedrick et al., 1986) as it continues the debate on effectiveness and costs of home care. The latter authors come to the conclusion that better studies are required to test whether home care is effective across multiple dimensions and to address the cost-effectiveness of home care.

Policy Comparisons

Some of these authors have taken a broad policy perspective, including health, health service, political and family policies as they vary across the jurisdictions that they are comparing. European countries (Jamieson, 1992) and selected western countries (Lesemann et al., 1993) have received the most attention with the selected sources containing recent examples. Others have concentrated on fewer jurisdictions (Litwin et al., 1996), in this case Ontario, Canada and Israel and have focused on more aspects of policy. Another category of comparative policy documents is those that are restricted to issues related to financing of home care (Henrard et al., 1995; Freedman et al., 1996). In a different vein, Chappell has demonstrated that home care research, and hence the home care literature in European and North American countries, has produced more in the areas of programme development and service delivery than in policy development or analysis (Chappell, 1994). She concludes that our current knowledge is not of as much help to policy makers as they would wish or would support, although it remains helpful to programme staff.

Caregiver Policy

The largest body of topical policy material is policy about caregiving, both formal caregivers, such as staff, and informal caregivers, usually family. Policies relevant to caregiving are also included in many of the other groups of references. The decision to list them, here, identifies those sources where the dominant policy issue is caregiving. Caregiving that is just one aspect of policies that are better characterized as specific to a geographic area are identified in the remainder of this section. In those cases where caregiving is specific to a single category of disease or service, the sources are included in later sections of this bibliography. In using the full data base, all of the above groupings may be identified by searching the data base using “caregiving” or “caregiver” as a title or keyword in the search strategy.

The first set of sources (Burbridge, 1993; Gordon, 1997; Hayashi et al., 1994; MacAdam, 1993) concentrate on labour market aspects; that is, policy
related to formal caregivers, although additional issues may be addressed. Informal or family care is the dominant policy issue in another set of sources (Doty, 1986; Gubrium et al., 1990; Hanley et al., 1991; Herrman et al., 1993; Tennstedt et al., 1993; Wuest, 1993). One final article (Gilhooly et al., 1997) deals with corporate policies that enable, or preclude, employees from being both primary informal caregivers and employees.

**Policy Issues in the United Kingdom**

Two sources from the UK deal with community care policies (Kershaw, 1994; Laczko et al., 1992) and one addresses the debate around providing care or cash to those who need home care (Craig, 1993).

**Policy Issues in the United States**

Two sources from the U.S. address home care funding (Logan et al., 1995; Weisert, 1991) and the third one places home care in a social insurance (or welfare state) policy framework (Hudson, 1996). One source is considerably different from all of the others (Reichel et al., 1986) in that it reports on the results of a comprehensive state-wide assessment of the needs of Alzheimer's Disease and Related Disorders patients and their families. This assessment used 16 surveys and the testimony from hearings over an 18-month period to develop policies and services in the State of Maryland.

**Policy Issues in Canada**

Two of the Canadian sources (Health Services Promotion Branch, 1990; Sorochan, 1995) are broad based and deal with the three most common models of home care. That is, the maintenance and preventive model, the long-term care substitution model and the acute-care substitution model of home care. The third source deals specifically with the acute-care substitution model (Shapiro et al., 1980). The final two articles (Fedyk et al., 1996; Havens, 1995) identify the major policy issues relative to care for the frail elderly population in Canada.

**Policy Issues in European Countries**

Cogan presents arguments for a single European Union (EU) model for home care policy (Cogan, 1993) based, in large part, on UK policy. One article is specific to home care policies in Italy (Facchini, 1993). Two sources deal specifically with financing home care (Glendinning et al., 1993; Henrard et al., 1995). Ungerson broadens the financing issues within a gender policy perspective (Ungerson, 1995). The final three articles in this group (Jamieson, 1991; International Social Security Association, 1992; Walker, 1993) are wide ranging in presenting policy and practice issues in a variety of European countries.
Policy Issues in Scandinavia

The two Scandinavian articles are quite unique in that they address policy issues that were not generally found in other categories or jurisdictions nor are they presented in a jurisdictional context. The first of these articles (Waerness, 1987) considers home care and community care policies from a feminist perspective. The second article (Joffe, 1989) deals with the implications and policy issues arising from the economies of scale and presents practice examples.

Policy Issues in Middle Eastern Countries

One article was found (Gezairy-Hussein, 1995) that presented issues in Cyprus, Egypt and Lebanon. Three articles (Brotsky et al., 1997; Factor et al., 1985; Mann, 1985) summarize the substantial work in the development and documentation of home care policies in Israel. Finally, a more specialized study of Bedouin men (Meir et al., 1993) is included because of the policy issues that surround migration of older persons.

Policy Issues in African Countries

Two articles were found that addressed health policy in Zimbabwe (Adamchak et al., 1991; Allain et al., 1997), but home care is only a small component of the material that is presented in these sources. Another article (Oshomuvwe, 1990) addresses health services policies in Sub-Saharan Africa, again, with little attention to home care policies; but interestingly, it includes a plea for improved data for policy making.

Policy Issues in China

Only one source (Chen, 1996) was found that addresses community care including home care policies in China. Chen places these issues in a cultural and historical context and contrasts the practices and policies in China with those in the West.

Home Care Services:

The next group of sources is primarily concerned with home care services and service delivery issues. In some cases home care services are placed in a broader health care services context. This section is organized in part in geopolitical regions to enable the reader either to immediately move to a particular subsection or to ignore one or more subsections. A second organising element is based on age groups; that is, home care with the elderly population as opposed to home care with all ages. In addition, the special situation of home care services during man-made or natural disasters is included in this section. Very few of these sources are based on research or evaluation, as they are most often descriptions of service and service delivery experiences. That is, these materials usually present
"best practice" examples of services and service delivery. Although they tend to lack evaluation content, they are reflective of the state of practice in the field of home care services.

**International Home Care**

The four articles in this group include material that is broader than any one geopolitical region. They are all consciously international in scope. They tend to describe innovations in home care services (Monk, 1993; Monk et al., 1989), development of home care service delivery mechanisms (Monk et al., 1995) and the attitudes of elderly persons to home care in five different countries (Rowland, 1992).

**Home Care in the "Developed" Nations.**

It was often difficult to identify national "best practice" material in these countries as the delivery of home care services in most of them varies among subnational jurisdictions. In smaller countries and those with highly centralized health care systems or programmes, this was less difficult than in larger, more decentralized countries. In the latter cases, the decision about including material was based on identifying examples that were believed to hold some promise of applicability to the "developing" nations. This principle was also used to determine whether any examples were included from a particular country. In other words, this section should not be viewed as an overview of home care in the "first world"; but rather, as examples that may inform programme planning staff and policy makers in those jurisdictions that are evolving home care services.

For example, only seven examples among the literally thousands of citations from the United States of America that were reviewed, are actually included here. Three of these sources relate to aspects of organizing the delivery of services (Quinn, 1995; Feldman et al., 1996; Burack et al., 1995). The others deal with the actual delivery of services in ways that are seldom reported or undertaken, but which hold considerable promise of transferability (Blanter et al., 1995; Keating, 1995; Simon et al., 1993; Clinco, 1995). The article by Feldman and associates applies to both categories.

The Canadian sources include one article that provides an overview (Havens, 1996), a second that deals with predictors for the use of home care service (Shapiro, 1986) and one that addresses case management (Shapiro, 1995). A recent Canadian source (Wilkins et al., 1998) documents the characteristics of those receiving publicly funded home care from the 1994 National Population Health Survey. Another Canadian source (Shapiro, 1993) describes the development and use of a "single entry" system in long-term care. The last two Canadian sources present case examples in home care (Havens, 1990) and of support services (Havens et al., 1993).
Five examples are included from Israel dealing with the Community Long-Term Care Insurance Law (Brodsky et al., 1993; Brodsky et al., 1997) and with the role of Non-Governmental Organizations (NGOs) (Schmid, 1993; Mann, 1997; Habot et al., 1985). One source from the United Kingdom deals with case management (Challis et al., 1986) and the other addresses the issues surrounding ageing with a disability (Zarb, 1993). One of the Australian sources also deals with case management (Halton, 1992) and the other with accelerated post-fracture rehabilitation (Cameron et al., 1993).

One of the articles from the Netherlands (Kempen et al., 1991) was selected because it is one of the few examples of a potentially transferable research study. The other example (Kuyvenhoven et al., 1995) from the Netherlands includes a strong evaluation component. Two of the Italian sources emphasize the strength of the family in home care (Facchini, 1993; Mercadante et al., 1993), while a third describes the evolution of an NGO that collaborated with the city-run home care programme (Rosengarten et al., 1990). The article based on Norwegian data (Lingsom, 1989) also describes family support. The Spanish example (Serra Rexach et al., 1992) describes a programme based on a clinical geriatric home care team. Overview articles from Germany (Dieck, 1993), France (Dumont, 1992) and Belgium (Handy, 1995) provide a variety of useful information. Two recent books (Jamieson, 1991; Hutten et al., 1996) deal with home care in the European Community countries. The latter book is based on the home care literature and a key informant survey in the 15 EU countries, while Jamieson used a research team from nine countries to provide thorough and consistent information from each of these countries.

**Home Care in the “Developing” Nations**

Very little published material on home care or even community care from the “developing” countries was found. However, the same criterion of transferability was applied to these materials, as was the case in the previous section.

Of the 12 sources in this section, five of them are from Japan\(^1\), and almost all of the 12 sources are set in urban centres within these countries. For example, three of the Japanese sources are urban centered (Endo, 1997; Kobayashi, 1994; Takahashi et al., 1996), one is set in a large village (Shimada et al., 1993) and the final article reports on rural home care (Takeda, 1973). All of the sources from China (Davis et al., 1995; Xu et al., 1996), the Philippines (Camagay, 1998), Taiwan (Chiu et al., 1997) and Thailand (Shiriphanich, 1986) relate to urban centres. The Nigerian article reports on family support in a mix of three cities and eight villages (Peil, 1991). The Indian article provides a statewide overview of geriatric care (Ghei, 1980).

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\(^1\) While Japan is a highly-developed country, it is grouped in this section with developing nations due to its strong traditional culture of family caregiving.
Home Care with Elderly Clients

As most home care is consumed by elderly clients, the majority of the age related sources were found in this category. It should be noted that this section contains only a small portion of the sources that it is possible to place in this category. Every section of this bibliography contains many references to sources that relate to home care with elderly clients. Those identified here do not fit well in any other category but are important to include. Three of these sources deal with long-term care with elderly clients (Clark, 1996; Shapiro, 1986; Hughes et al., 1987). Clark’s article provides an overview; Shapiro deals with predictors of the use of home care and Hughes looks at cost tradeoffs. Two additional sources are specific to financing issues (Halamandaris, 1990; Henrard et al., 1995), the former in the U.S. and the latter in five European countries. The three rural articles are research based (Berke, 1992; Dansky et al., 1998; Newhouse et al., 1987). The first two report on national studies, while the latter is based on a single U.S. state. The remaining four articles are more idiosyncratic, reporting on providing culturally sensitive services (Blanter et al., 1995) and the importance of providing correct and relevant information (De et al., 1985). Another article reports on the creation of a system that “banks” volunteer hours to be “spent” if the volunteers need care later (Nixon, 1990). A final article argues for the use of a disability approach to home care services as an advocacy strategy by and with elderly clients (Simon et al., 1993).

Home Care with Clients of All Ages

It is useful to remember that additional sources dealing with home care clients of all ages occur in several other sections of this bibliography. Those identified, here, do not fit well in any other category but are important to include. Three of the articles report on research into client satisfaction with home care (Braun et al., 1987) and with home care workers (Eustis et al., 1991; Eustis et al., 1992). In these studies, client age was found to be a powerful explanatory variable, hence their inclusion in this section. The final article provides a description of a generic home care model for clients of all ages in southwestern France (Morris, 1983).

Home Care During and Following Disasters

Given the disruptiveness of natural and man-made disasters, the complexity of home care service delivery and the vulnerability of home care clients, one might expect to find many appropriate sources in the literature. In fact, this is not the case; only six sources were found. Of these sources, only one, dealing with Hurricane Hugo (Chubon, 1992), addresses a natural disaster, and in this case the subjects are home care staff not clients. Famine is categorized as having elements of both natural and man-made disasters, but in both sources
dealing with care in cases of famine (Moore et al., 1993; Godfrey et al., 1989),
man-made wars were a complicating factor. The final three sources deal with the
war in the former Yugoslavia (Lang, 1997; Lang et al., 1997; Vespa et al., 1995).
The first two deal with elderly clients, while the third deals with all ages. All of
these sources identify the vulnerability of the old, the very young and those who
are disabled or ill, but present little concrete information on meeting the needs of
these groups.

Formal and Informal Caregiving:

Caregiving, and more directly caregivers, especially informal caregivers,
accounts for much of the literature about home care. This is the case regardless of
the focus, whether policy, component services or service delivery, whether free-
standing or integrated with other health care sectors and whether research or
practice based. Therefore, one of the challenges in constructing this annotated
bibliography was determining how to organize the references on caregiving. The
decision was made to focus initially on formal caregivers, followed by informal
caregivers from the traditional perspective of informal caregivers being unpaid
family members and friends, followed by a section addressing the current policy
debate on whether or not to pay informal caregivers. Another section discusses
the literature about informal caregivers of persons suffering with dementia, which
tends to be documented separately from the more general caregiving sources. The
last section in this grouping deals with terminal care relative to both formal and
informal caregivers.

Formal Caregivers

In addition to the sources included in this section, formal caregiving
sources are included in many of the other sections in this grouping and the
grouping below that deals with home care staffing as well as throughout most
sections of the bibliography. It should be noted that informal caregivers may be
considered in the sources within this section even though formal caregivers are the
focus of these sources. Quinn deals with case management as a mechanism to
organize the delivery of formal home care services (Quinn, 1995). A second
source (Doty et al., 1998) deals with the hours of formal care received by persons
whose primary informal caregivers are employed. Two sources, representative of
several similar studies, address the policy-maker's fear that formal care will
replace informal care (Tennstedt et al., 1993; Lingsom, 1992). Like most of this
literature, both of these sources document the fact that formal care complements or
supports and does not replace informal care, the former example from the U.S. and
the latter from Norway. The remaining three sources in this section deal with
relatively unique formal caregiver organizational configurations (Surpin, 1988;
White, 1994; Zimmer et al., 1985). Surpin describes a home care "worker
owned" co-operative that delivers paraprofessional home care services and has
reduced worker turnover. White describes a consortium of agencies that use free
training and worker placement services provided by the consortium in exchange for a commitment on the part of the worker to continue working within the consortium agencies for six months. Zimmer and associates conducted a randomised, controlled study of a new formal home care team delivering services to elderly home care clients.

**Informal Caregivers**

While formal caregivers may be mentioned in the sources on informal caregivers, the latter are clearly the focus of attention for the sources in this section. Two sources from Africa (Adamchak et al., 1991; Apt, 1998) emphasize the importance of intergenerational exchange, the former in the context of the support from elders to others and the latter by stressing the importance of keeping elderly persons involved in their communities. Several sources from Asia stress the importance and expectations of family caregivers (Choi, 1993; Nakamura, 1997; Ngan et al., 1992; Takeuchi et al., 1994). Choi describes the caregiver burden in South Korea from this cultural perspective and Nakamura broadens the cultural perspective to several Asian countries and to Asians living outside of their home countries. Ngan and Kwok find that many Chinese elders have very small support networks and Takeuchi and associates identify decreased functional mobility as being related to the likelihood of elders living with family members.

Two additional sources looked at ethnic differences in the provision of informal long-term care (Tennstedt et al., 1994; White-Means et al., 1990). The former documents little ethnic difference in patterns of care, suggesting that culture may not be as important as social factors in providing care. This is reinforced in the latter article where financial resources influence both caregiving and labour market decisions. Stone and Short also address the issue of competing demands of the labour force activity and informal caregiving (Stone et al., 1990). Grandparent–grandchild relationships are the subject of one of the sources (Uhlenberg et al., 1998), in which grandchildren are seen as being potential caregiving resources.

Four sources deal with aspects of what is often called caregiver burden or burnout (Snyder et al., 1985; Kasper et al., 1994; Wilson et al., 1990; Benton et al., 1991). Snyder and Keeffe identify caregiver health problems as a concern. Kasper and associates seek information on why primary caregivers discontinue providing care. Wilson and associates identify the importance for caregivers to have "robust" support networks themselves while Benton and Marshall point to the danger of burden leading to abuse of the elderly care receiver. The final source in this section (Bock, 1995) is one case manager’s attempt to provide very practical “tips” or assistance to informal caregivers.
Issues of Paying Informal Caregivers

In addition to the sources that are annotated on this issue below, Janice Keefe and Pamela Fancey from Mount Saint Vincent University in Halifax, Nova Scotia, have recently completed a knowledge synthesis report on paying informal caregivers for Health Canada. Health Canada has not yet published this report but readers are encouraged to contact the Ministry to receive a copy of this very thorough and comprehensive report which clearly outlines the policy implications of the three most frequent forms of caregiver compensation. These three forms of caregiver compensation are typically identified as direct compensation, indirect compensation and self-managed or consumer-directed programmes.

- Direct Compensation

Several sources provide a review of the forms of direct compensation and indirect compensation in Europe (Evers et al., 1994; Glendinning et al., 1993; McLaughlin et al., 1994). The general conclusion is that paying for informal care is becoming more important and that the forms of compensation used in any given country are based on the health and social welfare policies of that country. Two U.S. sources contrast pay and non-pay programmes largely based on comparisons of State programmes in Illinois, non-pay, and Michigan, pay (Keigher et al., 1988; Linsk et al., 1992). A third source (England et al., 1989) describes the Illinois programme and its modest use of informal caregiver compensation. Also in the U.S. (Hendrickson, 1988), State programmes that use indirect compensation; i.e., tax incentives to increase informal caregiving in Idaho and Arizona are described. Keefe and Fancey identify differences between caregivers who were paid and those who received services, or both (Keefe et al., 1997a), within the same home care programme in Nova Scotia. Finally, Stone and Keigher offer an overview of U.S. policies relative to providing financial support to family caregivers (Stone et al., 1994), based on the Family and Medical Leave Act of 1993. The latter legislation may provide an interesting example for industrialised jurisdictions.

- Indirect Compensation

Only one source was found that presents the pros and cons of paying informal caregivers in the same article (Sipila et al., 1993). Another source compares informal caregiver compensation in distinctly different social welfare and philosophical systems (Sipila, 1995). In a government report (Glendinning, 1992) and a journal article (Glendinning, 1990), Glendinning describes the financial dependency and interdependency that result from paying versus not paying informal caregivers. She demonstrates that when caregivers are not paid they are likely to become financially dependent on the care receiver, but when caregivers are paid the care receiver tends to become financially dependent on the caregiver. Perhaps even more importantly, Glendinning demonstrates that
informal caregivers incur costs in providing care whether they provide that care themselves or pay others to provide it on their behalf. In other words, informal care is not “free” care, as it is usually assumed to be. In this context, it should not be surprising that one article (Vinton et al., 1996) indicates that caregiver compensation is used primarily to pay for basic household necessities. In a somewhat more sophisticated analysis (Keefe et al., 1997b), long-term economic consequences to caregiving women were identified and recommendations are made that public policy and workplace changes should take these consequences into account.

It is also usually assumed that informal caregivers are family members, however, one source (Thornton, 1991) reports on the evaluation of a programme that pays volunteers to provide care to non-family care receivers. This British study is particularly interesting in that it suggests that nominal pay fosters and maintains a sense of volunteerism that is threatened by higher compensation.

- Consumer Directed Programmes

Self-managed or consumer-directed compensation programmes, also known as the Independent Living Movement in North America, is the third form of informal caregiver compensation (Doty et al., 1996). Doty and associates suggest that this model fosters integration of the formal and informal care systems. Younger adults tend to use these programmes more frequently than do elderly home care clients.

The Veterans Administration in the U.S. has used a system of allowances to pay a minimal amount to informal caregivers (Adamek, 1991; Adamek, 1992). This allowance is actually a variation of both direct compensation and consumer-directed programmes, consequently, these allowances do not fit clearly in any of the three forms of caregiver compensation.

**Informal Caregivers to Persons Suffering with Dementia**

Much of the home care literature dealing with informal caregivers views informal care of dementia sufferers as sufficiently different from other kinds of informal caregiving that they are seldom discussed in the same source. Therefore, in keeping with this division, this section focuses on informal caregiving with dementia sufferers.

- General Sources

One comprehensive source with a well-developed conceptual framework (Aneshensel et al., 1995), as well as some research data, describes five stages of
caregiving with dementia sufferers. These stages are acquisition of the caregiver role, in-home care, institutional care, bereavement, and social re-integration of the caregiver; that is, a "multistage career". Another more theoretically based source, (Birkel, 1987), demonstrates the utility of a social-ecological framework for research on, and understanding of, the provision of informal care to dementia sufferers. The problems surrounding a lack of clear and explicit definitions are addressed in one source (Askham, 1991). Askham particularly stresses the ambiguity of the term "community" which in this literature has a broad range of meanings. "Community" may refer to a whole village of supportive neighbours, friends and family or it may refer to a single caregiver only. In the latter case, this solo caregiver lives outside an institution and is caring for a dementia sufferer (another of her problematic terms) who also lives outside an institution. That is, both of them live "in a community" and therefore one is giving and the other is receiving "community" care. A fourth source reports on research with multigenerational families, who were caring for persons with Alzheimer's disease (Garwick et al., 1994).

• Asian Experience

A Japanese study (Yamamoto et al., 1997) identifies a "value of care" dimension which arises from societal norms as the underlying motive for continuing to care for family members with dementia. Two other Asian sources identified self-help groups for caregivers of persons with dementia as providing mutual aid and support (Nakajima, 1990; Shyu et al., 1996). However the fourth Asian source, (Asada, 1991), suggests that breakdown in family caregiving to persons with dementia is inevitable.

• European Experiences

Many of the sources from Europe are concerned with the network(s) that provide support to informal caregivers in large part to combat social isolation (Bledin et al., 1990; Commissaris et al., 1995; Van de Ven et al., 1983; Bodnar et al., 1994; Hibbard et al., 1996). In the U.K., Bledin identifies social isolation as occurring with expressed emotion among caregiving daughters. The Dutch team of Commissaris, et al., in their study of spousal caregivers, demonstrates the importance of both the general practitioner and the durability of the caregiver's social network in reducing stress and maintaining care in the community. Van de Ven & Hectors indicate that social isolation may continue even after the dementia sufferer is placed in an institution, while Bodnar & Kiecolt-Glaser note that social isolation continues to be problematic to the caregiver even after the death of their family member. Hibbard and associates report significant gender, age and socioeconomic differences in social networks that have important practice implications in identifying vulnerable caregivers.
Supporting Caregivers

Several sources were found that suggested ways of improving both the care to dementia sufferers and support to their caregivers. For example, one article (Christenson et al., 1994) identifies “intensive” case management and provision of educational programmes in which caregivers participate as helpful in delaying institutional placement of dementia clients. Another article (Gwyther, 1989) points to the low use of in-home respite services, even when these services are dementia-specific. This low use is seen as problematic and the authors make suggestions to improve the use of these services. In a somewhat more novel approach (Kocin, 1990), an occupational therapist is involved in creating a programme to train in-home service workers to use no-cost activities constructively to improve care of dementia sufferers by maintaining functional capacity and providing a pleasant distraction. When the initial negative reactions of staff were overcome, the training and the activity programme was assessed as being successful. Several sources addressed the special considerations involved in communicating with dementia sufferers, but the source selected to represent this genre (Richter et al., 1995), describes the importance of finding individualised interventions. Another source (Feinberg, 1995) reports on a public consultation process about the needs of family caregivers, with the goal of developing better policy, practice and resources appropriate to families caring for victims of adult-onset brain diseases and disorders, especially the dementias. A final example of assistance for caregivers (Brennan et al., 1991) reports on the use of computers by informal caregivers of dementia sufferers to seek information, communication and support with their decision making. While the existence of computers available to caregivers still represents a relatively small proportion of all caregivers, Brennan and associates point out that those with access to a computer do use them within the caregiving context. It might be expected that many more will do so in the future.

A large number of sources identified characteristics of caregivers that should be treated as danger signals or risk factors (Wackerbarth, 1998; Jerrom et al., 1993; Pruchno et al., 1990; Wallsten, 1993). Wackerbarth reports that caregiver’s health and health status, amount of sleep, privacy, subjective burden and disruption to everyday activities most strongly predict placement of the dementia sufferer in an institutional setting. Jerrom and his associates identify the caregiver’s own health, raised levels of distress and psychological status as predictive of continuing to care for dementia sufferers. Pruchno and associates also report emotional and physical health as causally related to providing care to dementia suffering spouses. Finally, Wallsten observes differences in stress related to daily experiences among caregivers as compared to non-caregiving elders.
Providing Care to the Terminally Ill

There is a fairly large body of literature that deals with palliative care and care to the terminally ill, particularly in North America and northern Europe. Home care with the terminally ill is generally not long-term; that is, seldom more than six months, is seldom seen as a substitute for acute hospital or long-term residential care, nor is it viewed as maintenance or preventive care. Therefore, while it is care in the home, it is more appropriately dealt with in a separate bibliography. As a result, only three examples have been included within this annotated bibliography, more by way of indicating the nature of this literature and the rationale for its general exclusion. Virtually all of the palliative care literature, not surprisingly, deals with pain and symptom management with terminally ill patients, largely those with terminal cancer. This is the case with one of these sources, based in Italy (Mercadante et al., 1993), which was selected precisely because it is not from North America or northern Europe. A second source reports on the double-edged sword of formal home care with the terminally ill (Murray et al., 1994). That is, the in-home surroundings foster a closer relationship and more effective communication between the formal caregiver and the client and family making it more difficult for the formal caregiver to accept denial as a viable response by the client or family. The final source may be viewed as reflecting the opposite end of the terminal care spectrum (Grabbe et al., 1995). These authors report that even in the last year of life, the primary risk factor for receipt of formal home care services is the level of functional impairment.

Issues with Specific Diseases:

The fourth grouping in this annotated bibliography documents a varied collection of sources that relate to single illnesses, rather than dealing with the more generic home care issues characteristic of the rest of this bibliography. For example, they generally integrate formal and informal care within the same source because the disease, not caregiving or service organization, is the focal point of this material. There are three sections in this group. The first section is, in some ways, a miscellaneous category within which home care that is provided to victims of several different diseases is discussed. Within the general criteria for this annotated bibliography, much of the known literature that is relevant to home care for persons with these diseases is included, even if that is only one article. The second section again deals with dementia, but in this section, unlike the section in the previous grouping, the disease is the focal point not the caregiving or caregivers. This is in part reflected in the titles of these sources which tend to refer to Alzheimer's Disease rather than dementia. The final section in this grouping deals with home care for persons with HIV/AIDS. This is a large and diverse section because very few of these sources were able to be categorized elsewhere, precisely because the disease, not the organization or delivery of formal and informal home care services, is the focal point even in those sources related to policy concerns.
Home Care with Specific Diseases Other than Dementia and HIV/AIDS

As stated above, this section deals with several diseases. It should be noted, however, that there is only one article that deals with cancer (Wills, 1978). In this article the emphasis is on the importance of maintaining continuity of care between episodes of hospital care; that is, during home care. Although there are many more sources relative to cancer care, almost all of them deal with palliative or terminal care and therefore are not included in this bibliography based on the decision that palliative care should be contained in a separate bibliography.

- Diabetes

Five sources were reviewed that dealt with diabetes (Fernando et al., 1994; Swai et al., 1992; Markell et al., 1990; Soni Raleigh, 1997; Parry et al., 1996). The Fernando, et al., article is a good example of the centrality of the disease as they report on an epidemiological survey of adults in Sri Lanka, in which home care is identified only as part of their policy concerns, to address prevention and control of diabetes. Similarly, the Swai and associates article reports on another epidemiological study in which they attempt to relate diabetes to malnutrition and low body mass index scores among rural Tanzanian residents. Markell & Friedman address caregiving to a greater extent in their article dealing with the care of diabetic patients with end-stage renal disease whom they identify as needing a “consortium” of formal caregivers with only a passing reference to the family of these patients. Soni Raleigh’s article recognizes home care but only as an extension of the care performed by primary and community health professionals. These professionals are seen as being required to deal with increasing numbers of ethnic minority patients in the U.K. who have diabetes with hypertension and will potentially need renal treatment. While Parry and associates discuss home care briefly, the primary focus is on the use of traditional or “folk” medicine to treat foot ulcers that are secondary to diabetes.

- Stroke

The two articles that are related to stroke patients (Yoon, 1997; Silliman et al., 1986) do address home care and informal caregivers. Yoon reports that family care is related to maintaining the quality of life among elderly stroke patients in Korea. The Silliman et al., article is particularly interesting in that they address the effects of caregiving on the health of the caregivers providing home care to elderly stroke patients. Their summary states: “If policy is going to advocate home care, its consequences for family caregivers must be known.” (p. 643).
• Multiple Sclerosis

Both sources dealing with multiple sclerosis explicitly address family caregiving and caregivers of persons with MS (Aronson, 1997; Dewis et al., 1992). However unlike the articles in the earlier grouping on caregiving, they suggest that their observations are specific to caregiving with MS patients, not generic to informal caregiving in general. Aronson reports on the quality of life of both persons with MS and their informal caregivers and finds, among other results, that the severity of the MS is significantly associated with the quality of life of both groups. In the Dewis & Niskala article, family caregivers in the home of persons with MS are seen as necessary to preclude institutionalization. They report on the health and satisfaction of these caregivers and discuss ways that the formal care system, especially neuroscience nurses, can better support family caregivers.

• Other Diseases and Conditions

The remaining sources in this section are single article per disease sources; in the first case, with progressive muscular dystrophy (PMD) in Croatia twenty years ago (Matutinovic et al., 1978). The authors describe the organization of a centre for the treatment of PMD patients that incorporates home care activities for these chronically ill children and youths. An ethnographic study in northern Canada is the only source specific to home care with chronic obstructive pulmonary disease (Miles-Tapping, 1994). Miles-Tapping, using 10 years of quantitative data to supplement her qualitative data, shows that home care, even in the relatively adverse conditions of isolated communities, provides a better quality of life in a culturally appropriate setting. Home care also is demonstrated both to improve health and reduce the economic hardship experienced with lengthy hospitalization or other institutionalization. In an article about tuberculosis (Nagpaul et al., 1977), home care is viewed as a means to improve the strategies for seeking care with respiratory symptoms. Another source deals with the characteristics of patients with end-stage uremia (Pearson et al., 1975) who are using hemodialysis at home. These patients may or may not be receiving other home care services. With the increase in hemodialysis in the home, more resources and training are being required and this demand is expected to continue to grow.

An epidemiological overview of hip fractures (Kannus et al., 1996) in the ageing world population and changing environment, simply mentions home care in passing while identifying the characteristics of persons experiencing fractured hips. The characteristics of patients who are incontinent are described with a discussion indicating that incontinence is seldom fully assessed nor are remedial efforts undertaken (Mohide et al., 1988). At the same time, incontinence is reported as problematic by 95% of the family caregivers of those patients who are incontinent. One source deals with depression among home care clients
(D'Arrigo, 1994), especially from the standpoint of identifying risk factors for suicide among these clients. D'Arrigo suggests that many more clients may be at risk than are diagnosed and proposes ways in which home care workers can identify and assist with treatment of depression. A review article deals with all age-related mental health problems in the developing world, together (Levkoff et al., 1995). These authors include dementia and depression in their review of nearly 200 studies, including some material on home care. While articles on vision impairment have become more plentiful over the past decade, only one article (Orr, 1987) was found that specifically addresses home care with visually impaired patients. Orr specifies ways in which the home care provider can help identify vision loss in its early stages. This source also suggests ways in which home care workers can be more effective in dealing with visually impaired clients, particularly through reinforcing independent-living skills.

**Home Care with the Dementing Diseases**

As noted above, much of the home care related literature that deals with dementia has been categorized in the previous grouping because the focus of most of the relevant material is on caregiving, both formal and informal. However, there are a few sources that focus on the dementing diseases rather than on the caregivers. It is these disease-focused sources that have been placed in this section. For example, one source (Keady, 1996) reviews over 200 articles on the experience of dementia, primarily as it relates to nursing practice. From a somewhat similar perspective, another source (Newens et al., 1994) deals with diagnostic difficulties for, and the importance of the general practitioner, especially in linking the patients and their families to appropriate resources. Two other similar articles (Smith, Jr., 1988; Williams et al., 1995) stress the importance of the physician with the family of the Alzheimer’s patient. In the article by Smith, this is seen as important to “managing the disease”. In the longitudinal work reported by Williams and associates, the emphasis is on the changing needs of the family as the disease progresses accompanied by changes in the symptoms and behaviour of the patient. A study that compared a district health experience in London with that of an Italian community (Riva et al., 1997) presents an approach to developing community resources for demented elderly persons and their caregivers. In a final article (Inechen, 1998), the author reports on a lack of community resources and a lack of community support to families, as well as the victims of dementing illnesses, in China.

**Home Care with HIV/AIDS**

As mentioned at the beginning of this grouping, there is a very substantial body of literature on home care with HIV/AIDS patients. In this section as with the rest of this group, the focus of these sources is the disease not the organization or delivery of services, including the formal and informal care, which happen to be
used by persons with HIV/AIDS. Where the latter is the case, the source has been included in the relevant sections of other groups in this annotated bibliography. This section presents the epidemiological context to home care with HIV/AIDS patients, first, followed by a broad ranging subsection on special services (usually one of a kind). The third subsection deals with the design and use of palliative care teams, usually multidisciplinary, while the fourth subsection deals with training issues, most frequently training indigenous persons to deliver home care. Informal care is addressed in the next subsection, which is followed by a small miscellaneous category and finally the section ends with a short component on costs.

• Epidemiology

As noted above, the initial sources deal with the epidemiological context of home care with HIV/AIDS patients (Wawer et al., 1994; Decosas et al., 1992; Albert et al., 1998). Wawer and associates reports on a classic epidemiological study of the prevalence, incidence and sero-conversion in persons with HIV/AIDS in a rural area of Uganda. This is particularly relevant because the authors demonstrate that the epidemic in rural areas is far from contained. Given the difficulties in delivering home care in rural areas, this information should lead to policy and services decisions to deal with these vulnerable areas. Decosas & Pedneault expand on the classic epidemiological information to identify the spread of HIV/AIDS to women and children in southern Africa. Again, these vulnerable groups are ill-served by home care policy and programmes. They recommend policies to decrease the male-to-female age difference in sexual partners as one strategy to partially address this issue. Albert and associates point out that in those jurisdictions that are experiencing a third wave of the epidemic, the afflicted persons are among the most marginalized groups in the population and with whom prevention strategies are largely ineffective. In Canada, these groups are identified as injection drug users, very young gay men, Aboriginal people and vulnerable women.

• Special Services

Within the broad ranging topic of special services, most of the examples are site specific but have a wider potential application in similar situations. For example, a Zambian source (Chandwe, 1994) reports that by integrating home care services to HIV/AIDS patients with the services to patients suffering from other diseases, the stigma attached to the disease was avoided. Consequently, home care became an acceptable option for receiving care at home in the community rather than being refused. In a source from Canada (Goldstone et al., 1995), the authors report on the lack of success with resuscitation of HIV/AIDS patients. There is no reason to believe that success with resuscitation would be greater in other jurisdictions, therefore, these findings would also seem to have greater
applicability than the site of the study. A Mexican source (Hernandez et al., 1994) describes the development of a non-profit health centre in which professional services are largely donated in order that services may be made available to those with extremely low or no incomes. Again, one would expect that this concept would be applicable to other low income areas. Another example drawn from a very low income rural area in Uganda (Ssemukasa et al., 1994), reports on the use of herbal remedies in lieu of high cost pharmaceuticals. In this case, 25 indigenous herbs were recommended for use at no cost to the patient following rigorous scientific analysis. An example from Singapore (Ong et al., 1994) reports on the use of a day centre to create a supportive atmosphere within which to both provide treatment and develop mutual aid or support among patients. A somewhat related source from Spain (Perez-Elias et al., 1994) reports a high level of satisfaction with home care that is thoroughly integrated with a tertiary hospital providing care to HIV/AIDS patients.

Reilly and associates (Reilly et al., 1994) report on the development and use of short-term respite by HIV/AIDS patients in Australia. Respite is provided in Respite House that operates 24 hours a day with a coordinator and 80 volunteers to provide care. Patients and their carers are encouraged to plan for this respite as part of an independent living policy of the service agency. AIDS, a specialized French agency, is successfully delivering care to HIV/AIDS patients, 60% of whom live alone. This care is provided in collaboration with the standard home care services (Rossert et al., 1994). The ability to respond to those who live alone is quite unique, but should be able to be replicated in other jurisdictions. Another source, (Chipfakacha, 1997), identifies the high risk of contracting HIV/AIDS by the traditional healers in Botswana. In this example, many of the traditional treatments put the healer in direct contact with the blood of HIV/AIDS victims who seek alternative treatments either in addition to or instead of Western Medicine. A final example of special services also comes from Australia (Duckett et al., 1994), where a State service planning exercise to develop a five year strategic plan is reported to have enhanced the quality of life of HIV/AIDS patients.

• Palliative Care Teams

Most of the sources that identified specialized palliative care teams report that the teams have originated from hospitals and are physician lead (Arrizabalaga et al., 1994; Garde et al., 1994; Ghirga et al., 1993; Orofino et al., 1994), or are, at least, hospital-based (Butters et al., 1993; Mansfield et al., 1994). The major differences among these examples are the staff-to-patient ratios, the total number of patients involved, the percentages of patients who died during the pilot or study period and their location. That is, the first two are Spanish, the next two are from Italy and the final two are located in London. The two sources using nursing models, Frederiksen (Frederiksen, 1994) in Denmark and Pereira et al. (Pereira et al., 1994) in Brazil, report essentially the same results as the authors reporting on
the palliative teams above, except that in these examples, the teams are headed by nurses.

- **Training**

  A rather substantial number of sources deal with training. The most common form of training is that with local and indigenous persons. For example in Uganda (Byngire et al., 1994), one local person per village is trained as a counseling aide and function as the link between the hospital or medical center and the patient in the local community. They are using a “train the trainer” model to extend this programme to more areas. Another Ugandan example (Katabira et al., 1994) stresses the importance of neighbours and urges the training of neighbours along with family members as the former are also often involved in the care of the HIV/AIDS patient. In Kenya (Onyango et al., 1994), the “train the trainer” model enabled an NGO to have each trainer train over 500 local people including many persons with AIDS (PWA). Including PWAs eliminated fear and stigma, improved knowledge and enabled everyone to work together more closely. In another example from southern Africa (Sabatier et al., 1994), indigenous training teams were established to spread the training to more communities. Again, in Rwanda (Schietinger et al., 1994), two nurses as the trainers trained Red Cross volunteers to teach families the necessary skills for providing palliative care in their homes.

- **Informal Care**

  Informal care in the sources dealing with HIV/AIDS is more frequently referred to as informal support, a further indication of the perceived difference between this literature and the general material on home care. It is also noteworthy that there are few sources that deal specifically with informal support as compared to the vast quantity of material on informal care in the general home care literature. One important example, however, is the source (Moller, 1997) that identifies AIDS in Africa as the “grandmothers’ disease”. This is because the burden of caring most often falls on grandmothers, as they are frequently the only ones left in the villages to care for the victims of AIDS and their children. Several sources identify the lack of resources available to carers; that is, the informal support providers (McCann et al., 1992; Parli et al., 1993; Perreault et al., 1994; Turner, 1994). McCann & Wadsworth note the resistance among this group of informal supporters to being labeled “carers”. Parli and associates identify the importance of providing social support to the supporters of HIV/AIDS victims and recommend including a social worker on the formal caregiving team. Perreault et al., indicate that these caregivers come to the formal system very late, because they either do not recognize or do not respect their own needs for support. Turner addresses the needs of the informal caregivers of HIV/AIDS patients to identify
and then deal with stress. As such, this source includes a plea for public health policy to include caregivers in AIDS related policy.

• Miscellaneous

As noted at the beginning of this section, there are three sources that could not be categorized and are therefore grouped together, here, as being miscellaneous. The first of these articles (Mercer et al., 1996) demonstrates the lack of, or limited knowledge about HIV/AIDS in high risk areas. In this case, the high-risk area is rural Zimbabwe. A second source (N$1a, 1994), indicates that while the government policy of Botswana and its community health practice supports home care for terminally ill patients, including AIDS patients, the patients themselves and their families do not support home based terminal care. Even with effective, continuous counseling of the patients and their families, only 75% of the patient group became home care clients. The final miscellaneous source (Sichone et al., 1994), reports that the provision of home care is not realistic in the extremely poor rural areas of Zambia where securing food and maintaining proper hygiene are already compromised. This is an excellent example of why the determinants of health, or population health model, is critically necessary to the development of all community health programmes and policies.

• Costs

The last three sources relating to home care with HIV/AIDS patients, address costs of care (Tramarin et al., 1992; Tramarin et al., 1994; Afheldt et al., 1993). The first source from Tramarin and associates reports that home care is cost effective, while the second one indicates that the palliative home care approach is less costly than ordinary clinic and hospital care. The final source describes a home intravenous therapy service within home care in Toronto. The authors demonstrate that it is appropriate to use home based intravenous therapy as it improves the quality of life of the patients, maintains a normal lifestyle and is less costly than the alternatives.

Home Care Staffing:

The sources in this group deal primarily with issues that arise from or relate to staff of home care services. One source (Havens, 1995) has been included because it presents a conceptual framework distinguishing the expectations and behaviours of clients and families from those of staff. Many of these sources relate to training issues and some to compensation. However, as this group has been divided, the first section primarily addresses itself to training, both pre-employment and continuing education of staff, training of informal caregivers
and clients. The second section deals with the special staff-related concerns in Adult Day Care and Respite Care which are treated as components of home care throughout this bibliography. The third and fourth sections address the concerns of Nurses and Physicians, respectively. In the case of nursing, the label is restricted, almost exclusively, to registered or licensed nurses. Both sections address the roles of these professionals in home care, especially in the case of physicians. The final section deals with technology, largely the use of "high" technology, in home care. Included in the latter section are citations that deal with information technology as a tool for home care but one that places different demands on staff as well as on clients and caregivers.

**Training Issues in Home Care**

There are essentially five categories of training that are addressed in this section, training of: professionals; supervisors; para-professionals; family; and the home care clients, themselves. The majority of material that was found related to the training of para-professionals, which has been further subdivided into three components: skills training; training in affective or interpersonal relationships; and the training of indigenous workers, typically volunteers.

- Professional Training

Little of the professional training literature is included in this bibliography. This omission stems from three reasons: first, most of it is highly country-specific and is, therefore, of limited utility to an international audience; second, it tends to concentrate on individual professions resulting in very little transferability; and finally, very little of this literature includes any content on home care. Consequently, should there be a need for information on training of specific professional workers or in specific countries, other bibliographies or training sources should be consulted. The five sources that are included here (Banoob, 1992; Amosun et al., 1994; Finlay, 1993; Nordin et al., 1992; Kaye et al., 1991) tend to be somewhat more generic although all but one (Banoob, 1992) deal with a single profession. They are also somewhat unique by specifically including home care. This most generic article addresses the multidisciplinary training needs of the developing countries in addressing home care and other forms of services that are designed for use by the rapidly increasing elderly population in these countries. The author draws on examples from Romania, Barbados and Kuwait relative to short-term, integrated training for physicians, nurses and social workers. The author further notes that this generic, integrated, short-term training strategy has been adopted by the International Institute on Aging (IIIA) in Malta. Both (Amosun et al., 1994) and (Finlay, 1993) relate to the training of physiotherapists to work with elderly clients, including working in home care programmes. The Amosun and Alawale article derives its examples from Nigeria, while the Finlay paper reports on an international training course. The fourth source (Nordin et al.,
1992) is specific to physicians in Malaysia receiving training in geriatrics as an "essential subject" in their education. This article has been included because it provides an example that might be used by both other countries and other professions to demonstrate the importance of training health care professionals to understand and to provide care to the rapidly increasing elderly population, especially in the developing nations. The final source (Kaye et al., 1991) is far less generic but is included because it is the only source found that deals specifically with the additional challenges that need to be addressed in training home care and other health care worker to use "high technology" and to use it appropriately. While "high technology" assistance with home care may be relatively rare, it is an emerging area that requires far more attention to the issues of training, staffing and ethics, as is suggested by Kaye and Reisman.

• Supervisory Training

Training by supervisors in home care programmes is primarily seen as a mechanism of securing higher retention rates among direct home care service providers, most of whom are paraprofessionals. The two relevant sources (Burack et al., 1995; MacAdam, 1990) included here, both address retention. The Burack and Rosengarten article reports on a successful experience in New York City that involved supervisors in in-service and on-the-job training to a greater extent than is usual in home care agencies. Although the authors demonstrate success in a large metropolitan area, the principles are much more broadly applicable which is why it has been included in this bibliography. The second source (MacAdam, 1990) also from the United States, is the only one found that suggests that for supervisors to be successful with an expanded training function, they, too, require enhanced training. Specific examples of what additional training is required are included. In addition, MacAdam identifies many of the State policy issues, including coalition building, that can create a supportive or inhibiting environment for increasing wages and providing supervisory training of direct service workers to secure better retention.

• Para-professional Skills Training

As noted in the introduction to this section, much of this literature relates to the training of para-professionals. As a result, this sub-section has been further subdivided into training relative to the skills required by para-professionals working in home care, followed by the training implications of the interpersonal relationships between worker and client, and finally with the training of indigenous workers. Six sources (Michel, 1998; Clinco, 1995; Ono et al., 1995; White, 1994; Timms et al., 1996; Kocin, 1990) were identified that addressed the area of skills training with para-professional workers. The first source (Michel, 1998) provides the rationale for training para-professionals quickly to respond to the rapid population aging that is occurring in the developing nations. As a result,
it provides a good introduction to this component of training. The second article (Clinco, 1995) suggests that recruiting and training middle-aged women as home care workers, whom they call personal assistants, has been more successful than they experienced with younger, more mobile workers. They found that the older women tended to stay with the same client longer and that their overall retention rate was better.

A Swedish source (Ono et al., 1995) identifies a higher rate of musculoskeletal injuries among home care workers than among other female workers. The most frequent cause was identified as lifting clients. As a result, specific training in body mechanics and lifting is recommended for these workers. Another U.S. example (White, 1994), which addresses retention, as well as skills, found that they were more successful when the training was staged with a period of guaranteed employment than with more traditional models where all the training preceded any employment. The fifth source (Timms et al., 1996) identifies the importance of including general knowledge about older adults in training home care workers to combat the myths that many of them hold. The final source in this component (Kocin, 1990) deals with a special training programme for para-professional home care workers, whose primary task within a dementia service agency is to provide supervision and companionship to the client rather than the more typical personal care assistance. These workers were trained to provide an activities programme rather than personal care. Initially, this change in tasks was viewed very negatively because it did not conform to the workers' expectations that home care workers were supposed to provide personal care and not socialize. After the specialized training including sessions to overcome worker resistance, both workers and families reported favourable reactions to the changes.

- Para-professional Affective Training

There is much literature that documents the importance of positive interpersonal relationships between home care workers and their clients; however, seldom is this affective domain of home care discussed as a component of the training of home care workers. Therefore, the choice of sources to be included in this component was relatively easy as only three sources (Chichin, 1992; Eustis et al., 1991; Kaye, 1986) were found that discussed the training implications of this important aspect of home care. All three sources identified positive interpersonal relationships as important to the client and to the job satisfaction of the workers and as a major determinant of enhanced client care. Each of these sources also makes specific training recommendations. The first source (Chichin, 1992) also notes the importance of agency supervision and support to foster positive interpersonal relationships. The second source (Eustis et al., 1991) provides a warning that these positive relationships may also produce risks of worker exploitation or decreased client control, which underlines the training issues. The final source (Kaye, 1986) identifies the greater importance of positive interpersonal relationships in the case of direct service providers as opposed to

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indirect service staff. This is an expected finding, but the implications are important in the training of home care personnel.

- Para-professional Volunteer Training

Material about indigenous workers in home care more frequently identify these workers as being volunteers, rather than staff. However in each of the sources cited (Gezairy-Hussein, 1995; John et al., 1996; Onyango et al., 1994; Schietinger et al., 1994) the training of indigenous workers is specifically addressed. The first source (Gezairy-Hussein, 1995) highlights the importance to maintaining the traditional cultural values of keeping older people at home in Mediterranean countries, as in many other countries. Accomplishing this is made possible through training local community volunteers as informal caregivers to elderly persons in their family homes. The second article (John et al., 1996) deals with training indigenous staff, not volunteers, in the American Indian Community Colleges in the U.S. These formal caregivers are trained to be nursing assistants or home health workers in their tribal communities upon successful completion of the course and the Medicare certification examination. This training, which is described in detail, supports the American Indian Eldercare Campaign initiated in 1991 to ensure cultural sensitivity in health care and other services. The third example (Onyango et al., 1994) reports on the training of local rural community members as volunteers in the care of HIV/AIDS patients in Kenya. These trained community leaders trained others in their own communities that helped combat the stigma surrounding HIV/AIDS patients in these rural areas of Africa. It also ensured that the patients and their caregivers received care and assistance consistent with their culture and customs, which often varied among communities. In a similar source (Schietinger et al., 1994) two Rwandan nurses taught seven Red Cross volunteers basic nursing skills appropriate to families caring for HIV/AIDS patients. These volunteers then taught the family members to care for these patients, again in rural areas of Africa. Both of these sources not only stressed the cultural issues, but also the varying customs among rural communities, which underlines the importance of indigenous volunteers working with the patients and their families.

- Training with Families

Only one source (Houts et al., 1996) was identified that specifically dealt with the training of family caregivers to care for their chronically ill older relatives. This programme designed in Pennsylvania was labeled the Prepared Family Caregiver model and used a summarizing acronym COPE for creativity, optimism, planning and expert information. The planning aspect is based on problem-solving training of the family or a family member and is especially important in this model.
Client Training

The final subsection to this training section is also represented by only one source (Worcester, 1990), related to the training of the home care client. Worcester provides a very complete guide to the appropriate training of elderly home care clients including aspects of vision, hearing, cognition and response time. This lengthy and thorough article includes several appendices. Two of these appendices provide a valuable learner assessment guide and a sample care plan using cognitive, affective and psychomotor domains in teaching a client about the use of one medication.

Adult Day Care and Respite Care Issues

Adult day care or day programmes are a form of collective or group home care that are appropriate to some, but not all home care clients. Attendance at an adult day programme may provide social opportunities that are otherwise unavailable to the isolated elderly home care client. They may also serve a monitoring function in the care of a client and in some cases they may provide a “break” for informal caregivers, especially spouses or other elderly caregivers. Respite care is designed to provide the caregiver with a rest, a break, the opportunity to conduct necessary business or occasionally to socialize with others. Both of these components are seen as likely to enable the informal caregivers to continue providing the majority of day to day care to elderly home care clients and to delay requests for residential placement or nursing home entrance. The timing of these components is especially important in enabling the informal caregivers to maintain care and prevent caregiver “burnout” or illness. Because these service components are used only periodically and the timing of that use is, of necessity, individualized, these resources must be very flexible. On the other hand, because these services are typically delivered in a congregate setting, certain fixed costs and minimum staffing exist regardless of whether the service is used by only one or by many clients, at any given time. As a result, each of these components represent staffing challenges which is the rationale for placing the discussion of these home care service components in this section of the bibliography.

Adult Day Care

Four sources about adult day care (Gutman et al., 1993; Watanabe et al., 1994; Morris, 1988; Tataru, 1997) were selected for their relevance to this discussion. It is perhaps useful to note that there are far more sources, especially from North America, should one wish to pursue more details about these programmes. The first source (Gutman et al., 1993) provides a good description of adult day care (ADC) and an overview of ADC in North America. Many of the ADC clients were unable to perform some of the activities of daily living unassisted, especially bathing, and were often restricted in their ability to
undertake the instrumental activities of daily living, especially shopping. The three most common referral reasons in their study of ADC in British Columbia were: to assist those who were socially isolated; to give family caregivers some respite; and to give clients emotional help. In the second source (Watanabe et al., 1994), the authors report that the Japanese day service centres helped to improve physical and mental conditions of the clients. The bathing facilities at these centres were considered to be especially useful. Both of these sources identified dementia as a typical condition of the clients that used the ADC services. The South African source (Morris, 1988) views ADC as a component of a coordinated community geriatric service to respond to a population that is rapidly aging and urges that it be developed for that reason. The final source (Tataru, 1997) identifies the principles for organizing ADCs in response to efforts to enable elderly clients to remain at home and to minimize the costs of care.

• Respite Care

There are many sources in the literature that describe and discuss respite care, especially around the theme of trying to determine why so many potential clients do not take advantage of this service component. The sources selected (Grasel, 1997; Burdz et al., 1988; Cox, 1997; Yamada et al., 1994; Thornton, 1989) demonstrate the diversity of these programmes. The first source (Grasel, 1997) reviews the studies describing those who use temporary institutional respite and as such provides a useful overview of this most typical form of respite care. Grasel identifies those with dementia as the primary client group and adult daughters or daughters-in-law as the primary caregivers of these clients. In the second source (Burdz et al., 1988), the authors specifically looked for differences resulting from use of respite care by those who were demented as opposed to those who were not suffering from dementia. Contrary to their hypothesis that non-demented clients would benefit most from respite care, positive results were found for both groups of clients and caregivers in their study. In the third source (Cox, 1997), the author presents the best synthesis of the issue of respite care users as opposed to those who stop using the service and those who, although referred, do not use respite services. The characteristics of users tended to be poorer cognitive status of the client, coupled with less anxiety and greater burden among the caregivers. Users reported fewer hours of informal assistance and fewer behavioural problems than non-users. The fourth source (Yamada et al., 1994) reports on the reduction of fatigue among Japanese caregivers who used respite care. The fifth source (Thornton, 1989) is one of the few books included in this bibliography. However, it was selected because it provides a thorough natural history of creating a respite care programme, including the policy and practice issues of the programme. It is particularly useful because the programme was developed and continues to be based on the use of volunteers to provide the respite services. This increases its potential to be used as a model in other locations where few formal services and service providers may be available.
Nurses in Home Care

The third staffing section addresses the concerns of nurses in home care programmes. In this rather lengthy section, as noted in the introduction to this section, nursing is restricted, almost exclusively, to registered or licensed nurses. This section has been divided into six sub-sections that address the number of nurses needed for home care, the extension of hospital nursing to include home care, the provision of sophisticated home care by nurses, the roles of nurse practitioners in home care, the performance of nursing assessments, and the involvement of nurses with informal caregivers. It should be noted that there is a much larger body of literature on nursing in home care than is annotated in this bibliography. The selection criteria that have been applied throughout this bibliography have reduced this literature to a manageable number of sources, however, should the reader wish more information specific to home care nursing, other bibliographies and several electronic data bases may be readily consulted.

- Numbers of Nurses

The sole included source (Okamoto, 1997) deals with projecting the number of nurses needed for home care, which was a result of planning for the proposed Japanese long-term care insurance programme. Many jurisdictions have produced projections in the process of planning home care services, however, the innovative use of secondary data sources makes this article especially useful. Okamoto’s data sources may not be able to be exactly replicated across jurisdictions, but the approach can be usefully repeated by many jurisdictions. Using available data to project future need for home care personnel is much more efficient and less costly than gathering these data in the field.

- Hospital Nurses in Home Care

Four sources (Bull, 1994; Cowart et al., 1987; Desrosiers, 1995; Hill, 1995) deal with hospital nurses whose role has been extended to include home care clients. The most common means of initiating this extension is for hospital nurses to follow patients as they are discharged from the hospital. In the selected source (Bull, 1994), the author indicates that hospital based home care nurses following patients into the community were able to inhibit readmission. The second source (Cowart et al., 1987) reports on a successful programme in Taiwan, where nurses deliver skilled nursing care to patients discharged from the hospital. This programme, known as the taxi nurses, has been in place since the mid-1970’s and serves an area that is within 30 minutes, by taxi, from the private hospital that initiated the service. The solution of taxis as the means of transportation provides a novel service delivery approach. A Canadian source (Desrosiers, 1995) describes a programme in which hospital based nurses lead cancer care teams for patients with cancer in and out of hospital. The author stresses the importance of
case management as the focus of these nurse-led teams. In a review article (Hill, 1995) the author identifies the multiple roles of hospital based nurses, across the care continuum, in providing care to patients with various forms of vascular disease and undergoing a variety of treatments.

• Complex Care

Sophisticated home care provided by nurses, also sometimes referred to as complex care, is the subject of six sources (Brunier et al., 1996; Kemp, 1996; Kreiseinrich, 1980; Morgan, 1997; Smith, 1987; Skipper, 1992). Historically, the earliest “high” technology home care involved peritoneal dialysis (Brunier et al., 1996), however as the age of home dialysis clients has increased, these authors identify the greatly increased complexity resulting from the large number of comorbid conditions among these clients. Therefore, this procedure has become more complex, demanding more sophisticated interventions in the home with more frail clients whom the authors argue are best served by highly skilled community nurses. Another example of complex care is the management of pain in the home (Kemp, 1996) especially when this condition is accompanied by a substance-related disorder. In this review article, Kemp provides home care nurses with practical assistance in managing the care of clients suffering with this combined problem. The third source (Kreiseinrich, 1980) describes a nursing system in Czechoslovakia that delivers services to elderly persons with diabetes. While this source is somewhat older than many in this bibliography, it is included because it describes what is still considered to be a sophisticated, best-practice model for diabetes care. Morgan, in an Australian source, (Morgan, 1997) identifies the particular challenges associated with providing palliative care in rural communities. Palliative care, may or may not be complex care, but Morgan convincingly argues that nurses in rural areas who are delivering palliative care are coping with complex and often under-resourced situations demanding sophisticated nursing performance. As a counterpoint to many of these sources, a first person report by a home care nurse (Smith, 1987) demonstrates that more sophisticated care may not mean more technologically skilled care, but rather, more ingenious delivery of services, often in spite of programme regulations, not because of them. She provides examples of care that certainly are not highly technical but demand a high level of professional sophistication. The final source in this subsection (Skipper, 1992) identifies one means of dealing with the ethical issues that are confronted daily in delivering home care. In this case, a visiting nurses’ organization established an ethics advisory committee to address these issues.

• Nurse Practitioner

Only one source (Burns et al., 1989) was found that addressed the role of the geriatric nurse practitioner in home care. Several sources indicated that nurse
practitioners were involved in delivering home care, however, no other source actually described the role of the nurse practitioner. Burns and Goff identify the following as essential components of the geriatric nurse practitioner role: case management, links to the broader health system, provision of needed services for chronic care and episodic acute treatment, providing preventive care and maintaining collaboration with physicians in the multidisciplinary team.

- Nursing Assessments

Nursing assessment is the subject of five sources (Keating, 1995; Kluckowski, 1992; Schirm, 1989; Helberg, 1994; O'Connor, 1996). The first source (Keating, 1995) describes a health promotion model. Keating discusses the elements of nursing assessment and the variations in each aspect of the model; that is, primary, secondary and tertiary prevention. In each case, the goal is to enable the elderly client to achieve or maintain the highest possible level of functioning. Medication compliance is the subject of the second source (Kluckowski, 1992). The goal of using a nursing assessment, according to Kluckowski, is to enhance compliance with drug regimes by improving the client and caregiver's understanding of the medication's functions and benefits by incorporating aids to adherence and including over-the-counter medications. A small descriptive survey of functionally impaired elderly persons is the basis for the third source (Schirm, 1989). The strength of this study is in its identification of the need for nursing assessments for both those who continue to receive care at home and those who eventually enter a nursing home. While the research reported in the fourth source (Helberg, 1994) is not particularly sound, Helberg provides one of the best descriptions of nursing dependency measures. Therefore, the reader is advised to read this articles only for the description of these measures and not for the research results. In a review article (O'Connor, 1996) on the importance of hope, O'Connor explores ways for nurses to assess hope.

- Involvement with Informal Caregivers

The final subsection includes four sources (Swanson et al., 1997; Pearson, 1993; Keady, 1996; Pasquali, 1991) on the helping relationship of nurses with the informal caregivers of home care clients. The first source (Swanson et al., 1997) focuses on family caregiving with the goal of using nursing interventions to promote or improve the health of these caregivers. In a similar vein, the second source (Pearson, 1993) identifies the same goals. Pearson calls particular attention to the potential for stress and deteriorating health among caregivers and argues that home care nurses are well positioned to monitor and intervene to prevent or lessen further problems for the client or the caregivers. Keady, in a review article from the UK (Keady, 1996) reports on the particular difficulties experienced in meeting the needs of those with dementia and their caregivers. Keady identifies nursing as providing care to those with dementia and their caregivers; but also, as
contributing to innovative service delivery and education. In the fourth source (Pasquali, 1991) humor is suggested as an underused type of respite to help prevent caregiver stress from becoming caregiver burnout.

**Physicians in Home Care**

There are relatively few sources (Grieco, 1991; Koenig, 1986; Koren, 1986; Finucane et al., 1995; Pannill, 1991; Stessman et al., 1997) that focus on physicians in home care. The majority of these sources deal with the roles of physicians (Grieco, 1991; Koenig, 1986; Koren, 1986) within home care programmes. All three of these sources identify the importance of physicians within home care programmes, especially in the role of patient oversight. It is interesting to note that the home care recipients are identified in these sources as patients, not as clients or consumers. These sources also stress the importance of incorporating house calls in the training of young professionals and Koren also points to inadequate compensation as an issue for physicians within home care. All three articles stress the necessity for physicians to be more involved in the home care of their patients. In a review article, Finucane and his colleagues describe the roles of the medical director in non-institutional long-term care; i.e. home care. They point out that these medical directors will have to face government constraints and will be responsible for establishing new policies relative to physicians’ roles in home care. Pannill reviews several instruments for screening functional capacity of elderly patients. While he notes that multidisciplinary geriatric assessments have been demonstrated to be effective with this patient population, they can seldom be used in office practices. Therefore, he proposes use of a screening instrument to target high-risk patients for a more complete multidisciplinary geriatric assessment. The hospital in the home or the home hospitalization programme is the subject of the final source (Stessman et al., 1997) from Israel. These programmes provide sub-acute or episodic acute intensive care in the home rather than in a hospital. While the home hospitalization programmes tend to include multidisciplinary teams that are led by nurses, they differ from those programmes included in the previous section on nurses in home care because they cannot function in the absence of regular in-home involvement of a physician.

**Technology, especially “High” Technology in Home Care**

This final section of the staffing group of sources deals with technology, especially the use of “high” technology, in home care. The section begins with five more generic sources followed by several citations that deal with the various technologies that have become relatively common in home care programmes over the past decade, albeit largely in the more developed nations. It should be noted that training issues are also addressed in many of these sources. The section ends with sources that report on information technology as a tool for home care but one
that places different demands on clients and caregivers as well as staff. It is acknowledged that "high" technology, including information technology, may not be a pressing concern in the developing nations; however, these applications will become more common and may be diffused even more rapidly in the developing world than has been the case in the more developed nations.

- Overview of Technology Issues

Five sources, all from the U.S. (Leader et al., 1988; Mehlman et al., 1991; Champlin, 1989; Cummings, 1987; Handy, 1989), set the stage for this section through more general discussions of "high" technology in the home. The authors of the first source (Leader et al., 1988) provide a brief description of the most common technologies in the context of pointing out issues that agencies should consider when deciding about introducing "high" technology. However, their major contribution is in identifying that there are many effects from the use of "high" technology not only on the client but also on their caregivers. They also raise the issue of whether or not the home is the appropriate location for such technology, especially when this introduces medicalization of the home thereby threatening the quality of life in the home or for informal caregivers. The second source is one of the rare full books (Mehlman et al., 1991) included in this bibliography. Given the book length, they are able to provide a comprehensive historical perspective and review the more common uses of "high" technology in home care in the U.S. They draw on a multidisciplinary group of experts to address clinical, moral, psychological, economic, organizational, legal and regulatory issues. The latter two elements, legal and regulatory, are of limited value outside the U.S., however the other issues are very relevant regardless of jurisdiction. They address staffing and training issues as well as the effects of "high" technology on clients, families and formal providers of these services. The remaining three sources present many of these issues from the perspective of physicians (Champlin, 1989) and nurses (Cummings, 1987; Handy, 1989). The Champlin article and the one by Cummings are both forthright and useful, particularly in view of the fact that they present both positive and negative aspects of "high" technology from the perspectives of their respective professions. In the final source (Handy, 1989) the author very specifically addresses the client and families. This is captured best by the following quote: "High-technology home care cannot and should not merely be care of the technology (the 'machines and tubes') at home; rather, it should emphasize the care of the patients and families who are receiving the technically complex therapies." (p. 46).

- Common Forms of "High" Technology

The next seven sources (Brunier et al., 1996; Bedder et al., 1991; Meuret et al., 1996; Ahfeldt et al., 1993; Greif et al., 1995; Kirisits et al., 1996; Smith et al., 1993) present specific examples of the more common types of "high" technology.
The first example (Brunier et al., 1996) deals with peritoneal dialysis as the earliest type of in-home "high" technology. The next two sources (Bedder et al., 1991; Meuret et al., 1996) deal with pain management in the home, which is probably the most prevalent form of "high" technology home care. The former analyses Canadian costs of two different forms of pain management while the latter describes a German programme of in-home pain management with terminally ill cancer patients. Afheldt and associates describe a home intravenous therapy programme with HIV patients in Canada (Afheldt et al., 1993). Training issues with infusion pumps are addressed in one U.S. source (Greif et al., 1995) related to AIDS patients who are receiving home care. In another German source (Kirisits et al., 1996) the authors describe a very intensive as well as "high" technology home care programme to improve the quality of life of patients with amyotrophic lateral sclerosis (ALS). A final article (Smith et al., 1993) deals with patient and family reactions to maintaining total parenteral nutrition at home.

- Information Technology

The final four sources in this section (Brennan et al., 1991; Ishikawa et al., 1995; Premik et al., 1996; Vlaskamp, 1992), deal with information technology. The first two deal with the use of computers in home care and the latter two with emergency response systems for home care clients. In the first source (Brennan et al., 1991) the authors detail the various uses of computers to support home care clients and caregivers. They point out that caregivers do use their computer networks to assist in providing care to relatives suffering with Alzheimer's disease. In the Japanese source (Ishikawa et al., 1995), a personal health data management system is the basis for an experimental computer-based home care support and monitoring program. Premik and Rudel report on the establishment of the Lifeline social alarm system in Slovenia in the early 1990's (Premik et al., 1996). They point out that for technology transfer to be successful, a social innovation process must support the transfer of the technology. Finally, Vlaskamp describes the various ways in which emergency response systems are organized in the Netherlands (Vlaskamp, 1992). The author predicts that emergency response systems will become just one component that will be integrated into the technologically- sophisticated homes of the future, sometimes known as smart houses.

**Component of the Health Care System:**

The final grouping in this bibliography includes a wide-ranging collection of sources within which home care is viewed as a component of some other part of the health care system. In the first section, home care in treated as a component of ambulatory care, followed by a section where it is seen as a component of community care. In both of these cases, home care is seldom well integrated within the larger portion of the system, whether ambulatory or community care.
The third section presents examples of home care as a component of hospital care. In this category home care is usually tightly integrated into the hospital system, in fact, in some cases it is difficult to identify where hospital care ends and home care begins. The final section treats home care as a component of the overall health system as a part of health care planning.

**Ambulatory Care**

As was suggested in the previous paragraph the sources that are contained in this section do not present home care as being well integrated with ambulatory care. All of these sources are from developing nations, with the exception of one source from Romania (Tataru, 1997). In two sources, home care is merely mentioned as a part of the existing ambulatory care that is available to elderly persons (Miralles et al., 1998; Kaplan et al., 1995) or as a desired component that has not yet been made available (Al Shammari, 1997). Tataru describes a new community care centre for the care of ambulatory and semi-ambulatory elderly persons affiliated with a neuropsychiatric hospital. This source is useful as a potential guide to others who are considering or actively planning a similar facility as it provides details on the establishment of this centre. The Miralles and Kimberlin article is primarily concerned with access to and availability of medications to ambulatory elderly patients, including those who are using home care in Brazil. Kaplan and DiTrollo make only passing reference to home care in their discussion of the care of elderly patients with cardiac disease in Argentina. In the final source, Al Shammari describes differences between hospital physicians and primary care physicians in Saudi Arabia in their practice patterns and opinions about home visiting of elderly patients. In the case of primary care physicians, their practice behaviour and attitudes relative to home visiting are very similar to those of physician- or nurse-led home care teams in other jurisdictions as discussed in the previous grouping of resources relative to home care staffing.

**Community Care**

Similar to the ambulatory care sources, many of the sources in this section discuss home care without much indication of home care being integrated with community care, even in those jurisdictions with relatively well-developed home care programmes. In most cases, efforts to better integrate home care with what is usually considered to be the broader community care programmes is either an explicit goal or recognized as desirable. The initial source (Buss, 1994) reports that most older persons and their informal caregivers prefer long-term care to be community based. This article nicely sets the stage for the discussion in the second source (Arnold et al., 1993) of the need for adequate and appropriate housing as a major concern for those planning and delivering community care in the U.K. They recommend that there be better coordination in the planning of community care programmes with housing investment programmes. In the third source, the author (Clark, 1996) provides a thorough overview of community-
based, long-term care in the U.S. Clark specifically addresses home care within this article. In contrast, the other overview source (Vargas, 1992) barely mentions home care in the report on the Pan-American Health Organization (PAHO) survey of community care and the ageing population in selected Latin American and Caribbean countries.

A next set of sources (Chan, 1993; Havens et al., 1993; Hildebrandt, 1994; Leutz, 1976) address community care from the perspective of community development. Based on a survey in China, Chan reports on the use of neighbourhood services in Guangzhou and particularly notes that those over 50 were very much over-represented among the volunteers of these services. Seniors, as the volunteer providers of local community services, are an important aspect in the Canadian example as described by Havens and Kyle. This source also provides rural as well as urban examples. Hildebrandt describes the community development process used in one area of South Africa to empower residents and to develop a range of community care responses to address the needs of older members of the community. Leutz identified indigenous caregivers in a New York City neighbourhood and suggests that formal community care agencies would be well advised to search out and involve these local caregivers in delivering services to elderly persons in the neighbourhoods.

The final sources in this section (Pushpangadan et al., 1996; Sahai, 1992; Scharf et al., 1995) are descriptive sources that relate to the delivery of community services. Pushpangadan provides examples of some innovative collaborations that have increased flexibility in the delivery of community care in one area of the U.K. Sahai provides another example from the U.K. based on community care nursing. Finally, the Scharf and Wenger source is a book that brings together "best practice" examples from eleven countries and in addition is noteworthy because of its explicit inclusion of rural community care examples from across much of Europe.

**Hospital Delivery of Home Care**

The sources in this section relate to hospital care; generally, in acute care or community hospitals (Tomlinson et al., 1995; Hickey et al., 1997). Most sources (Mor et al., 1987; Koren et al., 1986; Havlir et al., 1989; Hughes et al., 1992; Tolkoiff-Rubin et al., 1978) address the delivery of home care services from these hospitals. In the first source, Tomlinson and associates indicate that as fewer general or community hospital beds are being retained in the system in the U.K., data about the use of these beds are needed to enable patients, caregivers, physicians and other health professionals and planners to use these reduced resources most effectively. Hickey and colleagues studied the use of non-psychiatric hospital beds by patients suffering with dementia in one area of Ireland before the development of a geri-psychiatry programme with associated services. They demonstrated that in the absence of specialized services, preferably in the community, demented elderly persons will become inappropriate patients in acute
and long stay hospital beds, especially in medical units. In most cases, these patients do not require medical services but no appropriate services were available to meet their needs or those of their caregivers.

The source by Mor and associates explicitly identifies one home care programme as an extension of the hospital that was considered to be responsible for home care. The "patients" served by this programme are described as being old, having multiple medical problems and being homebound. Described in the article by Koren and Schrage is a psychiatric home care programme that was developed by a psychiatric consultation service of a major U.S. hospital. The patients, at least initially, all had a primary medical diagnosis but required psychiatric assessment or intervention. The next two sources (Havlir et al., 1989; Hughes et al., 1992) deal with home care for terminal patients who were associated with Veterans' Administration (VA) hospitals. In the first of these articles, the authors describe the development of do-not-resuscitate (DNR) decisions in one veterans' hospital-based home care programme. The second article reports on a randomized trial of hospital-based home care with terminally ill veterans. They measured the satisfaction of the patients and their caregivers as well as the costs of all services received. They conclude that the VA can expand their hospital-based home care programme to the terminally ill at no additional cost but with higher levels of satisfaction on the part of both patients and their caregivers. The final source by Tolkoff and associates describes another kind of hospital-based home care, where the home care programme is actually administered by a national voluntary agency on behalf of the hospital. This is a major deviation from the usual internal administration of hospital-based home care programmes and is included in this bibliography for this reason.

Health Care Planning

This section is a very diverse, lengthy and relatively general section where home care is viewed as a component of the health care system in question. Many of these sources specifically identify some aspect of the planning process and most of them explicitly address home care as a system component. In view of its length, this section is subdivided into several subsections. It starts with an overview followed by a subsection based on service and planning models, one that highlights survey-based information, another that deals with the planning process and finally a relatively diverse miscellaneous sub-section.

• Overview

Three sources (Kalache et al., 1998; Bowe, 1990; Kalache et al., 1995) present a systems overview of health care, including home care with ageing populations. Four additional sources (Berthold et al., 1994; Hollander et al., 1995; Havens, 1990; Havens, 1995) present the issues related to the appropriate choice
of home care or residential care. Kalache and Kickbusch present a global view of health and ageing from the perspective of WHO. Bowe’s article is also global but is more related to disabled persons than to ageing persons per se. Kalache and Coombes describe the health and ageing of Latin American populations. Berthold and associates discuss the differences between those in nursing homes and those using home care. In their Swedish study, they identified several nursing home residents who could have received adequate care at home, however very few of these residents were interested in leaving the nursing home. They conclude that if alternative forms of care are to be offered, residents must be presented with the possibility of these alternatives prior to admission. In the three Canadian sources (Hollander et al., 1995; Havens, 1990; Havens, 1995) the authors describe the operation of single point of entry systems in determining whether home care or residential care is more appropriate to the individual. The systems that they describe operate with a single administration and use uniform assessments of the need for care regardless of where that care is received.

- Service Models

The next four sources (Browne et al., 1995; Kennie, 1984; Weissert, 1990; Lamb, 1997) are related to service and planning models relative to health and ageing, usually including home care. Based on five studies, each one using a different care model, Browne and her colleagues conclude that offering a complete proactive health programme to chronically ill elderly persons in the early stages of their illness both increases well-being and reduces the cost of services. Kennie raises the question of whether the health maintenance model of care is appropriate to older persons, which results in the author asking whether resources are best invested in health maintenance programmes with ageing populations. Weissert indicates that home care can be made more cost effective by basing service planning on the known characteristics of the population to be targeted as potential home care users. Lamb recommends using gender-specific modeling to predict levels and amounts of disability in Egypt and hence need for services.

- Survey Based Information

Several sources (Bartlett et al., 1997; Davis et al., 1995; Dick et al., 1978; Droste, 1977; Factor et al., 1985) reported on surveys that were used for health care planning in view of an ageing population. Bartlett and Phillips report on a survey conducted in an urban centre in China and conclude that more capacity to provide care at home and in the community is needed in the face of decreasing family size. Davis and her colleagues also report results from a Chinese survey of caregivers and care receivers and arrive at virtually the same conclusions as Bartlett and Phillips. Dick and associates report on a survey conducted in South Africa that highlighted the need for comprehensive planning of health care and economic security of chronically ill persons. Also from a South African survey,
Droskie calls for closer cooperation among sectors, especially between physicians and non-governmental organizations. Factor and Habib reported results from a survey in Israel that enabled them to project an increased need for residential long-term care.

- Planning Process

A large number of sources are focused specifically on the planning process and outcomes. For example, a Japanese source (Ishizaki et al., 1995) explains that obtaining physical, mental and socioeconomic information from new residents of a geriatric intermediate care facility enabled the authors to predict whether residents will be discharged to their own homes or remain in the facility for an extended period. Litwin in a source from Israel (Litwin, 1997) used the types of support networks to predict the level of service use. In a Canadian source (McWilliam et al., 1994) the authors identified variations in the quality of care outcomes between urban and rural areas which has important implications for service planners. In a Nigerian source (Togonu, 1985) the author reports that self-perceived health status was a useful measure to use in planning health care utilization. The Netherlands, according to another source (Schrijvers et al., 1993) has been attempting to provide more terminal care in the home as opposed to providing such care in hospitals or nursing homes. Schrijvers and Dingemans conclude that the lack of cooperation among medical professions coupled with a lack of comprehensiveness within the primary health care system are the major barriers to meeting the planners’ goal of providing more terminal home care. A research team in Zimbabwe identified a planning problem in their study of three community types as reported in the next source (Wilson et al., 1991). These authors suggest that physical decline is typically followed rapidly by death, in large part due to a lack of medical and physical support available to elderly Zimbabweans. In another source from Zimbabwe (Matenga, 1994) the author recommends, based on the cost of care for terminal AIDS patients in developing nations, that these nations develop plans that would deliver care to these patients through nationally supported models focusing on home care programmes. In another source (Benjamin, 1988) relative to care of AIDS patients, the author warns that the preoccupation with community-based care derived in large part from models designed to deliver home care to elderly clients, may be inappropriate to the AIDS community. Benjamin takes this position based on the greater need of AIDS patients for medical care in the process of dealing with their disease.

Very little attention has been paid specifically to institutional long-term care in this bibliography; however, in view of the expectation that those using home care will not need institutional care, a selection of three sources have been included here (Shapiro et al., 1984; Shapiro et al., 1985; Jette et al., 1995). In the first source by Shapiro, she and Westbster identify the characteristics of institutional long term care users in an fully insured long term care system. In the second article, Shapiro and Tate extend the discussion to the area of predictors of institutional long-term care use. The strongest predictors were age and living
alone while health and functional statuses were found to be weaker predictors. In
the final source in this subsection, Jette and his colleagues likewise found that
service use and socio-demographic factors were strong indicators of institutional
long-term care use. They found that those older persons who were receiving more
formal services and whose informal caregivers were male were at greater risk for
institutional long-term care. By contrast, those older persons who lived in the
same household as their informal caregivers were at slightly less risk for
institutional long-term care.

- Miscellaneous

Five sources (Zhao et al., 1993; Woo, 1987; Al Shammar et al., 1997;
Jitapunkul et al., 1993; Yamamoto et al., 1992) while related to health care
planning simply do not fit in any of the previous subsections and are therefore
dealt with here as a miscellaneous selection. Zhao and associates found that
among a cohort of frail elderly people in Osaka, poor housing was strongly
associated with increased mortality. In Hong Kong, Woo determined that
supportive or sheltered housing programmes were important in the geriatric care of
frail elders. Al Shammar and associates reported that although physicians in
Saudi Arabia felt that almost half of their elderly hospitalized patients could be
cared for at home, less than half of these patients and over two-thirds of their
relatives preferred institutional care. Based on this preference, which is contrary
to the choices expressed in most jurisdictions, these authors recommend finding
more cost-effective facilities that will provide culturally acceptable alternatives to
these patients and their families. The final two sources deal with information
system needs relative to the planning process. Based on a study in Thailand,
Jitapunkul and associates recommend that health care for elderly people be
integrated with the overall primary care systems rather than developing separate
services. They point out that data on disability and life expectancy are essential
for health care planning, but they also identify these data as being insufficient in
many developing nations. The Japanese authors (Yamamoto et al., 1992) describe
the medical information system as an important component for the community
health care system planning process. They suggest that despite the problems
encountered in implementing the medical information system, its importance to
the planning process makes it an essential component of the overall system now
and even more in the future.

Conclusion:

It is hoped that this wide ranging and diverse selection and grouping of
sources relative to home care around the world is sufficiently well organized and
annotated to be useful to a wide variety of readers. However, readers are
reminded that there is a wealth of literature related to some aspects of this
annotated bibliography that has not been selected for inclusion. Much of the
additional literature is from European and North American jurisdictions and was deemed to be neither sufficiently transferable nor suitable for adaptation to the developing world. It is hoped that most of the original sources cited in this bibliography will be relatively easy for the reader to access, which is the reason that very few monographs, government documents and books have been included. Readers who have specific needs for information on selected aspects of the bibliography are encouraged to undertake additional searches of the electronic data bases used to develop this document.
PART II
ANNOTATED BIBLIOGRAPHY
Detailed Literature Review

Introduction:

Part II provides the complete citations, keywords, abstracts and more details on each of the studies identified in Part I of this Annotated Bibliography. These are presented in the same order as Part I.

Home Care Policy:

This first group of references is primarily concerned with policy issues, although service delivery issues are included in some of the sources. Many of these sources deal with policies that are broader than home care, but in most cases, home care policy is the major focus of the material. This section is organized primarily by geography to enable the reader either to immediately move to a particular subsection or to discard one or more subsections. Most of these articles are not based on research as they are more often developed from program or service experiences; that is, “best practice” material. Some sources are policy documents with a minimum of interpretation. However, they are reflective of the state of knowledge in the field of home care policy and tend to have a forward-looking perspective.

Policy Overview


Keywords: Policy Overview/Health Care Planning/Disabled/Elderly/Disabilities/United Nations/Projection/Development/Disability/Rehabilitation/Employment/Support

Abstract: While disabilities occur in all societies, their causes and effects differ in the First (developed), Second (communist) and Third (developing) “worlds”. Of the 500 million persons with disabilities, about 80% live in the Third World, and United Nations projections suggest that the proportion soon will be 90%. Two values, integration and normalization, may guide development of national policies in all three worlds. In addition, two design principles, accessibility and adaptability, may prove useful. It may also be that information-age technology will assist in disability prevention and rehabilitation, as well as in employment of
individuals with disabilities. First World economies facilitate application of
technology to meet special needs, Second World economies impede that, and
Third World economies often cannot support it. The challenge for policy makers is
to find ways of bringing together integration, normalization, accessibility and
adaptability so as to help nations fashion cost-effective solutions to their disability-
related problems.

Care for Older People. 243p. Brookfield, VT, Avebury, Aldershot, Hants,
England; and Ashgate Pub Co.

Keywords: Policy Europe/Community Care/Health/Aging/Europe/
Roles/Family/Review/Older Adults/Adults/Support/Rural/United
Kingdom/Netherlands/Canada/United States/State/England/Model/
Training/AgeLine: (Community Care NOT Home Care)/Models/Outside United
States/Conference Proceedings/Health Services/Social Services/
Community Services/Long-term Care/Informal Support Systems/Public Policy

Notes: Presents 11 papers that address common issues associated with transitions
in health and social care provision from an international conference (Ageing in
Europe: Innovation and Good Practice in Community Care) that took place in
Wales in October, 1993. Discusses the future of eldercare in Europe, examines the
status and role of families and women and suggests way in which greater
involvement for users of services can be developed. Reviews trends in community
care goals and in service provision concerning long-term care and discusses trade-
offs between these trends in a variety of countries. Examines variation in the
capacity of older adults for participation in formal community care decisions
affecting their own situation. Identifies five different types of informal support
networks among older adults. Reviews the distribution of different types of
support networks in rural areas of Wales (United Kingdom) and the Netherlands.
Examines the social integration of older adults in the rural areas of a range of
European countries. Explores policy and service changes in the Netherlands since
the 1980’s. Analyses the concepts of subsidiarity and empowerment and illustrates
the discussion with examples from Canada, the United States, and England.
Provides background information on the Baden-Wurttemberg model regions
project, a German community care project that has increased self reliance in older
adults. Describes two projects that demonstrate how constructive training
partnerships between West and East can be developed. Includes chapter
references. (AR) (AgeLine Database, ©1996, American Association of Retired
Persons, all rights reserved).

Hedrick, S. C. and Inui, T. S. (1986). The Effectiveness and Cost of Home Care:

Keywords: Policy Overview/Costs/Home/Home Care/Patients/
Outcomes/Chronically Ill/Mortality/Nursing/Nursing Home/Nursing Home
Placement/Hospitalisation/Hospitals/Ambulatory Care/
Family/Quality of Life/Quality of Care/MED66-2.(JMC)GOWAN)
Notes: 86139192 The effect of home care on patient outcomes and costs of care has been controversial. This information synthesis summarises results from studies of home care using experimental or quasi-experimental designs, explicitly including judgements of methodological soundness in weighing the results. In 12 studies of programs targeted at chronically-ill populations, home care services appear to have no impact on mortality, patient functioning, or nursing home placements. Across studies, these services either have no effect on hospitalisation or tend to increase the number of hospital days; ambulatory care utilisation may be increased by 40%. The cost of care either is not affected or is actually increased by 15%. The critical need at present is for better designed studies to test the effects of different types of home care, targeted at various types of patients, on the outcomes assessed in the existing studies, as well as on other important outcomes such as family finances, quality of life, and quality of care 8606.

Policy Comparisons


Keywords: Policy Comparisons/Home/Home Care/Denmark/United Kingdom/Germany/United States/State/Support/Hospitals/Institutionalization/Quality of Life/Caregivers/Health/Social Services/Treatment/ Economic/Frail Elderly/Elderly/AgeLine: Homecare/Cross Cultural Studies/Home Health Care/Homemaker Services/Public Policy/ Older Adults/Outside United States

Notes: Compares policy trends and the provision of home care in four countries: Denmark, the United Kingdom, Germany, and the United States. The reasons behind the support for home care vary. The goals include “unblocking” hospital beds, reducing the rate of institutionalisation, and improving the quality of life of older people and their caregivers. There are some fundamental differences between Denmark and the United Kingdom, on the one hand, and Germany and the United States, on the other. These differences are to a large extent due to differences in their health and social service systems. Thus, in Denmark and the United Kingdom, the need for home care as a general support service independent of sickness is recognized in practice, and services are available and allocated according to professionally perceived needs. The difference between these two countries is in the amount of care available and therefore the extent to which needs are covered. In Germany and the United States, the nature of the system is such that care--as opposed to medical treatment--is not automatically recognized as a matter of public provision, and clients as well as providers are driven towards medicalizing the problems of older people to obtain financial coverage. For economic as well as political reasons it is possible that more of the burden of care will be pushed onto informal caregivers, at least in three of the countries reviewed, and that governments will concentrate on targeting those who would clearly pose a burden on hospitals or who are at a crisis point. On this basis, it is considered unlikely that home care provision for frail elderly people will expand significantly
in the foreseeable future. (WD) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


**Keywords:** Policy Comparisons/Elderly/Family/Welfare/State/International/Social Policy/Article/Social Services/Support/United Kingdom/Sweden/United States/Home/Home Care/Canada/Netherlands/Chome/Italy/Ageline: Homecare/Older Adults/Caregivers/Outside United States/Frail Elderly/Supportive Services/Cross Cultural Studies/Informal Support Systems/Public Policy

**Notes:** Presents ways in which national social policy systems are attempting to respond to care needs among dependent elders. This collection of articles by multiple authors is based on overviews of seven industrial countries. Articles examine government interventions targeting frail elders and situate these in the framework of demographic change and a history of social services and social policy. They identify current challenges and highlight certain response strategies. Particular attention is accorded to links and the breakdown of ties between formal and informal support initiatives and between public and family support systems. Key government policies include an explicitly reduced commitment of public resources in the United Kingdom, an extremely extensive system of government intervention in Sweden, limited involvement in protection systems in the United States, broad public home care support systems in Canada, new care insurance schemes in the Netherlands, and deeply rooted traditions of state social services in France and Italy. (AR) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


**Keywords:** Policy Comparisons/Community Care/Development/Community/Elderly/Work/Israel/Canada/State/Economic/Welfare/Long-term Care/Home/Service Delivery/Funding/Health/Social Services/Private Sector/Relative/Family/Caregivers/MESED1.MDL (MEDLINE 1993-7: PRIMARY RESEARCH)/A:/B:/C:/D:/Relatives

**Notes:** 97062707 Paul Baerwald School of Social Work, Hebrew University of Jerusalem, Israel. A comparison of the development of community care for the elderly in the province of Ontario, Canada, and in the State of Israel is presented in the light of the economic constraints currently challenging the expansion of welfare state services. The inquiry identified several common issues regarding the nature of the policy mandate for long-term care delivered in the home, the structure of the service delivery system and matters concerning funding arrangements for community care. Issues that emerged in both settings include the relationship between health and social services in the delivery of care at the local level; the separation of purchaser and provider functions; the question of needs-driven versus service-driven social care provisions; accessibility concerns and the
aspiration for one-stop entry to the delivery system; the growing involvement of the private sector in the delivery of domiciliary-based personal care services; and the relative paucity of current efforts to address the needs of family caregivers.

_**Keywords:** Home Care With Elderly Clients/Policy Comparisons/Policy Europe/Financing/Disabled/Home Care/Nursing/Nursing Homes/Home  
_**Abstract:** All EEC countries are faced with an ageing population which means an increase of people in some way disabled in everyday activities. A comparison of the solutions adopted by five EEC countries in the sectors of housing, home care services, residential and nursing homes shows that a real medico-social policy has been worked out only in some countries where as in others public authorities have defined policies without providing corresponding resources. The concept of social protection appears to be one major factor which may account for these differences.

_**Keywords:** Policy Comparisons/Home/Home Care/Benefits/Review/United States/State/Long-term Care/Long-term Care Insurance/Disability/Funding/AgeLine: Homecare/Older Adults/Outside United States/International/Public Sector/Federal Funding/Financing/Public Policy/Insurance Benefits  
_**Notes:** Presents a framework identifying important home care benefit design decisions and reviews the existing designs that have been adopted in practice. Four basic designs were identified, based on a review of 55 home care benefits drawn from public programs in the United States and foreign countries, and from private long-term care insurance policies in the United States. Three of these designs--service entitlements, managed service benefits, and cash disability allowances--have each been adopted by public programs in the United States and abroad, and by private insurance policies in the United States. A fourth design--individualised cash benefits--has been adopted in only one experimental program. The home care benefit designs observed in practice are remarkably varied, providing a good deal of experience and a wide range of designs. Information is lacking, however, that ties the various designs to specific policy goals. It is recommended that investments be made in understanding the effects of alternative home care designs to ensure that public funding is spent on designs that best meet policy goals. (AR) _AgeLine Database_, ©1996, American Association of Retired Persons, all rights reserved.

_**Keywords:** Policy Comparisons/Home/Home Care/Review/Europe/Outcomes/Patients/Relative/Caregivers/Quality of Life/Institutional Care/
Longitudinal Study/AgeLine: Homecare/Relatives/Gerontological Research/Literature Review/Public Policy/United States/Canada/ Assessment/Non-institutionalized Elderly/Older Adults/Outside United States/International

Notes: Examines current literature on home care to assess its relevance for policy or program implementation. The review of literature in English from North America and Europe looks at the following three primary areas: Predictors of home care services, understanding the home care experience, and outcomes for users of home care. Studies on the use of home care services concentrate on the patients’ relative physical and mental functioning as a major predictor, but they often ignore other structural factors affecting home care, such as the availability of alternative services or informal caregivers. Studies on the experience of home care focus primarily on program implementation issues rather than macro policy issues. Studies have not found that outcomes of home care are less costly or necessarily better for the quality of life of seniors when compared with institutional care. Overall, the home care literature is guided by applied questions of value to policymakers and programmers. An absence is noted of longitudinal studies of the long-term preventive effects of home care. (TS) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).

Caregiver Policy


Keywords: Policy Caregivers/Home/Home Care/Home Care Workers/ Workers/Roles/Disabled/Hospitals/Public Policy/Nursing/Nursing Home/ Caregivers/Costs/Female/Model/Wages/Employment/Benefits/Work/ Patients/Training/State/Reimbursement/Health/Welfare/Welfare Policy/ Health Care System/AgeLine: Homecare/Nursing Homes/Females/ Models/Policy Making/Paraprofessional Personnel/Market Forces/Labour Force/Older Adults/United States

Notes: Discusses the supply and demand for home care workers and the role of the government in overcoming barriers to change in the home care labour market. During the 1980’s, demand for home care increased dramatically as disabled elders expressed their preference for living at home, hospital payment systems encouraged short stays, and public policy responded to efforts to limit growth in nursing home expenditures. Other factors influencing the demand for home-care workers included intensity of utilisation, availability of informal caregivers, and cost. The supply of home care workers relies on the existence of a group of “traditional workers”—persons, primarily female, with limited education and few opportunities. According to a traditional supply and demand model, any shortage of home care workers should not persist in the long run because new workers would enter the market in response to increased wages. There is a suggestion that home care workers occupy a secondary labour market with systemic rigidities that prevent firms from providing stable employment and high wages to their workers.
Issues other than low wages and lack of benefits affect the desirability of home care work, including long commutes to patients, little training, few opportunities for advancement, and the isolating and monotonous aspects of the job. Neither the supply/demand nor the secondary labour market model seems appropriate to the study of the demand and supply of home care workers because of the role of the government--federal, state, and local---as principal payer and regulator. It is anticipated that without structural change, there will be shortages of home care workers in the years to come. Three policy approaches are set forth: Reimbursement policies could be changed to make home care jobs more desirable in terms of wages, benefits, and opportunities for advancement; the minimum wage could be increased; federally-subsidised health care could be offered and welfare policies could be modified to stabilise and enhance the low wage labour market; and the health care system could be made more coherent and more cohesive to avoid contradictory policymaking. (It is noted that there is an irony in providing home care to some persons using workers who have access to little health care themselves.) (UH) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


**Keywords:** Policy Caregivers/Managed Care/Female/Caregivers/ Hospitals/Home/Article/Nursing/Nurses/Family/Costs/Cost Containment/ Patients/Support/Females/COSTM1.MDL/A:/B:/C:/D:

**Notes:** 97273683 This article explores the connection between layoffs of nursing staff in hospitals, replacement of nurses with poorly-trained aides, and the increasing burden on female family caregivers. It also discusses the centrepiece of managed care’s cost containment efforts--reduced use of the hospital and earlier discharge of patients to the home. The article argues that these policies add to an increasing burden of care on female family caregivers and that U.S. family policy does not support family caregiving. Finally, it recommends rigorous research to assess the social, emotional, and financial costs of nursing layoffs on nurses themselves as well as on female family caregivers.


**Keywords:** Policy Caregivers/Home/Home Care/Survey/Workers/Work/ Community/Quality of Life/Family/Caregivers/Female/Employment/State/ Wages/Benefits/Home Care Workers/HS2REF.TXT/A:/B:/C:/D:/Females

**Notes:** 94259483 University of Washington School of Social Work Home Care Services makes it possible for millions of older Americans to continue living in the community. Such services may enhance the recipients’ quality of life while providing essential respite to family caregivers. But while there has been increasing recognition of the burden borne by the predominantly female family caregivers, there has been less attention to the plight of the home care workforce. With the growth of the home care industry, the burden of care has to some extent
shifted from one category of female caregivers to another. This paper, based on a survey of 16 agencies and 1,900 workers, examines the employment conditions of home care workers in Washington State. The study reveals a pattern of harsh working conditions, low wages, and few benefits. The findings raise questions about the ethics and efficacy of government policies that are based on the exploitation of home-care workers. (Abstract by: Author).

**Keywords:** Policy Caregivers/Home/Home Care/Reimbursement/Review/Home-Care Workers/Workers/State/Costs/Cost Containment/Work/Careers/Funding/Financing/Personal Care/Wages/Benefits/Training/Health/Health Service/Social Services/AgeLine: Homecare/ Health Services/Health Service Costs/Public Policy/Paraprofessional Personnel/Literature Review/Home Care Agencies/Older Adults/United States  
**Notes:** Reviews the literature on the effects of reimbursement methods on providers’ ability to attract paraprofessional home care workers. In recent years, government agencies--federal and state--have effectively used the amount and structure of reimbursement rates to achieve such policy goals as cost containment, provision of high quality care, and adequate access to care. Several studies reviewed here demonstrate that reimbursement methods and policies (along with unreliable hours of work, inadequate supervision, poor job image, and lack of career ladders) are important reasons that agencies which are heavily dependent on public funding have problems offering competitive working conditions to potential and current employees. State agencies vary in the ways they establish rates, and within states, essentially the same service can be reimbursed at widely different rates. With so many rates and rate methods, providers must maintain a “payer mix” that allows them to cover their costs. They are particularly vulnerable if the vast majority of their business comes from a single-payer source and there is a change in policy or financing. Further, if reimbursement systems are not sensitive to case- mix changes, providers may be inclined to seek out “easy” care cases or to underserve complex cases. The merits of prospective payment schemes such as bid-payment and negotiated-payment systems are considered. Other innovations include the use of overhead allocations, optional incentive programs, personal care add-ons, final settlements, and enforcement of a mandatory wage and benefits floor. Given the reliance of the home care industry on an adequate supply of competent workers, providers and payers need to more clearly articulate desired service features and establish appropriate reimbursement rates that allow providers to compete in offering the needed care. Policy alternatives to improve recruitment and retention of home-care workers are set forth: State agencies could collaborate on uniform job definitions, training requirements, and career ladders that cross over programs; public payers could establish pay equity across long-term care settings to provide equal incentives for workers choosing between institutional and home care jobs; financing could be viewed as a health service, not split, as it currently is, between health and social service sources. (UH) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).

**Keywords:** Policy Caregivers/Family/Elderly/Roles/Public Policy/Support/Home/Relatives/Institutionalization/Taxes/MEDLINE 1966-92/A:/B:/C:/D:/Home Care/Policy/Care/Caregiving/Demographics/Trends/The Elderly

**Notes:** 86203114 There is little evidence to support the belief--and many policy initiatives flowing from it--that families are less willing or able to provide home care to elderly relatives. Informal caregiving remains at a high level; institutionalization rates have changed little over the past 30 years. But some demographic trends affecting both the elderly and families may change this picture in the future. Proposals for providing cash grants or tax allowances do not get to the heart of the matter.


**Keywords:** Policy Caregivers/Home/Home Care/Organizations/Family/Decision Making/Care Receivers/Caregivers/Welfare/State/Quality Assurance/Case Study/United Kingdom/United States/AgeLine: Home-care/Home Health Care/Cultural Anthropology/Public Policy/Family Relationships/Older Adults/Outside United States

**Notes:** Explores the home care experience, focusing on the social context of the home, how the caregiving process changes it, and how researchers can conduct quality research in these settings. Addresses the culture and social organization of the household as a care setting--its adaptations, ritual borders, cultural variations, crisis resolutions, interpersonal histories, and dynamics of affection. Discusses the diversity of caregiving relationships, highlighting the various "others" who enter into the care experience, ranging from family members and distant kin to neighbours, friends, and ostensible strangers. Illustrates how definitional and decision making issues in home care intertwine, regardless of the age of care receivers and caregivers. Raises policy questions concerning the borders of household care and its privacies on the one hand and the increasing demand for surveillance by a welfare state intent on quality assurance in the care of its citizenry on the other. Includes chapter references and case studies from both the United Kingdom and the United States. (WD) *AgeLine Database*, ©1991 American Association of Retired Persons, all rights reserved.


**Keywords:** Policy Caregivers/Home/Home Health Care/Support/Disabled/Elderly/Informal Care/Long-term Care/Survey/Interviews/Disability/Health/Income/Caregiver/AgeLine: Homecare/Disabilities/Marital Status/Supportive Services/Informal Support Systems/Community Services

**Notes:** Analysed whether the provision of paid home care for disabled elderly persons leads to a decline in the level of informal care. Data were drawn from the
1982 National Long-term Care Survey, which included personal interviews with more than 6,000 functionally impaired, elderly persons. Respondents identified any help they had received because of their disability or health problem as formal (paid) or informal (unpaid). Those who used formal care were the focus of this study; they were classified into four subgroups of the disabled elderly—the mentally intact, those with higher than average incomes, those who lived alone, and those who were restricted in three or more activities of daily living or who suffered cognitive impairment. The results suggest that for all disabled elderly with paid home care, the amount of formal care received in the previous week did not significantly reduce the amount of informal home care they received during the same period. This conclusion held for the four subgroups of care users, among whom substitution was expected. In fact, the informal caregivers significantly increased the amount of care they provided for the most severely disabled group. The quantity of informal care received was more strongly influenced by the care recipient’s physical or mental disability, level of income, marital status, and number of children. It is concluded that paid help for the elderly does not mean less unpaid help. (UH) (AgeLine Database, ©1991, American Association of Retired Persons, all rights reserved).


**Keywords:** Policy Caregivers/Health/Caregivers/Review/Family/Home/Support/Disabilities/Home Care/Hospitals/Nursing/Nursing Homes/Outpatients/Community/Community Care/Ageing/Disability/Development/Community Services/Social Policy/Health Promotion/Funding/MED92-2.(IMCIGWAN)/A:/B:/C:/D:

**Notes:** 94114662 Department of Psychiatry, University of Melbourne. Informal caregivers are the families and other unpaid caregivers in the home who support people of all ages with severe and chronic mental or physical disabilities. Home care of this sort has been increasing over the past 30 years because of the reduced number of beds in hospitals and nursing homes and increased outpatient and community care. Moreover, with an ageing population and increasing rates of disability, the demand for family caregiving will continue to rise. This has important implications for the development of health, community service and social policy. At the same time, however, very little is known about the impact such changes are having on the caregivers of various ages and in various circumstances. The Victorian Health Promotion Foundation is funding a research and intervention program in Melbourne to promote well-being and prevent ill health in caregivers 9404.


**Keywords:** Home Care - Caregivers/Policy Caregivers/Family/England/Costs/Long-term Care/Community/Caregivers/Roles/Home/Disabled/MESE4.MDL (MEDLINE 1993-7:PRIMARY RESEARCH)/
A/B/C/D

Notes: 94066925 Institute for Studies on Ageing, New England Research Institute, Watertown, MA 02172. The focus on rising costs of long-term care now encompasses community as well as institutional care. Policy makers cite the potential impact of changing social trends on informal caregivers’ availability to continue as the main source of care and the possibility that formal services will then replace this informal care. They fear that families will relinquish their caregiving role if publicly funded home care services are available. Longitudinal data from a sample of disabled elders were used to investigate the substitution of formal services for informal care over a seven-year period. The substitution that was detected could be traced to the limited availability of informal care, and it represented a temporary change in the informal care pattern rather than a permanent replacement for it. Instead, use of formal services has supported the elderly person’s continued residence in the community.


Keywords: Policy Caregivers/Health/Community/Home/Elderly/Disabled/Roles/Family/Social Policy/MED92-2./JMCGOWAN/

Notes: 94012270 Current Canadian health policy is based on the implicit assumption that women are available to provide care in the home to the dependent, the ill, the elderly, and the physically and mentally disabled. Women are socialised from birth to accept caring roles within a traditional family structure, and current societal expectations and social policy reinforce this value system. Women’s health can only be understood within the context of their lived experience of social inequity, medicalization, and family caregiving. Health care professionals are complicit in sustaining women’s oppression by reinforcing these institutions of social control. For health policy to be responsive to women’s needs, it must be based on research that considers the social complexity of ordinary women’s lives.


Keywords: Policy Caregivers/Private Sector/Survey/Caregiving/Employment/Workplace/Community Care/Employers/Health/Health Promotion/Questionnaire/Support/Community/Policy/Analysis/Care

Abstract: The aim of the study was to examine Scottish private sector employers’ policies with regard to flexible working arrangements for carers of physically and mentally impaired older people. The questions addressed by this study were as follows: 1.) Are employers aware of the needs of carers? 2.) To what extent do they view carers’ needs or responsibilities as problematic? 3.) What proportion of companies have specific policies regarding flexible working arrangements to accommodate carers’ responsibilities? 4.) What is the “nature” of these policies? 5.) Are flexible policies with regard to caregiving responsibilities viewed by companies as part of “health promotion” in the workplace? 6.) In what ways do company characteristics influence policy on carers’ responsibilities?, and

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7.) What, if any, initiatives have been adopted to help employees plan for caregiving responsibilities? One thousand questionnaires were sent to companies drawn from the Scottish Chamber of Commerce National Directory 1993; 32% were returned completed and in time for analysis. The majority (92%) of companies had never previously considered the issue of employees' elder care responsibilities. Although expressing considerable sympathy, as well as some responsiveness and flexibility with regard to working arrangements for caregiving employees, the results of the survey indicate that Scottish companies in the private sector are providing little in the way of direct or indirect support to the UK community care reforms. However, informal contacts during the project indicated that the public and voluntary sectors may be more flexible and have begun to develop specific policies with regard to the needs of caregiving employees.

Policy Issues in the United Kingdom


Keywords: Policy United Kingdom/Community/Community Care
Home/Great Britain/Legislation/Support/Personal Care/Nursing/Nursing
Home/United Kingdom/Costs/Survey/Physicians/Geriatrics/Hospitals/
Elderly/Patients/Nursing Homes/Volunteers/Organizations/Roles/Level
of Care/Long-term Care/Social Services/AgeLine: (Community Care NOT Home Care)/Home Care/Outside United States/England/Older Adults/
Day Care Services/Government Services/Community Services/
Non-institutionalized Elderly/Respite Care/Service Delivery

Notes: Evaluates how the 1990 Community Care Act has affected delivery of home care, day care, and respite services to community-dwelling elders in Great Britain. The legislation was enacted to encourage communities to provide appropriate support to elders while promoting personal choice and control. Local authorities must provide community-dwelling elders with necessary assistance in personal care, housework, shopping, meal provision, and home adaptation. Elders also have the option of being transferred from home to any residential or nursing home in the United Kingdom, at the cost of the local authority. Local authorities, however, are free to interpret the guidelines as they choose. A recent survey indicated that 85% of physicians thought that community care services had deteriorated or had not improved in the past year, and 72% of geriatric physicians indicated that service delays were blocking hospital discharge of elderly patients. Owners of private residential and nursing homes feel that they are not getting sufficient referrals, and volunteer organizations and charities must cope with the problems of an increasing number of community-dwelling elders. General practitioners play a key role in ensuring that elders receive the appropriate level of care required. Sidebars provide advice on planning for long-term care fees and suggestions for obtaining necessary social services. Addresses of community care resource organizations are provided. (PH) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).

**Keywords:** Policy United Kingdom/Social Policy/Elderly/Roles/
Community/Community Care/Gerontology/Caregivers/Respite
Care/Support/Home/Care Management/Management/Consumers/
Satisfaction/Nursing/Housing/Institutional Care/AgeLine: (Social or Health Policy AND Home Care or Community Care)/England/Housing Programs/ Housing Improvement/Public Policy/Community Services/Patient Care/
Home Care/Service Utilisation/Older Adults/Outside United States

**Notes:** Examined the role of community care in British social policy regarding the elderly. Most of the contributions in this volume were first presented at the 1990 British Society of Gerontology Conference. They explore the following topics: The “invisibility” of caregivers and the resulting research difficulties, eldercare and the labour market, respite care, neighbourhood support units, domiciliary services and dependency, the relationship of social and material resources to service use among elderly persons living at home, case management, consumer satisfaction with the community nursing service, using housing to fund care, and institutional care. One chapter examines “Care and Repair Limited”, an umbrella group that encourages the establishment of independent, locally managed projects (of which 50 served the elderly) to improve the homes of those in need. Another project, “Staying Put”, fulfils a similar function. Chapter references are provided. (UH) *AgeLine Database*, ©1992, American Association of Retired Persons, all rights reserved.


**Keywords:** Policy United Kingdom/Community/Community Care/
Review/United Kingdom/Welfare/Relative/Elderly/Disabled/State/Roles/
Benefits/Income/Perception/AgeLine: (Community Care NOT Home Care)/Outside United States/Literature Review/Older Adults/Financing/
Home Care/Community Services/Social Services/Government Services/
Reimbursement/Care Recipients

**Notes:** Reviews policies and debates within the United Kingdom regarding offering care receivers cash rather than services to meet their care needs. Examines the meaning of monetary welfare and its relative advantages and disadvantages as compared with the provision of services in kind. Looks at what the “choice” between cash and kind might represent in reality, both for the individual care user and for care-providing agencies. Outlines the ways in which debate about public policy has developed in relation to care provision on the one hand and cash provision on the other. Provides a short analysis of current demographic and other trends regarding the elderly and disabled. Summarises the current state of knowledge regarding the differing sources of money potentially available to those at whom community care programs are being targeted, highlighting the significant role of state benefits as a major source of income for elderly and disabled people,
and differing perceptions of their scope and adequacy. Organizes the outstanding issues arising from this discussion around a series of themes, each of which raises important (and at times, overlapping) policy questions. Concludes that the role of cash in achieving the objectives of community care is as yet virtually undefined. Includes an 18-page bibliography. (WD) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).

Policy Issues in the United States


Keywords: Policy United States/Funding/Community/Public Policy/ Home/Home Care/Older Adults/Adults/Ohio/Taxes/Elderly/Aged/ Medicaid/Income/Poverty/Costs/Disability/AgeLine: Homecare/ United States/Program Description/Community Services/Eligibility Determination/60+/Disabilities

Notes: Examines public policy issues and choices of a home care program for older adults in Hamilton County, Ohio, that is funded by a $13 million annual property tax levy. The Elderly Services Program (ESP) was approved by voters in 1992 and currently serves over 4,700 residents aged 60 and over needing in-home care. The age criterion for the program has not been a problem, although funding from a private foundation to explore serving the under-60 population was recently received. Before ESP, county agencies were concerned that many low-income and moderate-income people were in need of in-home assistance but were not one of the 700 residents eligible to receive such care under the Medicaid waiver program. ESP accepts clients regardless of income, with payment for services based on a sliding scale. Currently, 13% of the service recipients have incomes over 150% of the poverty level, the point at which individuals are required to share in the costs of service. The decision about the level of disability has been affirmed by network agencies and program staff, and both groups identify the ability to serve a moderately impaired population as important. The perceived success of the program will be put to the ultimate test when the levy goes back to the voters in 1997. (AR) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Policy United States/Home/Home Care/Public Policy/ Funding/Elderly/Costs/Health/Health Status/Hospitals/Review/ Outcomes/AgeLine: Homecare/Screening/Home Health Care/Health Service Costs/Cost Effectiveness/Cost Containment/Service Needs

Notes: Examines some public policy aspects of home care funding, and offers suggestions to increase efficiency and reduce spending for these services. While home care remains a highly popular and preferred choice to enable the elderly to
live in their own homes, numerous studies and estimates of the high and escalating costs of such services have repeatedly demonstrated that home care is neither cost-effective nor efficacious in improving health status. But since the demand for these services is not likely to disappear, strategies for improving the efficiency of home care must be considered. Among the proposals presented are improving screening procedures—it has been estimated that three out of four persons receiving home care services are not really in need of them—and finding ways to reduce hospital admissions, and therefore costs, through changes in home care. In addition, there is a need for practice norms for care planning and utilisation review, procedures to uniformly assess outcomes, and the implementation of a budget cap to keep overall costs down. (CB) (AgeLine Database, ©1991, American Association of Retired Persons, all rights reserved).


Keywords: Policy United States/Home/Development/Health/Social Policy/Long-term Care/Central/Support/Public Sector/AgeLine: (Community Care NOT Home Care)/United States/Older Adults/Public Policy/Home Care/Home Health Care/Community Services/Social Services/Projection

Notes: Traces the development of home and community-based care to its current place in the worlds of health and social policy, arguing that it has attained a new and needed legitimacy in policy circles. Argues that such services should continue to gain a more prominent place within long-term care policy and that long-term care issues deserve a more central place within social insurance policy. Documents the heightened system capacity now associated with home and community-based care operations in many parts of the country. Suggests reasons why home and community-based care should attain yet greater standing in the policy world, speculating that home and community-based care’s broad legitimacy and high potential might serve to breathe some modest level of support for public-sector activity back into today’s political discourse. (AR) (Ageline Database, ©1996, American Association of Retired Persons, all rights reserved).


Keywords: Dementia/Family/Physicians/Caregivers/Nursing Homes/Home/Geriatrics/Training/Public Policy/MESED7.MDL (MEDLINE 1966-92: MEDLINE 1966-92: PRIMARY RESEARCH) A:B:/C:/D:

Notes: 87134085 The Maryland Governor’s Task Force on Alzheimer’s Disease and Related Disorders conducted a comprehensive 18-month assessment of the extent of dementing illness in Maryland, the needs of Maryland dementia victims and their families, and the availability of resources to meet these needs. A major tool in this assessment was a series of 16 specially designed surveys which were sent to physicians, family caregivers, nursing homes, geriatric aide training programs, and other populations. The survey findings, along with hearing
testimony, provided the basis for the Task Force’s 18 principal and 35 further recommendations, published in the Maryland Report on Alzheimer’s Disease and Related Disorders (Governor’s Task Force, 1985). These recommendations have become the basis of public policy discussion for services to dementia victims and their families in Maryland.

**Policy Issues in Canada**


**Keywords:** Policy Canada/Home/Home Care/Development/Canada/Review/Costs/Benefits/Models/Model/Health/Long-term Care/Non-Institutionalization/Service Costs/Dementia/Community/Careers

**Ageline:** Homecare/Older Adults/Outside United States/Home Health Care/Cost Effectiveness/Health Service Costs/Public Policy/Service Utilisation

**Notes:** Outlines the basic issues affecting the development of home care in Canada. This report is based on a review of government documents on home care, reviews of literature on home care, cost-benefit analyses of home care programmes, reviews of attempts to forecast the need and demand for home care, and models of how home care can be conceived in theory and applied in practice to meet stated objectives. The three basic models of home care are the maintenance and preventive model, which serves people with health or functional deficits in the home setting so they can live independently; the long-term care substitution model, where home care meets the needs of people who would otherwise require institutionalization; and the acute care substitution model, where home care meets the needs of people who would otherwise have to remain in, or enter, acute care facilities. If properly applied, all three models can result in more efficient service costs, as costs per unit of need met are lower than in the institutional sector. However, home care cannot lower total systemic costs unless its growth is accompanied by actual reductions in the supply of institutional services. It is suggested that the following major home care issues need to be addressed: the need and demand for complex care, requiring in some cases sophisticated equipment and staffing; the growing need to assist people with Alzheimer’s disease and other dementias; the growing demand for palliative care for people with terminal diseases; the need to make services available on a 24-hour-per-day, 7-day-per-week basis to ensure essential standards of services; and the need to ensure that staff are adequately educated to deal with increasingly complex cases in the community setting and that health education programs provide appropriate orientation toward home care careers. Policy recommendations are offered. References, tables, and charts are included. (WD) *(AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved)*


**Keywords:** Policy Canada/Home/Home Care/Canada/Costs/Health/
Health Care System/Funding/Health Promotion/Decision Making/Community/Community Care/Hospitals/Consumers/Management/Models/Long-term Care/Case Management/Support/Program Evaluation/AgeLine:Homecare/Federal Funding/Outside United States/Older Adults/Home Health Care/Service Delivery/Service Utilisation/Preventive Health Services/Public Policy

Notes: Discusses the evolution of home care in Canada and what the future holds for this growing industry. Cost escalations of the traditional health care system and a reduction in federal funding have resulted in a major expansion of the home care sector by provincial and territorial governments. Government objectives emphasise prevention and health promotion; decentralisation of decision making and expansion of community care at the expense of hospital care; integration of services, programs, and service agencies; greater consumer involvement; and better management. Comprehensive home care services and co-ordinated home care programs (CHCP’s) are relatively new additions to the Canadian health care scene and have developed at different rates and in different patterns in the provinces and territories. Despite annual growth rates in home care of up to 7% in some jurisdictions, home care comprises no more than 2% of total provincial health care budgets. The three models of home care—maintenance and prevention, long term care substitution, and acute care substitution—are discussed, as well as the current status of home care in terms of CHCP administrative structures, methods of delivery, finances, eligibility criteria, and services provided. Several initiatives to enhance delivery of home care services are reported, including single-entry case management, self-managed care, home care as gatekeeper, and informal support recognition. For the home care sector to develop in a more rational, cost-effective, and client-focused manner across the country, common standards, a common home care database, and programme evaluation will be necessary. Provincial level expenditures on home care services in Canada for 1992-1993, including per capita expenditures, are provided. (SW) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Home Care Canada/Patients/Care/Manitoba/Canada/Geriatrics/Policy/Nursing/Nursing Home/Home/Rehabilitation/Home Care/Hospitals/Health/Health Services/Elderly/United States/State/Admissions/Long-term Care/Costs/Hospital Bed Usage/Patient Admissions/Patient Discharges/Hospital Costs/Institutional Costs/Older Adults/Outside United States

Notes: Major changes suggested in Manitoba, Canada, to solve problems of geriatric acute care beds and actual changes in use are described to assess the impact of program and policy revision. In 1972-1976, nursing home and rehabilitation beds were increased, home care programmes were started or expanded, and both home care and nursing home care became insured services based upon assessed need in Manitoba. Press reports, however, continued to highlight the problem of geriatric long-stay patients unnecessarily occupying acute-care hospital beds. Data from the Manitoba Health Services Commission suggested that fewer of Manitoba’s elderly, as compared with figures for the
United States, are entering the acute hospital but that they are staying longer once there. Investigation of the causes suggested that, despite the provision of alternatives to acute care and the removal of financial barriers to their use, long hospital stays were disproportionately associated with transfer problems. Providing new resources may not solve these problems, as long as each facility to which patients are referred retains the right to determine its own criteria for admission. One possible solution is to re-allocate a percentage of acute-care beds to long-term care, since the cost of caring for the long-stay patient is considerably less than that for the acutely ill patient. (NJ) (AgeLine Database, ©1984, American Association of Retired Persons, all rights reserved).

Keywords: Home Care Canada/ Frail Elderly/Elderly/ Policy

Havens, B. (1995c). Canadian Long-Term Care Use: What is the Future?
Denton, TX, North Texas University.
Keywords: Home Care Canada/ Long-term Care/ Care/ Ageing

Policy Issues in European Countries

Keywords: Policy Europe/ Community/ Benefits/ State/ Europe/ Elderly/ Priority/ Health/ Community Care/ Central/ Home
Abstract: Issues concerning elderly people are among the Government’s most important priorities and for the Department of Health in particular they come very high on the agenda. It is a welcome coincidence that the implementation of the community care reforms took place during the European Year of Older People and of Solidarity between the Generations. It is apt because of the linking central principle that individuals should be at the centre of decisions made about their lives. Their individual needs should be addressed and their individual voices heard. One of the benefits of an European approach is that we can learn from each other’s experience. The European Year offered an opportunity to highlight innovation and good practice across the member States and a wider Europe including the growing links between the Community and the EFTA countries. There is broad agreement across Europe that the policy that the UK Government has been pursuing over the last twenty years of helping people to live independently in their own homes wherever possible is the right one.

Keywords: Policy Europe/ Home Care European/ Home Care/ Elderly/ Development/ Italy/ Social Welfare/ Welfare/ Home Health Care/ Health/ Economic/ Support/ Personal Care/ Activities of Daily Living/ State/

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Housing/Day Care Services/Aged/Community/Family/Adult/Adult
Children/Stress/Caregiving/AgeLine: Homecare/Community
Services/Adults/Population Ageing/Public Policy/Non-institutionalized
Elderly/Historical Perspectives/Older Adults/Outside United States/
60+/Care/Home/The Elderly
Notes: Describes the development of home care policies for the elderly in Italy. Details the social welfare services available to Italian elders including the following: home health care services, such as injections, catheter changing, and massage against bed sores; telephone advice services; economic support initiatives; and personal care services, such as assistance in activities of daily living, domestic jobs, and errands. Describes other services provided by the state, including elder housing, day care services, and prevention and leisure services. Provides a description of home care services in the Lombardy region, where approximately 2% of the population aged over 60 receive home care services. Discusses the general approach to community services, and home care in particular, as simply “patching over” in various emergencies, with few links between social assistance and health care. Describes the experiences of setting up a state-run home care service in Lombardy, including the emphasis on family care in Italy. Presents the implications of home care for unmarried persons, some 15% of the Lombardy population, and the rising average age of adult children. Stresses the ability of home care services, particularly in-home helpers, to fill the caregiving gap in the future. (TS) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


Keywords: Home Care Using Paid Informal Caregivers/Policy Europe/
Financial Support/Support/Informal Care/United Kingdom/Ireland/Italy/
France/Germany/Finland/Sweden/Caregivers/Economic/Models/Develop-
ment/Ageline (Paid Home Care)/Older Adults/Outside United States/Inter-
national/Cross Cultural Studies/Informal Support Systems/Public Policy/
Supportive Services/Government Expenditures/Community Services/
Service Needs/Service Demand
Notes: Documents existing arrangements for financial support of informal care in seven European countries: United Kingdom, Ireland, Italy, France, Germany, Finland, and Sweden. Considers why various forms of financial support have been introduced and what effects they have had. Outlines existing arrangements for formal service support of informal care and examines how financial support overlaps and interacts with such provision. Investigates the relationship between both financial and service provision and the labour market behaviour of caregivers. Provides information on the demographic and public expenditure context of these issues in Europe. Concludes that all the countries are currently facing growing demands for care services in a time of declining birth rates and economic recession. Describes the different responses to this common set of pressures. Compares the different models of providing financial support that each country’s arrangement seems to reflect and evaluates their adequacy in supporting informal caregiving. Discusses the implications for a range of possible policy developments
in the United Kingdom. Includes references. (AR) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care With Elderly Clients/Policy Comparisons/Policy Europe/Financing/Disabled/Home Care/Nursing/Nursing Homes/Home

**Abstract:** All EEC countries are faced with an ageing population which means an increase of people in some way disabled in everyday activities. A comparison of the solutions adopted by five EEC countries in the sectors of housing, home care services, residential and nursing homes shows that a real medico-social policy has been worked out only in some countries whereas in others public authorities have defined policies without providing corresponding resources. The concept of social protection appears to be one major factor which may account for these differences.


**Notes:** U Southampton, S09 5NH England JSCPBB aj Abstract-of-Journal-Article English United States. Explores policy developments taking place in GB and other European countries that are dissolving the boundaries between formal and informal care, particularly as far as payment for care is concerned. It is argued that, in this case, benefit systems are actually a form of co-modification of the caring relationship. These empirical developments are investigated, and their gendered nature and gendered impact, and the possible consequences of these for the relationship between caregiver and care recipient, considered. 48 References. Adapted from the source document. (©1995, Sociological Abstracts, Inc., all rights reserved.) 7210; 7200 SOPODA 95P10304 UMI.


**Keywords:** Home Care European/Policy Europe/Home/Home Care/Europe/Community/Health/Health Status/Caregivers/Nursing/Personal Care/Belgium/Denmark/England/France/Germany/Israel/Italy/Netherlands/Organizations/Funding/Development/AgeLine/Healthcare/Health Care/Cross Cultural Studies/Public Policy/Service Needs/Service Delivery/Service Planning/United Kingdom

**Notes:** Reports on a cross-national study of home care in Europe, “Age Care Research Europe”, (ACRE), which was commissioned by the European Community. Research teams from 9 countries pursued 3 related research
strategies. The first sought to document the health status and social conditions of elderly people living at home and to describe the availability and use of formal and informal support. The second, organizational, approach studied the structure and pattern of services in each country from the perspective of clients and their caregivers. The third approach involved a review of policies, their formulation and implementation, and of the structure of services relevant to the care of the elderly. Types of help provided were divided into 3 core areas: Professional nursing help (termed “home care”), personal care, and homemaking (“home help”). Chapters on the individual countries (Belgium, Denmark, England and Wales, France, Germany, Israel, Italy, and the Netherlands) detail each country’s formally stated policies of home care for older people, the range of home care services, the kind of personnel employed to deliver services, the organization and funding of services, the formal policy aims and target populations for specific services, the historical development of the home help service, the operation of the service, the relationship between formal care provision and informal care, the achievements and shortfalls in provision and operation of the services, and the current policy issues and debates about the future of home care services. Appendixes provide background data for the country studies. Chapter references are included. (AY) (AgeLine Database, ©1992, American Association of Retired Persons, all rights reserved).


**Keywords:** Policy Europe/Home/Home Care/Elderly/International/Social Security/France/Model/Independent Living/Israel/Roles/Social Services/ Denmark/United Kingdom/Netherlands/Benefits/Germany/Savings/ Statistical Data/AgeLine: Homecare/Models/Europe/Home Health Care/ Home Care Agencies/Supportive Services/Non-institutionalized Elderly/ Sweden/Cross Cultural Studies/Older Adults/Outside United States/ Conference Proceedings

**Notes:** Records the proceedings of a meeting of the International Social Security Association (ISSA) entitled “Home Care Policies with Special Reference to the Elderly: Repercussions for Social Security Schemes” held in Paris, France, from 6 November to 8 November 1991. Delegates from twenty European countries attended. An introductory report described the collective effort required to maintain home care as an option for elderly persons. Three alternative approaches to home care were presented: The Swedish model of independent living, a program of home care within an institutional framework in Israel, and the role of municipal government in providing social services in Denmark. Trends in home care policies in the United Kingdom, the Netherlands, and the Czech and Slovak Federal Republics were described. Discussion of social protection and the elderly centred on the introduction of a new assistance-based dependency benefit in France and Germany. Home care was not presented as a means of considerable financial savings but was viewed as a necessary response to strong social demand. References and tables containing statistical data are included. (PH) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).

**Keywords:** Policy Europe/Home/Home Care/Public Policy/Elderly/ Europe/State/Community/Community Care/Hospitals/Caregivers/Support/ Community Services/Socioeconomics/Family/Consumers/AgeLine/Homecare/ Advocacy/Long-term Care/Demographic Characteristics/Cross Cultural Studies/Older Adults/Outside United States/International/Care/The Elderly

**Notes:** Examines the similarities and differences among European nations in their public policies and programmes to promote home care for their elderly populations. Five major common themes across Europe are identified: The state preference for community care as opposed to residential or hospital care; shortages of home caregivers; territorial inequalities, particularly between northern and southern European countries, in the levels of state support for community services; fragmentation of community care policies among public, private, and voluntary agencies; service innovations, such as hospital care delivered in the home; and pressures for change in community care services. Socio-economic and political pressures for policy reform are discussed, particularly the changing nature of family life and the subsequent need for increased formal services. Additional pressures for change come from the elderly as consumers of home care and the caregivers—both professional and informal—leading to users' rights and other forms of empowerment. (TS) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).

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**Policy Issues in Scandinavia**


**Keywords:** Home Care - Caregivers/Policy Scandinavia/Community/ Community Care/Roles/Family/Relative/Home/Organizations/State/ AgeLine: (Community Care NOT Home Care)/Relatives/Welfare/ Community Services/Norway/Finland/Sweden/Females/Social Change/Public Policy Older Adults/Outside United States

**Notes:** Examines the different meanings attached to the concept of “community care” as an ideology in Scandinavia from both social policy and feminist viewpoints. Historically, care of the elderly and handicapped has been dependent on the subordinate position of women in society. Current public debate about old age care is based on myths rather than realities about the preferences of the elderly and about women’s roles in the family and society. Four of these myths are discussed: That an increasing proportion of the elderly are cared for in public institutions; that the situation of the elderly has deteriorated relative to other age groups; that the problems of the elderly are dominated by the shock of retirement; and that there is an antagonism between public and private care. From their inception, home help services have been based on the traditional role of the
housewife, but the organization of the service is changing because of the decreasing numbers of full-time middle-aged housewives. Possibilities for reform are suggested within the context of the Scandinavian welfare state. (CM) (AgeLine Database, ©1988, American Association of Retired Persons, all rights reserved).

Policy Issues in Middle Eastern Countries


Keywords: Home Care-Training/Policy Middle East/Home/HomeCare/Elderly/Health/Health Status/Family/Costs/Relatives/Community/Organizations/War/Training/Volunteers/Caregivers/Primary Health Care/Workers/AgeLine/Homecare/International/Egypt/Outside United States/Lebanon/Cyprus/Developing Nations/ Older Adults/Health Services/Home Health Care

Notes: Discusses home care provisions and the health status of the elderly in eastern Mediterranean countries. The major concerns for the vast majority of families in the region are financial— the inability to bear the day-to-day living expenses and costs of medical care for the elderly. A number of countries in the region are exploring a system of providing financial assistance to families with elderly relatives to help them acquire part-time helpers from the community. The complementary efforts of governments, non-governmental organizations, religious bodies, and communities in the region strengthen the age-old tradition of keeping elderly relatives at home. For example, in Beirut, even in the midst of war, feeding programmes for the elderly and outdoor clinics continued to provide services. The concept of training community volunteers as informal caregivers for the elderly in individual homes is receiving increasing attention in the region. Primary health care is viewed as a powerful approach in bringing health care for the elderly to individual homes. The eastern Mediterranean regional office of the World Health Organization is incorporating its “Manual for Primary Health Care Workers in Health Care of the Elderly” into the training course of workers in these countries. (SW) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Policy Middle East/Development/Home/Home Care/Home Care European/Organizations/Disabled/Israel/Long-term Care/Long-term Care Insurance/Elderly/Community

Abstract: This paper provides an overview of the major trends in the organization of services for the disabled elderly, and the implications for the elderly of the emphasis in recent years on remaining at home in the community. The paper presents an example of changing policies from the experience of Israel, which recently enacted a Community Long-term Care Insurance Law to increase levels of home care entitlements to the severely disabled.

Keywords: Health Care Planning/Policy Middle East/Roles/Community/Community Services/Long Term Care/Elderly/Israel/Chronically Ill/State/Aged/Central/Development

Abstract: Israel faces a major challenge to its capacity to deal adequately with the needs of the chronically ill. This paper describes the present state of long-term care services for the chronically ill and documents the extensive disparities in the rate of institutional and community services by region. In view of the expected dramatic increase in the number of aged greater than or equal to 75 years old (from 106,800 to 181,500 between 1980 and 1990), the authors project a 50% increase in the need for institutional and community services just to maintain existing service patterns. The paper discusses the central issues related to the development of both types of services in response to the increase in needs.

Mann, K. J. (1985). Recommendations for the Formulation of the Nursing Care Insurance Law. Israel Journal of Medical Sciences 21[3], 244-248.

Keywords: Policy Middle East/Nursing/Aged/Home Care/Central/Israel/Pension/Income/Benefits/Personal Care/Home/Family/Community/Community Services/Institutionalization/Dependence/Surveys

Abstract: In Israel, old-age pensions for men aged greater than or equal to 70 years and women aged greater than or equal to 65 years are provided by the National Insurance Institute. A supplementary allowance is given when the pension is the sole income. However, in 1980 these benefits were recognized as insufficient in cases of functional incapacity, so a change in the existing National Insurance Law was considered necessary. A national committee was appointed to formulate the Nursing Care Insurance Law, which would extend the activities of the National Insurance Institute. Monies were to be allocated for personal care, home maintenance, assistance to families and community services. Home care was considered preferable to institutionalization for psychological and social reasons; however, institutionalization was recognized as necessary when home care is no longer feasible in cases of total dependence and illness. Regional Committees and a Central National Committee will be established for planning and supervision. Government surveys were used to determine the percentage of the aged needing help, according to which the overall budget is to be calculated. The Nursing Care Insurance Law was passed in 1983, but so far no agreement has been reached concerning the distribution of monies.


Keywords: Policy Middle East/Welfare/Support/Elderly/Family/Rural/The Elderly

Abstract: We interviewed 120 Bedouin men to elicit their views about the traditional Bedouin support system for the elderly (a collective family fund) and
the more recent welfare support allowances that all Israeli elders are entitled to. Desire to maintain or return to the traditional system varied with the respondent's place on a continuum of seminomadism to rural sedentarization to semiurbanization. Differences were also found between the real Bedouin and the fellahim Bedouin respondents.

**Policy Issues in African Countries**


**Abstract:** This paper describes elderly support and intergenerational transfer by gender, marital status, and place of residence for 150 elderly persons in Zimbabwe. The survey was conducted in September 1988, and includes information on background characteristics, income and cash support from all sources, non-cash support, and the support of elders to others. Conclusions and implications are discussed.


**Abstract:** BACKGROUND: The population aged over 60 years in Zimbabwe is expanding. Despite the likely increased demand on medical services that this will bring, little is known about the health needs of this elderly population. OBJECTIVE: To record the prevalence of disability (impairment of activities of daily living), subjective morbidity (symptoms), the social circumstances and utilisation of health services in a group of elderly Zimbabweans. DESIGN: Cross-sectional community survey. SETTING: A remote rural area in North Eastern Zimbabwe and two urban townships located approximately 80km from Harare. SUBJECTS: 278 subjects (154 women, 174 rural), aged >60 years (range 60-92) living at home. METHOD: Subjects were selected by random cluster sampling. They were assessed in a structured interview and underwent physical examination including visual acuity, inspection for cataracts and assessment of mobility. RESULTS: Less than 4% experienced difficulty with self-maintenance activities of daily living, but 30% had difficulty with instrumental activities. The former were all visually impaired and both visual and mobility problems contributed to the latter. Elderly people experienced many symptoms but had inadequate access to health services and used medication infrequently. Subjects were mainly self-sufficient for financial income and 60% still worked. They had declining resources with age and received little help from the social welfare department. Their health and functional abilities deteriorated with age but it was older subjects
who had most difficulty getting to the clinic. Simple measures such as cataract surgery and analgesics were available only to the minority or not at all.

CONCLUSIONS: This study highlights problem areas where simple, low-cost measures could make a difference to the morbidity and disability of elderly Zimbabweans.


**Keywords:** Policy Africa/Health/Health Services/Aged/Africa/ Development/Public Policy/Prescription

**Abstract:** This paper addresses itself to the problems faced by the aged with regards to the use and availability of health services in Sub-Saharan Africa (SSA). The paper maintained that the development of a sound public policy on ageing in SSA requires two types of knowledge: an understanding of what consequences will follow from a particular course of action, and an evaluation of the desirability of those consequences. It concluded that there is need to improve the database that will form a basis for any policy prescription that is geared towards alleviating the problems of the aged in this sub-region.

**Policy Issues in China**


**Keywords:** Policy China/Social Policy/Economic/State/Community/Community Care/Aging/Family/Urban/Welfare/Older Adults/Adults/Support/Institutionalization/Social Welfare/Elderly/China/Review/Social Change/Model/Policy Making/Public Policy/Development/Survey/AgeLine: (Social Or Health Policy AND Home Care Or Community Care)/Outside United States/Old AgeAssistance/Community Services/Social Services/Family Assistance/Institutional Care/Models

**Notes:** Examines China’s approach to community care for its older adults. Compares the Chinese and Western experiences of community care and social policy. Analyses community care in the West, exploring its origin, meaning, elements, foundation, debates, and practical implications and develops a referential framework under which China’s experience can be conceptualised and compared. Profiles China’s traditional support for older adults and the institutionalization of social welfare for the elderly since the founding of the People’s Republic of China. Reviews the historical conditions, current changes, and future trends of the system in the period of “open-door” reform, and modernisation. Discusses social policy issues including care of the elderly, re-moulding of the family, rapid social change, and the dilemma of state policy. Introduces a community care model, in conjunction with a radical and mixed welfare model of the powerful “economic state” based on an interpretation of China’s practice and policy making. Suggests that the core of socialist China’s general public policy is revealed through its economic and pluralistic approach to social welfare as well as the state’s capacity

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to balance social and economic demands and developments. Offers some preliminary empirical evidence in support of welfare modelling. Appends a bibliography, a review of ageing research in China, and an account of a field survey of community care in Guangzhou, China. (AR) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).

**Home Care Services:**

The next group of sources is primarily concerned with home care services and service delivery issues. In some cases home care services are placed in a broader health care services context. This section is organized in part in geopolitical regions to enable the reader either to immediately move to a particular subsection or to ignore one or more subsections. A second organizing element is based on age groups; that is, home care with the elderly population as opposed to home care with all ages. In addition, the special situation of home care services during man-made or natural disasters is included in this section. Very few of these sources are based on research or evaluation, as they are most often descriptions of service and service delivery experiences. That is, these materials usually present “best practice” examples of services and service delivery. Although they tend to lack evaluation content, they are reflective of the state of practice in the field of home care services.

**International Home Care**


**Keywords:** Home Care International/Home/Home Care/Home Health Care/Health/Canada/Manitoba/Canada/England/Netherlands/Norway/Sweden/ Model/United States/State/Community/Models/Public Policy/Institutionalization/Central/Roles/Case Management/Evaluation/Family/Caregivers/ Health Insurance/Public Sector/Quality of Care/Consumers/AgeLine: Homecare/Institutional Care/Private Sector/Argentina/Cross Cultural Studies/Service Delivery/Community Services/Institutional Costs/Older Adults/Outside United States/International/Care/The Elderly/Elderly

**Notes:** Compared the public and private provision of home health care for the elderly in six countries—Argentina, Canada (province of Manitoba), England, the Netherlands, Norway, and Sweden. The study sought to identify innovative home care practices and experiences in other parts of the world that could serve as a model for the United States. These six countries exhibit a substantial commitment to community services strategies, a fairly high degree of experimentation with new service models, and the adoption of public policies that especially favour home service solutions. Examples from each country provide the rationale for a public
policy on home care, including Sweden's "normalization" principle that individuals should be assisted to live and function in their own homes and the "substitution" of services in the Netherlands, emphasising the replacement of costly services with less expensive ones. Alternatives to institutional care are described, including congregate living arrangements in Sweden and the integration of institutional care and home care in Norway. The ability of home care to reduce institutionalization rates is discussed, with evidence that despite active promotion of home care in all six countries, levels of institutionalization remain high. Other issues addressed include central and local government roles, decentralisation of services, co-ordination of home care services, case management, referrals and assessment, staffing problems, and the roles of family members and professional caregivers. Comparisons from the study showed countries with comprehensive health insurance programmes tend to extend home care services as a basic entitlement, usually free of premiums, deductibles, or co-payments. When services are offered through the public sector with literally no competition from private or independent providers, there is little incentive to institute quality-of-care standards. As the private sector increasingly makes inroads into home care, the pressure for standards and licensing requirements increases. The trend in the six countries is towards mixed public and private services to allow more choices for consumers of home health care services. (TS) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


Keywords: Home Care International/International/Home/Home Care/Models/England/Canada/Sweden/Norway/Netherlands/Argentina/Nursing/Assessment/Training/Service Delivery/Health/Health Services/United States/State/Community/Long-term Care/Workers/AgeLine: Homecare/Home Health Care/Homemaker Services/Program Description/Program Management/Continuum of Care/Older Adults/Outside United States

Notes: Examines programme models and innovations in home care currently taking place in England, Canada, Sweden, Norway, the Netherlands, and Argentina. In all six countries, home care services include domestic, personal, nursing, and medical care; coverage for home care is universal. The countries are experimenting with new approaches in administration, co-ordination, client assessments, personnel training, methods of service delivery, and personnel practices. All countries distinguish between home health services and homemaker functions; however, the domains tend to overlap. The following guidelines, taken from the models in these countries, are adaptable to the United States: Access to home care should originate from diverse referral sources; determination of eligibility and preparation of service plans should take place at the community level by local agencies; consideration should be given to social and environmental needs as well as functional capacity of clients; a single standardised assessment procedure should be instituted for all long-term care services; home care should be co-ordinated with other services; homemaking and home health services should be placed under a single authority; and clients should be assigned to a multidisciplinary home care team rather than to a single worker. Special
experiments and programme examples from the countries are described. (AW)
(AgeLine Database, ©1990, American Association of Retired Persons, all rights
reserved).

Keywords: Home Care International/Development/Home/Home Care/
International/Public Policy/Institutionalization/Europe/Costs/ Sweden/
Netherlands/ Independence/Service Delivery/Housing/Case Management/Benefits/
AgeLine: Homecare/Developed Nations/Outside United States/ Older Adults/
Noninstitutionalized Elderly/Long-term Care/Cost Containment/Quality of Life/
Congregate Housing
Notes: Reviews trends and developments in home care services in the developed
countries of the world. Argues that the turn in public policy from
institutionalization toward home care services is epitomised by two ideological
positions formulated in western Europe: One underscores cost efficiency, while the
other is centred around quality of life concerns. Refers to the “substitution” policy
of the Netherlands in which costly services are systematically replaced with less
expensive ones, as an example of the cost-efficient position, and uses the
“normalization” principle of Sweden, in which individuals should be assisted to
live and function in their own homes and maintain their independence, as an
example of the concern with quality of life. Discusses the extensive and
systematic volume of experimentation with new patterns and methodologies of
service delivery in western Europe that cluster around three main foci: New
patterns of budgetary allocations, including personal budgets for care and cash
allowances; flexible uses of sheltered or congregate housing; and decentralisation
of planning implementation of long-term care services at the local level with more
intensive use of case management methods. Notes that despite the extensive
experimentation with new formulas for the delivery of home care services, the
proportion of needy older persons who benefit from these services in Europe is
rather low. (SW) (AgeLine Database, ©1996, American Association of Retired
Persons, all rights reserved).

Health Affairs 11[3], 205-215.
Keywords: Home Care International/United States/State/Canada/Costs/Attitudes/
Aged/United Kingdom/Germany/Japan/Satisfaction/Community/Health
Abstract: This study examines the attitudes and experiences of those aged 65 and
older in five nations: The United States, Canada, the United Kingdom, western
Germany, and Japan. The study was undertaken to illuminate issues critical to the
well-being of older people, including satisfaction with life, opportunities for social
interaction and community support, and expectations and use of medical care. The
results reveal a great deal of commonality in the experiences of elderly people
across the five nations but also show striking differences. Most notably, the fear of
the cost of health care is astoundingly different for elderly people in the United
States compared with their counterparts in the other four nations.

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Home Care in the "Developed" Nations


Keywords: Home Care - Caregivers/Case Management/Home/Community/Community Care/Health/Frail Elderly/Disabled/Caregivers/Development/Nursing/Nursing Homes/Costs/Assessment/AgeLine: (Community Care NOT Home Care)/Long-term Care/Service Delivery/United States/Older Adults/Home Care/Community Services/Continuum of Care/Service Planning/Service Needs

Notes: Provides an overview of case management in home and community care. Discusses the evolution of long-term care case management service that integrates the health and social support systems of care for the consumer. Reviews the objectives of long-term care case management for frail elderly and disabled populations: Client-oriented objectives such as ensuring that services are appropriate to client needs, improving client access to the continuum of long-term care services, supporting the client's caregivers, and serving as a bridge between institutional and community-based care systems; and system-oriented objectives such as facilitating the development of non-institutional services, promoting quality and enhancing the co-ordination of long-term care service delivery, targeting individuals most at risk of nursing home placement to prevent inappropriate institutionalization, and containing costs by controlling client access to services. Discusses the administration of case management services, qualifications of case managers, and caseload size. Considers six case management functions: Comprehensive assessment, care plan development, care plan implementation, monitoring, reassessment, and termination and discharge. Provides advice on staffing of a case management agency, discusses for-profit versus non-profit case management, and looks at quality improvement issues. (SW) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Caregivers/Home/Home Care/Frail Elderly/Disabled/Costs/Outcomes/Service Delivery/Medicaid/Model/Interview/Satisfaction/AgeLine: Homecare/United States/Older Adults/New York/Program Evaluation/Cost Effectiveness/Functional Ability/Depression/Quality of Care

Notes: Evaluated the effects of New York City's Medicaid cluster care demonstration, a shared-aide model of home care, on home care hours and costs and selected client outcomes. Data for 229 clients at the first seven demonstration sites were compared with data for 175 clients at four comparison sites, both before and after cluster care implementation. The sites were distributed across four of the city's five boroughs and included clients from diverse racial and ethnic backgrounds. Multiple regression methods were used to control for baseline
differences between individuals in the respective groups. Data were extracted from personal interviews with clients, agency billing and payroll data, Medicaid claims data, and vendor agency records. On average, a cluster care client used 6 fewer hours per week of home care than a traditional care client, and cluster care reduced costs by approximately 10%. Most savings occurred among clients with five or more activity of daily living (ADL)/instrumental (IADL) limitations. Clients at cluster care sites who started out with fewer than five limitations appeared to decline more slowly than similarly impaired clients at comparison sites, while those with more than five ADL/IADL's tended to decline more rapidly. Cluster care was associated with a significant decline in satisfaction but was unrelated to depressive symptoms among clients. (AR) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care - Training/Home/Home Care/Training/Home Care Agencies/New York/Elderly/Social Workers/Workers/Manager/Service Needs/ Family/Case Management/Geriatrics/Community/Health/Assessment/Work/ AgeLine: Homecare/United States/Older Adults/Home Care Workers/Home Health Care/Service Delivery/Housebound

**Notes:** Addresses the administrative, service, and training responsibilities of the home care supervisor. The examples of supervisory practice are drawn from the procedural guidelines and client charts of a non-profit home care agency in New York City, Concerned Homemakers for the Elderly (COHME). Most home care supervision at COHME is performed by a professional social worker who serves as case manager and team co-ordinator. Organizational structure, marketing/outreach, and recording requirements are discussed. When one agency cannot meet all of the direct service needs of clients and families, the case management team co-ordinator (CMTC) builds a geriatric team in the community that augments COHME services through collaboration with certified home care agencies, allied health professionals, and home health aides. Assessment, case planning, and intake procedures are examined, followed by a look at training and consultation issues. In-service training, team meetings, one-on-one interventions, and annual evaluations of home managers are discussed and accompanied by case examples. The practice principles and COHME experience are a work in progress, a point of departure for consideration for an area of gerontological practice that has not received adequate attention. (SW) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care With Elderly Clients/Home/Community/Home Health Care/Health/Community Services/Home Care/Language/Nurses/ Training/AgeLine: Homecare/Massachusetts/Consumers/United States/ Older Adults/Minority Groups/Ethnicity/Foreign Origin/Bilingual Services/Noninstitutionalized Elderly/Program Description/Service Delivery

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Notes: Describes the Multicultural Community Outreach Program (MCOP) developed by Staff Builders Home Health Care Services in Boston, Massachusetts, to address the needs of non-English-speaking clients. More than 23,000 refugees and twice as many immigrants settled in Massachusetts from 1990 to 1994. The MCOP, which consists of Russian, Haitian, and Chinese community service teams, provides clients with home care services in their native language by professionals who serve as a cultural bridge between the client and the American health care community. In the Russian Community Service Team, for example, American-trained, Russian-speaking nurses provide care, and home care aid training is provided for Russian-speaking persons from various professional backgrounds. The MCOP also includes a community education component focused on creating a network of culturally sensitive health care providers and increasing consumer knowledge of the home care industry. (PH) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Nursing/Health/Home/Home Care/Home Health Care/Caregivers/Family/Nurses/Caregiver/Assessment/Patients/Treatment/AgeLine: Homecare/Health Promotion/Falls/United States/ Older Adults/Home Care Workers/Visiting Nurses/Gerontological Nursing/Preventive Health Services/Supportive Services/Intervention Strategies

Notes: Describes health promotion and disease prevention strategies for elderly home health care recipients and their caregivers. Three levels of prevention are described and illustrated: Primary care to prevent disease, secondary care to curtail disease progression and restore health, and tertiary care to intervene in the process of active disease and promote optimal functioning. All levels of prevention apply to the elder, the care provider, and family members. At the primary level, home care nurses should assess the primary caregiver and family members for potential health problems and review factors such as immunisation status, diet, and home safety. At the secondary level, periodic assessment of the caregiver's health can assist in early diagnosis and prevention of secondary infections, complications from chronic disease, and organ decomposition and help maintain the caregiver's ability to provide care. Most home care patients fall within the realm of tertiary levels of prevention activities--activities with the goal of achieving the highest level of functioning possible. Examples include respiratory therapy, maintenance of prescribed medications and treatments for cardiovascular diseases, use of antibiotics to combat infections, physical therapy to restore mobility, and wound care to promote healing. Nurses should include all three levels of services for the home care patient, the caregiver, and family members. (PH) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Home Care With Elderly Clients/Disability/Home/Home Care/Older Adults/Adults/Benefits/Community/Disabled/ Outcomes/
Institutionalization/ Caregiver/Consumers/AgeLine: Homecare/ Advocacy/ Disabilities/Rehabilitation/Caregivers/ Needs Assessment/Public Policy

Notes: Explores the benefits of adopting a disability approach to personal assistance for older persons and encourages joint efforts between the ageing and disability communities, where appropriate, potentially resulting in better personal assistance services for disabled persons of all ages. The goal of the discussion is to identify commonalities and legitimate differences to be negotiated by a society committed to empowering disabled persons of all ages, particularly in relation to personal assistance services. Access and full participation in society have been key goals for younger disabled persons but have not been routinely applied to disabled elders. Home care for older disabled persons addresses a more limited goal of maintaining current levels of functioning and avoiding institutionalization. Elders are likely to benefit from the disability approach’s emphasis on client empowerment, mainstreaming, and rehabilitation services. Other ethical, practice-oriented, and political arguments are set forth to examine possible benefits for elderly home care clients from a disability approach to services, including broader goals regarding client outcomes for example, improvement and return to community activities, better client outcomes on physical and psychological dimensions, greater client choice in selecting a caregiver, a broader array of services in settings beyond the home to allow consumers to participate in mainstream community activities, and active participation in assessing care needs. (WD) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Training/Home/Home Care/Aged/Costs/Nurses/Nurses Aides/Nursing/Nursing Homes/Community/Workers/Family/Training/AgeLine: Homecare/Activities of Daily Living/United States/Older Adults/50+/Females/ Middle Aged/Home Care Workers/Home Care Agencies/Cost Effectiveness/ Recruiting

Notes: Discusses one home care agency’s experiences employing middle-aged women as personal assistants to provide home care to individuals needing help with one or more activities of daily living (ADL’s). The high cost of other care options, such as live-in nurses aides, nursing homes, and retirement communities, is compared to the relatively low cost of hiring a personal assistant, at about $11-12 per hour, for as many hours as needed. Catalina In-Home Services in Tucson, Arizona, has found that women in their 50’s make the best personal assistants, in that they are usually prepared to stay with a client longer than a younger, more mobile worker, and that they often have a lifetime of homemaking and family management skills to draw upon. To ensure the availability of a reliable pool of qualified home care aides, Catalina created its own 150-hour training program for certified nurses aides and a 60-hour training program for personal assistants. (MM) (Aegline Database, ©1996, American Association of Retired Persons, all rights reserved).

**Keywords:** Home Care Canada/Long-term Care/Care

Shapiro, E. (1986). Patterns and Predictors of Home Care Use by the Elderly When Need is the Sole Basis for Admission. *Home Health Care Services Quarterly* 7(Spring), 29-44.

**Keywords:** Home Care With Elderly Clients/Home/Home Care/Canada/Health/Relatives/Relative/Family/AgeLine: Homecare/Manitoba/Longitudinal Study/Activities of Daily Living/Poverty/Institutionalization/Home Health Care/Service Utilization/Demographic Characteristics/Health Status/Service needs/Older Adults/Outside United States

**Notes:** Data from the Manitoba (Canada) Longitudinal Study on Ageing were analysed to identify home care utilisation patterns among the elderly from 1975 to 1978 in a jurisdiction with universally insured services based on assessed need. Socio-demographic and health-related variables associated with home care use were also examined. This study revealed that when home care is based entirely on assessed need (without a requirement for medical service), about 5%-6% of the elderly are admitted for service each year and about 10% receive service for some time during the course of the year. Age was the strongest predictor of home care enrolment, with fair-to-bad self-rated health and problems in instrumental activities of daily living also being strong predictors of home care enrolment. Additional variables associated with home care use were having daily contact with relatives, being a woman, problems in basic activities of daily living, a metropolitan residence, and relative poverty. Home care services appeared to supplement family efforts and to permit the elderly to avoid institutionalization for a relatively long period of time. (LS) *AgeLine Database, ©1987, American Association of Retired Persons, all rights reserved.*


**Keywords:** Home Care Canada/Case Management/Management/Long-term Care/Health Care Utilisation/Work/Care/Status/Trends/Models/Article/Manager

**Abstract:** After briefly reviewing the goals of long-term care, the goals of case management, and the models in which they currently function, this article focuses on the importance of recognising the differences in culture, values, ideology, and policies in which case management takes place and the main issues confronting case managers. These issues can be divided into two broad categories: 1.) Policies that have serious implications for case management but over which case managers have little or no individual control; and 2.) those in which case managers are directly involved, partly because of the context in which they work and partly because of the case management function itself. The issues must be addressed so that case managers individually and collectively can do the best possible job in serving vulnerable sub-populations in need of long-term care.

Keywords: Home Care/Care/Canada/Article/Socioeconomics/Home
Health/Survey/Analysis/Aged/Logistic Regression/Elderly/Female/Income/Cancer

Notes: OBJECTIVES: This article describes the social, socio-economic and other health-related characteristics of people receiving formal, publicly funded home care services. DATA SOURCE: The data are from the household component of the 1994/95 National Population Health Survey. The analysis covers 16,291 respondents aged 18 or older. ANALYTIC TECHNIQUES: Recipients of publicly funded home care services were profiled, using weighted univariate frequencies and multivariate logistic regression. MAIN RESULTS: Recipients of publicly funded home care services in 1994/95 numbered over half a million. People who were elderly, female, had two or more chronic conditions or were living with others accounted for large proportions of these recipients. Characteristics significantly associated with receiving home care included old age, poor or fair general health, abstinence from alcohol (compared with regular use), low income, living alone, needing help with some activity of daily living, and having cancer or the effects of a stroke.


Keywords: Home Care Canada/Long-term Care/Care/Health Care/Manitoba/Single-entry System


Keywords: Home Care Canada/Care/The Elderly/Elderly/Health/Home/Home Care


Keywords: Home Care Canada/long-term care/care/Long-term Care/Health/Social Services/Support/Home/Home Care/Nursing/Nursing Home/Hospitals/Physicians/Pension/Housing/Educational Programs/Roles/Technology/Rural/Community/United States/Older Adults/Continuum of Care/Ageing in Place/Case Management/Service Needs/Needs Assessment/Health Services/Patient Care/Independence/Aging

Notes: Discusses the co-ordination of formal and informal long-term care services for seniors and examines four different case examples. The full continuum of health and social services includes not only informal care, support services, home care, nursing home care, extended and rehabilitative institutional care, day hospitals, acute care, and care from physicians and other health professionals, but also the broad spectrum of social services including pensions, affordable housing, senior centres, senior educational programs, and all the age-integrated social programs. Co-ordination of these options is the key to making the continuum responsive to individual need. With the “system” providing the co-ordinating role, there is one focus of responsibility for examining all available options to develop the right mix of services to keep each individual functioning at the most independent level possible. Even with the support of the formal long-term care
system and all of the new technologies available, it will still be the strength of the informal, interpersonal networks in rural communities that will provide a long-term care continuum uniquely adapted to meeting the needs of individuals, albeit differently in each community. (AR) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


Keywords: Home Care European/Home/Home Care/Israel/Community/Long-term Care/Disabled/Family/Caregivers/Institutionalization/Care/Benefits/Follow Up/Females/Disabilities/Aged/Male/Disability/Activities of Daily Living/Health/Questionnaire/Interview/Costs/AgeLine: Homecare/Long-Term Care Insurance/Males/Noninstitutionalized Elderly/Public Sector/Service Delivery/Old Age Assistance/Caregiving Burden/Older Adults/Outside United States/Notes: Examined the effect of Israel's Community Long-Term Care Insurance (CLTCI) Law on home care services for the disabled elderly. The overall objectives of the 1986 law were to reduce unmet needs of the disabled elderly, lessen the burden on family caregivers, and preclude unnecessary institutionalization. In addition to covering personal care in the home, benefits could be used to purchase day care services and limited homemaking and laundry services. The research study was based on a follow-up sample of 263 disabled elderly living in the community and 251 primary caregivers. Females with disabilities were aged 60 and older, males were aged 65 and older, with 45% of the sample older than 80. Disability was defined as needing assistance in performing at least one of the activities of daily living. Participants and their primary caregivers were interviewed in their homes twice—once before the CLTCI law was implemented (1988) and again one year later. The dependent variables were improvement in the number of areas of unmet needs, improved sense of well-being based on the General Health Questionnaire, improvement in the caregiver's sense of burden, and change in the number of hours of help per week provided by the caregiver. Independent variables included provision of additional services, initial disability level, improvement in disability, living arrangements, and age. Follow-up interviews reported the following: 40% of the elderly received additional services, 32% experienced an improvement in the level of disability, 58% reported an improvement in their sense of well-being, and 49% reported a decrease in the number of areas with unmet needs. Forty-three percent of the caregivers reported a lessening of their sense of burden after implementation, even though the average number of hours of assistance they provided increased by an average of 2 hours per week. The findings indicate that the addition of formal services supplemented informal assistance to the elderly without replacing it. Unfortunately, the findings also indicate that despite the improvements brought by the expansion of services, the elderly still have many unmet needs, and caregivers still feel burdened. It should be noted that implementation of the law has exceeded costs far beyond expectations, and the law has become virtually the sole source of personal care for

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the elderly regardless of disability levels. (SW) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


**Keywords:** Policy Middle East/Development/Home/Home Care/Home Care European/Organizations/Disabled/Israel/Long-term Care/Long Term Care Insurance/Elderly/Community

**Abstract:** This paper provides an overview of the major trends in the organization of services for the disabled elderly, and the implications for the elderly of the emphasis in recent years on remaining at home in the community. The paper presents an example of changing policies from the experience of Israel, which recently enacted a Community Long-Term Care Insurance Law to increase levels of home care entitlements to the severely disabled.


**Keywords:** Home Care European/Organizations/Home/Home Care/Israel/Frail Elderly/Nursing/Central/Questionnaire/Human/Environment/ Personal Care/ Family/AgeLine: Homecare/For Profit/Organizations/Home Care Agencies/ Supportive Services/Nonprofit Organizations/older Adults/Outside United States

**Notes:** Analyzed differences in the organizational, structural, and strategic behaviour of non-profit (NPO) and for-profit (FPO) organizations in Israel that provide home care services for the frail elderly. In Israel, 44% of the available nursing care services are supplied by NPO’s, 49% by FPO’s, and 7% by other organizations such as charities. A sample of 27 FPO’s and 14 NPO’s was selected on the basis of central location in Israel and delivery of home care services. A questionnaire focused on these areas of each organization: Background information, ideology and goals, management of human resources, and organizational structure and effectiveness. Univariate analysis of differences in organizational features was undertaken, followed by comparative analyses. Findings include the following: NPO’s have a more organized environment than FPO’s—funding for NPO’s is ensured by government authorities, while FPO’s compete for scarce resources; NPO’s do not provide as wide a variety of services, and their area of specialization is primarily personal care and housekeeping; NPO’s are more formally organized and centrally managed than FPO’s; turnover and absenteeism rates are higher in FPO’s; and the number of complaints filed by the elderly and their families was larger in FPO’s. It is concluded that the strategic, structural, and organizational patterns of NPO’s have a greater impact on achievement of organizational effectiveness and efficiency than analogous services provided by FPO’s, and these patterns may affect the quality of services. Implications for policy making are discussed. (SW) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).

Keywords: Home Care European/Home/Health/Costs/Social Services/Home Care/Organizations/Disabled/ Volunteers/Elderly/Institutionalization/Institutional Care/ Human/Community/Community Care/

Abstract: The past two or three decades have witnessed a steep rise in the cost of health and social services. It is anticipated that this uphill climb will continue and bring these systems to a complete collapse within a few decades. The prevention of this crisis depends on the elimination of some of the causes of the rise: 1.) We do not want to save costs by sacrificing the quality of our services; 2.) we have no control over the quantity of clients utilising these services, or the seriousness of their problems; 3.) we can, however replace part of the expensive institutional care by the more natural and cost-effective home care, supplied by volunteers, strengthened by human and technological services. These principles guided an Israeli organization called Yad Sarah, whose leadership in the supply of home and community care enables thousands of ill, elderly and disabled people to remain at home and thus save the high cost of institutionalization.


Keywords: Home Care European/Models/Israel/Organizations/Patients/Social Services/Health/Work/Development/Aged/Geriatrics/Care

Abstract: The rapid increase in the elderly population of Israel has made it necessary to find new solutions to the problems that their special health needs present. Pioneering work has been done since the 1950’s by the Joint Distribution Committee (JDC), which has established non-profit institutions with high standards of care for elderly immigrants. The Association for the Planning and Development of Services for the Aged in Israel (ESEL) - an organization run jointly by the JDC and the Ministries of Finance, Health and Labor and Social Affairs - developed non-profit institutions to provide quality care for geriatric and psycho-geriatric patients. Another key issue in geriatric services that must be faced in the future in Israel is the development of linkages between all health and social services serving the total population of a region.


Keywords: Home Care European/Case Management/Community/Community Care/Home/Home Care/Workers/England/Costs/Outcomes/Hospitals/Long Term Care/Frail Elderly/Quality of Life/AgeLine: (Community Care NOT Home Care)/ Dependence/Program Evaluation/Community Services/Older Adults/Outside United States

Notes: Evaluates the Personal Services Research Unit approach to community care of the elderly, which decentralises responsibility, authority, and accountability for the core tasks of care management by field workers in Kent, England. This evaluative study examined the costs and outcomes of care by comparing 92 elderly persons receiving community care with 116 receiving standard services. Results indicate that elderly persons receiving community care evidenced lower rates of institutional admissions (both residential homes and hospital long-term care
facilities) in the initial 12 months of the program and over 3 subsequent years. On the whole, the scheme was a more cost-effective response to the needs of the physically and mentally frail elderly, particularly for those who enjoyed considerable informal social support and those with moderate levels of dependence. There also was evidence that resources under the program were better matched to levels of needs. Further, reduced institutional admissions among programme participants was not achieved at the cost of quality of life: On indicators of quality of care and subjective well-being, programme participants scored higher than those receiving the usual range of services. Includes two appendixes containing supplemental research materials and a bibliography. (AC) (AgeLine Database, ©1990, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care European/Disability/Disabilities/United Kingdom/Disabled/Follow Up/Interview/Model/Roles/Satisfaction/Independence/Public Policy/Development/AgeLine (Paid Home Care)/Models/Outside United States/Older Adults/Physically Handicapped/Quality of Life/Life Satisfaction/Biological Aging/Psychological Aging/Loss of Function/Attitudes Toward Aging/Adjustment

**Notes:** Examined the ageing experience and the personal and social consequences of ageing for persons with disabling illnesses or long-term physical disabilities in the United Kingdom. Three studies were conducted: The first involved 77 men who had been disabled as a result of spinal cord injury for up to 15 years; the second included 42 men and women who had been disabled by spinal cord injury for 20-50 years; and the third included 290 persons who had been disabled for 20-80 years, 100 of whom completed follow-up in-depth personal interviews. A model was developed that integrates the dual experience of disability and ageing in the "disability/ageing career"—a series of physical, emotional, and social processes punctuated by triggering events in older age. Results showed that nearly 70% of those interviewed in the three studies were currently dissatisfied with the disabled role, with their level of dissatisfaction increasing between ages 50 and 59. Factors influencing level of satisfaction and overall quality of life were the onset of a "second disability" caused by ageing, disruptions in personal life, lack of appropriate support, and reduced levels of motivation. Many participants expressed great anxiety about threats to their personal and physical independence. Gender and race affected their experience of ageing. Implications for public policy development are discussed. (PH) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care European/Community/Community Care/Case Management/Assessment/Models/State/United Kingdom/Roles/Central/Model/Manager/Work/Caregiver/Costs/AgeLine: (Community Care NOT Home Care)/Caregivers/Australia/Program Description/Community Services/Service Delivery/
Older Adults/Outside United States

**Notes:** Describes a case management programme introduced in Australia in 1986 to provide more effective community care as an alternative to residential care. Australia established 115 community options projects in a variety of situations in all parts of the country as a way of overcoming problems of lack of co-ordination of services, inadequate assessment, and inappropriate or inflexible service provision. The initiative was intended to test models of community care that would provide tailored rather than standardised services, ensure co-ordinated rather than independent services, and see clients as active participants rather than passive recipients in the process of care. The name “community options” was first used in the state of Wisconsin and then in Kent in the United Kingdom. Unlike the Wisconsin and Kent experiences, in Australia the major initiating role has been taken by the central government, so the programme has been applied on a much greater scale and in considerably more diverse situations. The Australian model is based on a case manager or co-ordinator whose job is to work out individual care plans with and for the client and caregiver. The community options projects have been evaluated by consultants in each state. Findings indicate that comprehensive assessment is a major factor in the success of the projects. They have enabled highly dependent people to remain in the community at a cost to the government that is comparable with the cost of care for a similarly dependent person in residential care. (WD) (*AgeLine Database*, ©1992, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care European/Rehabilitation/Hospitals/South/Australia/Treatment/Urban/Patients/Independence/Disability/Nursing Homes/Disabilities/MEINT4.MDL (MEDLINE 1993-7)/A:/B:/C:/D:

**Notes:** 93160516 Hornsby Ku-ring-gai Hospital, New South Wales, Australia. This randomised controlled trial compared accelerated rehabilitation after surgical treatment of proximal femoral fracture with conventional care and was conducted in a general hospital in an outer urban area. Participating were 261 sequentially admitted patients over the age of 50 years who met predetermined inclusion criteria and all were followed up until death or 4 months after fracture. Patients who were treated with the accelerated rehabilitation programme had a 20% reduction in length of hospital stay. Improved physical independence (as measured by Barthel Index) was observed after fracture in accelerated rehabilitation programme patients with limited pre-existing disability. Non-nursing-home patients receiving accelerated rehabilitation were also less likely to be discharged to nursing-home care or die in hospital. Accelerated rehabilitation led to a substantial reduction in length of hospital stay with a modest short-term improvement in level of physical independence and accommodation status after discharge.

**Keywords:** Home Care European/Home/Home Care/Model/Netherlands/Nursing/Disability/Income/Models/AgeLine: Homecare/Disabilities/Living Conditions/Social Networks/Home Health Care/Service Utilization/Service Needs/Older Adults/Outside United States

**Notes:** Applied the Andersen-Newman model to the utilisation of professional home care services by the elderly in the Netherlands. This model relates the use of services to predisposing, enabling, and need-for-care variables. A total of 101 Dutch residents 60 years of age and older who were “new users” of professional home help or nursing services provided information on disability, living conditions, socio-demographic characteristics, income, well-being, social networks, social support, and home care utilisation. The findings indicated that predisposing and enabling characteristics had relatively smaller effects on the use of home care services than the need characteristics. The amount of received informal care was strongly related to the amount of received professional care and was mainly responsible for the contribution of the enabling variable. However, at a certain level of disability in activities of daily living/instrumental activities of daily living, the relationship between the amount of informal care and the amount of formal care became negative. It is concluded that the Andersen-Newman model is an adequate descriptive framework for selecting, identifying, and sequencing relevant variables in the research on professional home care use by the elderly. (UH) (AgeLine Database, ©1991, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care European/Disabled/Home/Home Care/ Health/Netherlands/Health Status/Service Utilization/Questionnaire/Satisfaction/Housing/Disability/Interview/Manager/Male/Physiotherapist/Nursing/AgeLine: Homecare/Independent Living/Males/Activities of Daily Living/Older Adults/Outside United States/Program Description/Program Evaluation/Noninstitutionalized Elderly/Quality of Life/Living/Conditions/Supportive Services/Service Delivery/Disabilities

**Notes:** Assessed the effects of a home care project on the well-being, health status, and service utilisation of disabled elders in The Netherlands. From 1990 to 1991, 108 of 409 elders eligible for admission to an “old people's home” in Haarlem moved into the Zuiderpolder project, which consisted of 66 independent-living units for singles and couples. Home care services and house adaptions were delivered according to residents’ individual needs. In 1992, 76 residents (average age 76) completed a questionnaire regarding their general well-being, level of satisfaction with housing conditions, use of home care services, loneliness, level of functional disability, and functional health status. Residents’ age, sex, marital status, and degree of impairment were compared with those of the 301
elders not living in the Zuiderpolder project. Interviews with project managers were used to describe the process of integration and co-operation of care. Results indicated that the 108 residents were more frequently male, married, younger, and less disabled than the 301 non-residents. Ninety-eight percent of residents were satisfied with their housing situation. Thirty-nine residents (52%) had used home care services or physiotherapist facilities, and 72% were satisfied with the care provided. Twenty-five percent of residents were not familiar with several home help and nursing services and did not know how to apply for them. Residents with greater problems in instrumental activities of daily living (IADL) had a poor well-being, tended to live alone, were not satisfied with the housing situation, were lonely, and had a lower health status than less-disabled residents. Project managers reported great difficulty in co-ordinating and integrating care delivery. (PH) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).

Facchini, C. (1993). Risks and Achievements in Strengthening Home Care for Elderly People: The Italian Situation. 231-251. Bunnik, Netherlands, Netherlands Institute of Gerontology; European Center for Social Welfare Policy and Research. Keywords: Policy Europe/Home Care European/Home Care/Elderly/Development/Italy/Social Welfare/Welfare/Home Health Care/Health/Economic/Support/Personal Care/Activities of Daily Living/State/Housing/Day Care Services/Aged/Community/Family/Adult/Adult Children/Stress/Caregiving/AgeLine: Homecare/Community Services/Adults/Population Aging/Public Policy/Noninstitutionalized Elderly/Historical Perspectives/Older Adults/Outside United States/60+/Care/Home/The Elderly

Notes: Describes the development of home care policies for the elderly in Italy. Details the social welfare services available to Italian elders including the following: Home health care services, such as injections, catheter changing, and massage against bed sores; telephone advice services; economic support initiatives; and personal care services, such as assistance in activities of daily living, domestic jobs, and errands. Describes other services provided by the state, including elder housing, day care services, and prevention and leisure services. Provides a description of home care services in the Lombardy region, where approximately 2% of the population aged over 60 receive home care services. Discusses the general approach to community services, and home care in particular, as simply “patching over” in various emergencies, with few links between social assistance and health care. Describes the experiences of setting up a state-run home care service in Lombardy, including the emphasis on family care in Italy. Presents the implications of home care for unmarried persons, some 15% of the Lombardy population, and the rising average age of adult children. Stresses the ability of home care services, particularly in-home helpers, to fill the caregiving gap in the future. (TS) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).

Keywords: Home Care Terminal/Home Care European/Patients/Italy/ Symptoms/Quality of Life/Physicians/Nurses/Social Workers/Workers/ Volunteers/Family/PSYCG84.(JMC)GOWAN/A:/B:/C:/D:
Notes: 81-03140 Ospedale Buccheri La Ferla FBF, Palermo, Italy. describes a home therapy service for the pain and symptoms of patients with advanced cancer, established in Palermo, Italy, in 1988. The goal of the service is to help these patients maintain an acceptable quality of life and to enable them to remain at home. The service staff includes physicians, nurses, a social worker, and volunteers, and the service cares for about 350 people yearly. The strong structure of the family in Mediterranean society reinforces the likelihood of successful home care for these patients. (PsycINFO Database ©1994, American Psychological Assn., all rights reserved).


Keywords: Home Care European/Cooperatives/Home/Home Care/Italy/ Organizations/Health/Social Services/Health Care System/Chronically Ill/Work/ Training/Physicians/Nurses/Workers/AgeLine: Homecare/SocialWorkers/Health Services/Case Management/Home Health Care/Service Delivery/Program Description/Supportive Services/Older Adults/Outside United States
Notes: Examines the organization of health and social services for the elderly in Bologna, Italy. Especially prominent in the Bolognese health care system is a privately managed co-operative agency, Cooperative Home Care for Children, the Elderly, and the Chronically Ill (Italian acronym CADIAI). CADIAI was founded in 1974 by a group of women who had become aware of strains placed on the home care services provided by the city. It functions to upgrade the dignity of home care work through programs of systematic education, group problem-solving techniques, close supervision, and in-service training organized in a non-authoritarian, democratic fashion. Heavy emphasis is placed on helping the elderly assume as much responsibility as possible for their life choices. Although there are tensions between the city-run system of home care for the elderly and CADIAI, the interdisciplinary teams, composed of CADIAI aides, physicians, nurses, and social workers, have had a substantial positive impact on the Bolognese health and social service systems. The socio-political and historical context of CADIAI are described to explain why CADIAI has become so accepted by city leaders and citizens. (CB) (AgeLine Database, ©1984, American Association of Retired Persons, all rights reserved).


Keywords: Home Care European/Welfare/State/Frail Elderly/Home/
Family/Urban/Aged/Norway/Adult/Adult Children/Roles/Child/Disability/
Disabled/AgeLine(Paid Home Care)/Service Utilization/Supportive Services/
Social Services/Government Services/Home Care/Older Adults/Outside United States/Adults/Disabilities

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Notes: Assesses the impact of state-provided services for the frail elderly at home on the level of family involvement in caregiving. A random sample of 490 urban working-class and lower middle-class persons aged 70 and over living in Oslo, Norway, were asked about the help they received from public and private sources for a variety of practical activities of daily living. Despite the wide availability of public services, adult children played an active role in caring for their parents. About one-third received some assistance from an adult child, and 13% received help on a regular basis. The number receiving help from sons and daughters was about the same, but sons and daughters differed in the quantity and type of help provided. Home help did not affect the frequency of caregiving by daughters but reduced the likelihood of sons providing help. Filial support appeared to increase parents' access to public services when disability levels were moderate but not when disability levels were high or low. Levels of filial support were high in families with home help, primarily because these recipients were more severely disabled and more often lived alone. The results suggest that state services complement but do not substitute for filial support. (CM) (AgeLine Database, ©1989, American Association of Retired Persons, all rights reserved).


Keywords: Home Care European/Geriatrics/Geriatric Care/Hospitals/Home/ Home Care/Patients/Health/Article/Nurse/Social Workers/Workers/Occupational Therapist/Disability/Follow Up/Mortality/Disabled/MEINT5.MDL (MEDLINE 1966-92)/A:/B:/C:/D:/Nurses/Disabilities

Notes: 93141739 Servicio de Geriatría, Hospital Universitario San Carlos, Madrid. Geriatric home care (GHC) can help elderly patients by providing comprehensive health care and avoiding prolonged hospital admissions. In this article we discuss our experience in this field. METHODS: From February 1990 to October 1991, 171 elderly patients have been followed periodically at their homes by our GHC team, formed by two geriatricians, a nurse, a social worker, an occupational therapist and a driver. RESULTS: Our patients were very old (81.3 +/- 77 years), had multiple medical problems and high levels of disability (48.6% had a Katz ADL index worse than E). The frequency of hospital admissions was high (50% of the patients) but the total number of days in hospital was low (16.1 +/- 18.6 days for a 211.7 +/- 162.3 days of follow-up). Total mortality was 33.9%; 56.9% of them happened at home. CONCLUSIONS: Geriatric home care units can reduce long hospital stays of severely disabled or terminally ill elderly patients, and can provide adequate health care to this group of patients.


Keywords: Home Care European/Home/Home Care/Development/State/ Costs/Community/Community Care/Social Welfare/Welfare/Health/ Community Services/Nursing/Homemaker Services/Long Term Care/
Family/Outcomes/AgeLine: Homecare/Germany/Treatment/Health Services/Historical Perspectives/Public Policy/Housing/Nursing Homes/ Institutionalized Elderly/Noninstitutionalized Elderly/Older Adults/ Outside United States/Sheltered Housing/Care/The Elderly/Elderly

Notes: Examines the development of home care, elder housing, and institutional policies for the elderly in Germany. Presents a historical summary of elder housing in Germany, including the emphasis on sheltered housing and state subsidies for elder housing and the more recent emphasis on allowing the elderly to stay in their apartments and houses for longer periods of time--an emphasis that may result from the decreased costs associated with non-institutionalized care. Describes concurrent developments in community care provisions to help the elderly remain in their homes through home care and other social welfare services. Discusses briefly the housing situation in the former East Germany, where, since the 1970's, specialised housing for the elderly had been a priority, leaving home care available to only 3% of the elderly population. Suggests that over 90% of the German population believes that financial support for those in need is an obligation of the state; nearly 80% believe medical treatment and health services are also the state's responsibility; and only 50% of the general population believes that health and medical services for the elderly should be the responsibility of the state. Describes the transformations of community services, home nursing, homemaker services, and home help in light of decreasing public support for state intervention in elderly long-term care. Believes that as Germans strongly rely on family cohesion and informal networks for home care, any erosion of existing emotional ties and feelings of commitment may have very tangible financial outcomes. (TS) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


Keywords: Home Care European/Home/Home Care/State/Community/ Housing/Environment/Benefits/Aged/Nursing/Health/Supportive Services/ Transportation/AgeLine: Homecare/France/Public Policy/Community Services/ Service Delivery/Home Health Care/Homemaker Services/Aging in Place/Older Adults/Outside United States

Notes: Describes the home care services provided by the local authorities to the elderly in France. The activities devoted to improving the living arrangements of the elderly underwent an important institutional change owing to the decentralisation that was promoted in the years 1982-1983. Even though the state still retains a number of powers, local governments now play an essential part, and communities are allowed to engage in various options. While promoting the humanising of the living arrangements of the elderly who are put into institutions, the local authorities also aim at a policy helping the elderly to stay in their own homes. To do this, local authorities take action in various fields of daily life such as housing and the environment, resources, and home support services. As a statutory social assistance benefit since 1962, domestic help is compulsory for persons aged 65 and over who are no longer sufficiently independent to lead an active life on their own. Home nursing services are designed to provide care in the home for older persons whose state of health requires it. Other supportive services
provided include remote-controlled alarm systems, home guarding, meals on wheels, day centres, short-term group shelters, transportation services, mobile town halls, aid to associations of older persons, laundries and small-jobs services for those receiving domestic help, subsidies for telephone bills, allowance for energy consumption, and a card giving a reduced rate on public transportation. (WD) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


Keywords: Home Care European/Home/Home Care/Elsewhere/organized/Health System/Healthcare/Health Care System/Physicians/Nursing Homes/Patients/Treatment/Family/Level of Care/Disability/Insurance/Nursing/Financing/United States/State/AgeLine: Homecare/Belgium/Disabilities/Outside United States/Health Care/Health Care Services/Service Costs/Government Expenditures/National Health Insurance/Health Insurance

Notes: Profiles home care in Belgium, based on a visit by 40 American home care executives through Belgium, France, and the Netherlands. The group, sponsored by the National Association for Home Care, visited home care organizations, hospitals, and community service providers in these countries. The Belgian health care system blends national health insurance with private provision of services. Eighty-five percent of the population is covered by compulsory health insurance, yet people have a free choice of physicians and other providers, most of whom are paid on a fee-for-service basis. Home care dates back to 1937 when the first White-Yellow Cross Association (WYC) was founded. It was made up primarily of nuns who were registered nurses and who set up local dispensaries to provide treatments and to educate families in hygiene and diet. Currently, Belgium has 175 of these WYC’s, employing 5,200 nurses, grouped into nine provincial associations that are part of a national federation. The primary service is nursing--care of the sick, services to the elderly, and maternity care--with home care aide or home help services co-ordinated by the WYC’s but delivered by separate organizations. The unique payment scheme is based on the patient’s level of care as measured by the Katz scale of functional disability or dependency. In 1994, total home care expenditures will be about 4% of total health care expenditures, which compares with 5% of total expenses for nursing homes. In 1992, the WYC served close to one million patients, of whom two-thirds were women and 85% were older than age 60. It is concluded that the Belgian home care system retains its historical neighbourhood structure and simplicity of form, yet possesses a sophisticated data and financing system that the United States still strives to create. (SW) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Home Care European/Policy Europe/Home/Home Care/Europe/Community/Health/Health Status/Caregivers/Nursing/Personal Care/Belgium/
Reports on a cross-national study of home care in Europe, "Age Care Research Europe", (ACRE), which was commissioned by the European Community. Research teams from nine countries pursued three related research strategies. The first sought to document the health status and social conditions of elderly people living at home, and to describe the availability and use of formal and informal support. The second, organizational, approach studied the structure and pattern of services in each country from the perspective of clients and their caregivers. The third approach involved a review of policies, their formulation, and implementation, and of the structure of services relevant to the care of the elderly.

Types of help provided were divided into three core areas: Professional nursing help (termed "home care"), personal care, and homemaking ("home help"). Chapters on the individual countries (Belgium, Denmark, England and Wales, France, Germany, Israel, Italy, and the Netherlands) detail each country's formally stated policies of home care for older people, the range of home care services, the kind of personnel employed to deliver services, the organization and funding of services, the formal policy aims and target populations for specific services, the historical development of the home help service, the operation of the service, the relationship between formal care provision and informal care, the achievements and shortfalls in provision and operation of the services, and the current policy issues and debates about the future of home care services. Appendixes provide background data for the country studies. Chapter references are included. (AY) (AgeLine Database, ©1992, American Association of Retired Persons, all rights reserved).


Keywords: Home Care European/Home/Home Care/Europe/Organizations/Financing/Nursing/Questionnaire/Interview/Belgium/Finland/France/Germany/Italy/Netherlands/Sweden/United Kingdom/Health/Health Care System/Development/Funding/Nurses/AgeLine: Homecare/Outside United States/Older Adults/Home Health Care/Homemaker Services/Home Care Agencies/Home Care Workers/Projection/International/European Union/Austria/Denmark/Greece/Ireland/Luxembourg/Portugal/Spain

Notes: Provides a systematic overview of the organization and financing of home care (defined as nursing care at home and home help services) in the 15 countries of the European Union (EU). An introductory essay discusses the nature of the study and provides cross-national comparisons on the main trends in the financing and organization of home care in the EU. The study is based on a review of the literature on home care in EU countries, the results of a survey questionnaire mailed to experts on home care in each country, and interviews with experts in nine countries. Country-specific chapters focus on home care in Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, the
Netherlands, Portugal, Spain, Sweden, and the United Kingdom. Each chapter provides detailed information on the setting of home care within the health care system and the organization of home nursing and home help services, including organizational structure, personnel, client populations, type of care provided, relationship between home nursing and home help services, and recent developments. Each chapter also contains information on the financing of home nursing and home help services, including insurance systems and required co-payments, funding of home care organizations, salaries of home nurses and helpers, and recent developments. (MM) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).

**Home Care in the “Developing” Nations**


**Keywords:** Home Care - Developing Nations/Home/Home Care/Long Term Care/Patients/Disabilities/Assessment/Attitudes/Quality of Care/ Nurse/Embase/Health Insurance/Geriatric Care/Japan/Health Care System/ Disability/Manager/Health Care Quality/Conference Paper/Nurses

**Notes:** AB- The Japanese government will start new long-term care insurance for the elderly in the year 2000, which will completely change care. Systems for institutionalized and non-institutionalized patients will need to be established. Frail patients will be assessed through municipal government. Physical or mental disability will be determined by six different grades and patients will get different services for each grade. The key person in handling this new long-term care insurance has new assessment tools. The attitude for candidates of care manager were surveyed: 41% think that the quality of care will improve with this new system; 89% think the medical aspect of the care of the elderly will change. A nurse station in each local area will be requested first. In conclusion, the new long-term care insurance will change the care of the elderly and the quality of services. The support of Geriatricians will be needed in this new care system.


**Keywords:** Home Care - Developing Nations/Health/Health Care System/Japan/ Disability/Patients/Hospitals/Roles/Geriatrics/Costs/Training/Workers/Nursing/ Home/Disabilities

**Abstract:** In recent times, significant reforms have been instituted in Japan’s health care system, such as the introduction of hospital categorization and the clarification of hospital roles, together with the establishment of geriatric health care facilities, and the reform of the pharmaceutical distribution and pricing system. These reforms are expected to improve the efficiency and quality of the health care system in Japan and to provide better care for the ageing society. The changes will also eventually affect health care costs and patterns of services. This
paper describes Japan’s health care system, including the recent reforms, and then examines the costs and patterns of health care services for the elderly in the light of the recent changes in the system. While more resource allocation is necessary for training of workers for nursing, rehabilitation and care-giving, drugs should be more cost-effective and fit for use at home and in non-medically oriented institutions. Health care providers, health care industries and the government need further to properly respond to the changes in demography, patterns of diseases and disabilities and patients’ wishes for better quality of life.


Keywords: Home Care - Developing Nations/Home/Patients/Home Care/Nurses/ Human/Quality of Life/Family/MED92-1.(JMC92WAN)/A:/B:/C:/D:

Notes: 97136944 Sapporo Dental-Oral Surgery Clinic. Recently, the importance of home medical care has been stressed. But patients, those assisting them and home care nurses do not attach much importance to oral and dental care in home medical care. When we visit patients who have asked for dental treatment through home care nurses, they appeared to have very poor oral hygiene; cavities were uncarried for, dental plaque and dental calculus built up, and they used ill-fitting dentures. Through home dental care visits, it was not just the dental treatment but advice on dental hygiene management and diet that helped patients regain their appetite and bring back a smile to their face, while giving a rhythm to their life. This created a certain human feeling and brought about better patient quality of life (QOL), while at the same time helping to improve the QOL of the family as well 9703. Entry Week: 97034.


Keywords: Home Care - Developing Nations/Aged/Community/Disability/ Young Old/Old/Activities of Daily Living/Independence

Abstract: Prevalence rates of functional dependency in older community residents are a crude way to plan the future of the various care programmes for the elderly. We assessed the activities of daily living (ADL) dependency of elderly subjects living in a Japanese village, in which individuals over 65 years account for as much as 29% of the population. Nine basic ADL were assessed about the help the elderly needed for each activity by use of the validated disability rating scale. We interviewed 1408 elderly individuals (97% of the eligible population). About 90% of residents aged 65-74 were able to do all activities alone without any help – i.e.: were totally independent in ADL. The proportion of independent people was reduced to roughly 75% in the age group 75-84, and in those over 85 years, about 40% were independent. Statistical analysis showed that in each comparison of two successive age groups of 4-5 year span, the proportion who were independent in the groups below and above 75 years and those below and above 85 years differed significantly. Comparisons between any other successive age groups showed no significant differences. Thus, the cross-sectional data imply
that the independence of the elderly in ADL may decline in a stepwise rather than linear fashion after age 65, and seem to support the prevailing age stratification of the old – i.e.: “young old” for the individuals aged 65-74, “old old” for those from 75-84, and “very old” for those aged 85 and over.


**Keywords:** Home Care - Developing Nations/Aged/Home/Home Care/Nurses/Family/Workers/Health/Care

**Abstract:** A study of 3,000 aged Japanese living in agrarian districts determined that 4%-5% of the subjects have some sort of care, 30% have no one to care for them, and 30% receive inadequate care. In city districts care is provided by spouses or persons outside the family. In agrarian districts care is more likely to come from children or grandchildren. Many are entirely dependent on their families. When there is good care provided, the study notes that family relations are usually good. Little assistance is provided by medical workers, health nurses, etc. and the study emphasised the urgent need for more care of this kind.


**Keywords:** Home Care Informal Caregivers/Health Care Planning/Home Care - Developing Nations/Home Care/Urban/Chronically Ill/Elderly/China/Caregivers/Activities of Daily Living/Health/Patients/Family/Work/Nursing/Nursing Homes/Relative/Roles/State/Health Care System

**Abstract:** This study examines the home care situation of seventy-five urban chronically ill men and women and their caregivers in three cities in the People’s Republic of China. It documents the type of home care provided, the severity of illness, and the dependency in activities of daily living in order to appreciate the complexity of these care situations. The findings reveal that women serve as the caregivers in the majority of the cases and often they are elderly spouses with health problems of their own. The physical, social, psychological, and financial problems experienced by these patients create an enormous burden for the caregivers whether spouses or younger family members coming home from work to a second shift. If alternatives to home care, such as nursing homes, were available, 54% of these caregivers would be willing to institutionalize their elderly relative. All caregivers express the need for more assistance in providing home care. This study raises questions regarding the role of the family, the state, and specifically the health care system in caring for the elderly chronically ill in light of their increasing numbers in the population.


**Keywords:** Home Care - Developing Nations/home/Home Care/China/Health
Abstract: An outline is given of Health care for elderly people in China with particular reference to conditions in Shanghai and suggestions are made for improving the services provided.


Keywords: Home Care - Developing Nations/Elderly/ Older Adults/Urban/ Community/Physicians/Costs/Adults/Health

Abstract: The Coalition of Services of the Elderly (COSE) in part serves to train members of the programme to become community gerontologists. They are educated on the basics of diseases and ailments common to people of advanced age, as well as simple remedies that may be helpful until a physician becomes available. COSE has three main objectives: 1.) To encourage exchange services to reduce the costs to older adults, 2.) To emphasise the respect older adults should receive, and 3.) To train leaders for community-based programmes for the elderly, especially in poor urban areas. To date, 35 of these community-based programmes have been established in the Philippines providing members with health care and an insurance system.-GH.


Keywords: Home Care - Developing Nations/Family/Satisfaction/Home/Home Care/Health/Long Term Care/Caregivers/Patients/Home Care Workers/Workers/ COSTM1.MDL/A:/B:/C:/D:

Notes: 97280510 School of Public Health, Taipei Medical College, Taiwan, R.O.C. BACKGROUND: Among all types of long-term care, many studies have shown that home care is preferable. The increasing growth of an ageing population with a predictable increase in chronic illnesses emphasises the need to re-evaluate the current long-term care system. Because long-term care requires family members to participate as caregivers, there are resulting emotional, physical, and financial burdens, while interacting with patients who suffer severe functional impairment. As these burdens exacerbate through time, family caregivers often seek assistance from home-care services. Evaluating the quality of home care provides an opportunity to adjust future planning and to envision a more ideal and effective home care plan in the Taipei metropolitan area. METHODS: This research was designed to evaluate the quality of home care by examining family caregivers' satisfaction with home-care services they render. Nineteen attributes of home-care services are cited in this study. The degree of satisfaction with each attribute of services was measured, using the Likert method of five response alternatives from "does not need to be improved at all" to "needs to be improved completely", coding from 5 to 1. The degree of general satisfaction with home care was reflected by averaging respondents' replies across 19 attributes. RESULTS: More than 91.0% of the family caregivers believed that respect from, consideration
of, concern for, questions by and acceptance of suggestions from home-care workers did not need any improvement. In contrast, at least two-thirds of the family caregivers felt the speedy provision of services in an emergency and the degree of ease of contact with home-care workers by telephone were acceptable only to some degree. For general satisfaction, 79.3% of the family caregivers scored in the range of 4.00-5.00, which indicated a need for mild improvement in services. The number of attributes desired which were in fact received was a significant determinant of general satisfaction with home-care services provided. Family caregivers who were credited with at least 14 attributes tended to be more satisfied with home-care services than the respondents who received fewer than 14. CONCLUSIONS: Overall, subjects receiving home-care services were generally satisfied. However, they were less satisfied with the ease of contacting home care workers by telephone and the speed of receiving needed services in an emergency. The more desired attributes of home care received reflected higher satisfaction with home-care services.


Keywords: Home Care – Developing Nations/Economic/Development/Elderly/Review/Health/Health Status/Family

Abstract: Describes how changes brought on by Western culture, economic development, and medical advances have lead to the breaking up of the traditional pattern of the young caring for the elderly in Thailand. Reviews the social, cultural, occupational, and health status of the elderly in Thailand and how they view themselves. Notes that the main regular activity of the elderly in Thailand is participation in religious services. Argues that the government should promote respect for the elderly by the younger generation and gratitude for their contributions to the family and society. Suggests that the elderly be encouraged to participate in activities connected with their children, such as babysitting, so as to strengthen the bonds between generations. Also advocates the expansion of the formation of clubs for the elderly within the grounds of Buddhist temples. Describes a pilot scheme of this type of club that has been implemented in villages in four regions and has provided curative, preventive, and rehabilitative health care for the elderly along with possibilities for activity participation.


Keywords: Home Care – Developing Nations/Family/Elderly/Roles/Survey/Males/Females/60+/Model/Support/Economic

Abstract: Modernisation theorists have argued that the breakdown of the family is an inevitable result of urbanisation and industrialisation, and that it deprives the elderly of many of their roles. Data from a survey conducted in three southern Nigeria cities and eight neighbouring villages (M=668 males (Ms) and 336 females (Fs), ages 60+) questions the accuracy of this model. It is found that the family is still a strong basis for support for the elderly, though varying resources and opportunities produce different levels, types and frequency of support. Economic help is more often given to Fs than to Ms, M-headed households are
more likely to include service providers than are F-headed households, and elderly widows without children are least likely to get adequate assistance. It is concluded that the major problem of support for the Nigerian elderly is not modernisation but inflation.


**Keywords:** Home Care - Developing Nations/Aged/Geriatric Care/Home Care/Geriatrics/Pension/Community/Work/Health/Hospitals/Home/Economic

**Abstract:** A general essay on care of the aged in India is presented. The average life expectancy now (1980) stands at 55 years; typical geriatric conditions are described together with available resources. The author points out that Western solutions such as old-age pension, free medical services, libraries, indoor recreation and community integration will not work in India. Instead a number of proposals for geriatric care which can be achieved are outlined: Education, also of the young, to create more understanding and concern; free check-ups for health as is available for babies; availability of voluntary work through specialised agencies; preference of home-care programmes above hospital geriatric units and availability of special equipment to cope with accident hazards in the home. Medical facilities will not solve what is in essence a social and economic problem.

**Home Care with Elderly Clients**


**Keywords:** Home Care With Elderly Clients/Community Care/Home/Community/Long Term Care/Aged/United States/State/Home Health Care/Health/Nursing/Nursing Homes/Financing/Medicare/Medicaid/Health Services/Social Services/Incomes/Frail Elderly/Independence/Quality Of Life/Caregivers/AgeLine: (Community Care NOT Home Care)/Older Adults/65+ / Public Policy Noninstitutionalized Elderly/Home Care/Community Services

**Notes:** Discusses the evolution of and trends in home-based and community-based long-term care (LTC) for those aged 65 and older in the United States. The American LTC system is large and complex, consisting of informal care, formal home-based and community-based care (including home health care), and institutional (mainly nursing home) care. Home-based and community-based care includes a variety of services and financing streams, including Medicare home health care, Medicaid home health services, Medicaid home-based and community-based services, programmes and services under the Older Americans Act, state-sponsored social services, Supplemental Security Income payments, and a range of supportive housing arrangements. Data on the LTC system in the United States are available from national surveys, administrative records, inventories, state and local data systems, and demonstration programs. Over the past decade, there has been significant growth in LTC databases, accompanied by major shifts within the LTC system; however, the system remains decentralised.
The frail elderly want dignity and independence in the latter years, plus access to needed services and an acceptable quality of life. In policy terms, their caregivers and the taxpaying public continue to struggle to find the appropriate mix of public and private support to meet the needs of the LTC population. (AR) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).

Shapiro, E. (1986). Patterns and Predictors of Home Care Use by the Elderly When Need is the Sole Basis for Admission. Home Health Care Services Quarterly 7[Spring], 29-44.

Keywords: Home Care With Elderly Clients/Home/Home Care/Canada/Health/Relatives/Relative/Family/AgeLine: Homecare/Manitoba/Longitudinal Study/Activities of Daily Living/Poverty/Institutionalization/Home Health Care/Service Utilization/Demographic Characteristics/Health Status/Service Needs/Older Adults/Outside United States

Notes: Data from the Manitoba (Canada) Longitudinal Study on Ageing were analysed to identify home care utilisation patterns among the elderly from 1975 to 1978 in a jurisdiction with universally insured services based on assessed need. Socio-demographic and health-related variables associated with home care use were also examined. This study revealed that, when home care is based entirely on assessed need (without a requirement for medical service), about 5%-6% of the elderly are admitted for service each year and about 10% receive service for some time during the course of the year. Age was the strongest predictor of home care enrolment, with fair-to-bad self-rated health and problems in instrumental activities of daily living also being strong predictors of home care enrolment. Additional variables associated with home care use were having daily contact with relatives, being a woman, problems in basic activities of daily living, a metropolitan residence, and relative poverty. Home care services appeared to supplement family efforts and to permit the elderly to avoid institutionalization for a relatively long period of time. (LS) (AgeLine Database, ©1987, American Association of Retired Persons, all rights reserved).


Keywords: Home Care With Elderly Clients/Home/Home Care/Hospitals Nursing/Nursing Homes/Costs/Health/Community/Service Utilization/Aged/Community Care/Mortality/Quality of Life/AgeLine: Homecare/Savings/Home Health Care/Patient Admissions/Length of Stay/Health Service Costs

Notes: Analyses the effects of a long-term home care programme for chronically impaired elderly on hospital and nursing home use and health care costs. Information was obtained over a 4-year period on community care service utilisation, hospital admissions and lengths of stay, and nursing home admissions and lengths of stay for a group of 157 participants aged 60 and older in the Five Hospital Program (FHP) in Chicago, Ill., and a comparison group of 156 homebound elderly persons receiving home-delivered meals. The level of non-FHP community care services used by both groups was similar over the 4-year period. The mean number of hospital admissions was identical for both groups
but, once admitted, the FHP group had longer hospital stays. This difference is attributed to a large drop in the comparison group mortality rate in the last year, which may have been due to unmeasured differences in disease severity at baseline. The FHP group had a significantly lower risk of permanent admission to sheltered and intermediate-level nursing homes, but the two groups did not differ in risk of permanent admission to skilled-level nursing home care. Despite savings in low-intensity nursing home days, the overall costs of care were 25% higher in the FHP group. This increase in costs was accompanied by improved access to care, increased autonomy, and improvements in quality of life, however. (CM) (AgeLine Database, ©1988, American Association of Retired Persons, all rights reserved).


Keywords: Home Care with Elderly Clients/Home/Home Care/Home Care Agencies/Hospitals/Disabled/Older Adults/Adult/Case Management/Medicare/Transportation/Health/Nursing/Income/Pharmacy/Community/Funding/AgeLine: Homecare/Adults/Taxes/Public Sector/Program Description/Minnesota/Home Health Care/Community Services/Supportive Services/Housebound

Notes: Describes the services offered by the Minneapolis (MN.) Age and Opportunity Center (MAO), a home care agency. In co-operation with Abbott Northwestern Hospital, MAO offers a comprehensive array of services to help homebound and disabled older adults. It is non-profit in its structure, with one for-profit subsidiary to handle private-duty care. This makes it possible to receive gifts and provide the giver with a tax deduction. A community-based board of seniors runs MAO. Services offered at MAO include information and referrals, counselling or case management, help with Medicare paperwork, home-delivered meals, legal services, and transportation services. Also provided are home maintenance, chores, homemaking, home health, skilled nursing and physical therapy services. Seniors may obtain help with finding a job or developing new job skills, and those with low and moderate incomes are entitled to use MAO’s medical care and pharmacy services. Additionally, MAO’s meeting rooms are available for a variety of community activities. MAO has been successfully operating for 21 years, with funding coming from a variety of private- and public-sector sources. (WD) (AgeLine Database, ©1984, American Association of Retired Persons, all rights reserved).


Keywords: Home Care with Elderly Clients/Policy Comparisons/Policy Europe/Financing/Disabled/Home Care/Nursing/Nursing Homes/Home

Abstract: All EEC countries are faced with an ageing population which means an increase of people in some way disabled in everyday activities. A comparison of the solutions adopted by five EEC countries in the sectors of housing, home care services, residential and nursing homes shows that a real medico-social policy has been worked out only in some countries where as in others public authorities have
defined policies without providing corresponding resources. The concept of social protection appears to be one major factor which may account for these differences.

**Keywords:** Home Care with Elderly Clients/Home/Health/Questionnaire/State/Medicare/Regulation/Home Health Care/Training/Costs/Patients/AgeLine: Homecare/Rural/Federal Regulations/Home Care Agencies/Surveys/Service Accessibility/Transportation/Nurses Aides  
**Notes:** Presents the results of a survey of home health care providers in rural and frontier areas conducted by the National Association for Home Care (NAHC). Survey questionnaires were mailed to NAHC members, and responses were received from agencies in 27 states. Agencies serving clients in rural areas were asked to elaborate on Medicare or other federal regulations that hindered their operations, and to offer suggestions for improvement. The special problems faced by rural home health care providers were identified as poor accessibility, increased travel times, and staffing shortages. Distances travelled to serve clients ranged from 30 to 150 miles each way, with an average of 60 miles. The vast majority of respondents reported difficulties in providing physical therapy, occupational therapy, speech therapy, or medical-social services. Federally-mandated training requirements for home care aides sometimes exacerbated staff shortages, because it was not cost-effective for agencies to provide training for small numbers of employees. Respondents recommended increasing cost limits for rural services, expanding the definition of "homebound" to improve accessibility for patients who lack nearby facilities, reducing supervisory visits of home care aides from every two weeks to once a month, and reducing paperwork. (AY) (AgeLine Database, ©1992, American Association of Retired Persons, all rights reserved).

**Keywords:** Home Care with Elderly Clients/Hospitals/Physicians/Home/Health Services/Rural/Medicare/Home Health Care/Health Service/Survey/Health Care/Care/Research  
**Abstract:** Using data from the Medicare Current Beneficiary Survey, we identify differences in hospital days, home health visits and physician office visits across five geographical categories. After controlling for individual characteristics and availability of health care providers, we find significant differences in service use. Results show greater use of home health care and less use of physician office visits and hospital care in rural areas. Because service use exhibits patterns of substitution and complementarity, future research on the use of health services needs to move beyond modelling the use of single services to modelling the range of services used.

**Keywords:** Home Care with Elderly Clients/Rural/Aged/Assessment/ Questionnaire/Nursing/Personal Care/Caregivers/Economic/Health/ Activities of Daily Living/AgeLine: Homecare/Virginia/Functional Assessment/ Service Utilization/Home Health Care/Informal Support Systems/Supportive Services/Home Care

**Notes:** Examined predictors of the utilisation of informal in-home care in rural Virginia. Information was collected on 1,196 rural respondents aged 60 or older from the State wide Survey of Older Virginians, which used an instrument based on the Older Americans Resources and Services, (OARS), multidimensional functional assessment questionnaire. Use of six in-home care services was considered: Telephone and visiting reassurance; continuous supervision; homemaker/household assistance; meal preparation; nursing care; and personal care. More than half of respondents used no services. Of those that did use in-home services, 91.7% used only assistance provided by informal caregivers. Of the 20 independent variables studied, two enabling variables (having a car and distance to a friend) and three need variables (economic resources, physical health, and performance in activities of daily living) were significant predictors of service use. Discusses implications for preserving and enhancing the existing informal caregiving structure in rural areas and for targeting elders needing services. (LS) (AgeLine: Database, ©1988, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care with Elderly Clients/Home/Community/Home Health Care/Health/Community Services/Home Care/Language/Nurses/Training/ AgeLine: Homecare/Massachusetts/Consumers/United States/Other Adults/ Minority Groups/Ethnicity/Foreign Origin/Noninstitutionalized Elderly/ Program Description/Service Delivery/Bilingual Services

**Notes:** Describes the Multicultural Community Outreach Program, (MCOP), developed by Staff Builders Home Health Care Services in Boston, Massachusetts, to address the needs of non-English-speaking clients. More than 23,000 refugees and twice as many immigrants settled in Massachusetts from 1990 to 1994. The MCOP, which consists of Russian, Haitian, and Chinese community service teams, provides clients with home care services in their native language by professionals who serve as a cultural bridge between the client and the American health care community. In the Russian Community Service Team, for example, American-trained, Russian-speaking nurses provide care, and home care aid training is provided for Russian-speaking persons from various professional backgrounds. The MCOP also includes a community education component focused on creating a network of culturally sensitive health care providers and increasing consumer knowledge of the home care industry. (PH) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).

**Keywords:** Home Care with Elderly Clients/Geriatrics/Assessment/Nursing/Development/Community/Organizations/Aged/Workers/Occupational Therapist/Physiotherapist/Home

**Abstract:** A major deficiency during the initial stages of development of a geriatric unit was a lack of easily available information concerning facilities and services already existing in the community. A postal survey undertaken in conjunction with the Cape Peninsula Organization for the Aged resulted in the production of an information manual of services available to the elderly in the Cape Peninsula. In the introduction to this manual an invitation was extended to readers to direct requests for information to the Geriatric Unit at the Medical School of the University of Cape Town. This paper reports on the first 50 enquiries received, as a result of which 73 items of advice or information were given. Unmet community needs were revealed in 9 instances. Useful assistance was known to have resulted on 30 occasions, consisting, in the main, for geriatric and psycho-geriatric assessments and for domiciliary assessments by community nursing sisters or social workers, sometimes assisted by an occupational therapist or physiotherapist. Those who care for the aged at home need to be put in touch with correct sources of relevant information, and this appears to have constituted an additional and useful function of our information service.


**Keywords:** Home Care with Elderly Clients/Home/Home Care/Disabled/volunteers/Relative/Health/Organizations/Patients/Caregiver/Benefits/State/Savings/AgeLine: Homecare/Relatives/Health Maintenance Organizations/Cregivers/District of Columbia/Volunteer Services/Home Health Care/Housebound

**Notes:** Introduces a new concept in caring for homebound elderly or disabled persons whereby volunteers earn “time dollars”, or service credits that are banked for future use. A volunteer in Michigan describes how she spends 3 hours a week caring for a woman with multiple sclerosis. Through this state-administered program, the volunteer explains that she can bank unlimited hours and “spend” them later on her own needs or transfer them to a relative. Services centre mainly on home care, although in Brooklyn, N.Y., subscribers to a health maintenance organization can pay one of their quarterly premiums with 100 service-credit hours. The idea that both patient and caregiver can benefit was the idea of Dr. Edgar Cahn, a professor at the District of Columbia School of Law, who founded the programme in 1986 in Washington, D.C. The idea spread rapidly to nine other states. Homebound individuals get free services, which cut their health-care bills, and the volunteers are saving for their own future health care if and when it is needed. An address is provided for those who would like information about becoming a volunteer or starting a program. (AW) (*AgeLine Database*, ©1984, American Association of Retired Persons, all rights reserved).

**Keywords:** Home Care with Elderly Clients/disability/home/Home Care/Older Adults/Adults/Benefits/Community/Disabled/Institutionalization/Outcomes/Caregiver/Consumers/AgeLine: Homecare/Disabilities/Rehabilitation/Caregivers/Advocacy/Needs Assessment/Public Policy

**Notes:** Explores the benefits of adopting a disability approach to personal assistance for older persons and encourages joint efforts between the ageing and disability communities, where appropriate, potentially resulting in better personal assistance services for disabled persons of all ages. The goal of the discussion is to identify commonalities and legitimate differences to be negotiated by a society committed to empowering disabled persons of all ages, particularly in relation to personal assistance services. Access and full participation in society have been key goals for younger disabled persons but have not been routinely applied to disabled elders. Home care for older disabled persons addresses a more limited goal of maintaining current levels of functioning and avoiding institutionalization. Elders are likely to benefit from the disability approach’s emphasis on client empowerment, mainstreaming, and rehabilitation services. Other ethical, practice-oriented, and political arguments are set forth to examine possible benefits for elderly home care clients from a disability approach to services, including broader goals regarding client outcomes (for example, improvement and return to community activities), better client outcomes on physical and psychological dimensions, greater client choice in selecting a caregiver, a broader array of services in settings beyond the home to allow consumers to participate in mainstream community activities, and active participation in assessing care needs. (WD) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).

**Home Care with Clients of All Ages**


**Keywords:** Home Care - All Ages/Patients/Home/Home Care/Nursing Homes/Training/AgeLine: Homecare/Satisfaction/Age Differences/Disabled/Nursing/Attitudes/Personal Care/Transportation/Disabilities/Hawaii/Home Health Care/Physically Handicapped/Medicaid/Program Evaluation

**Notes:** Assesses age differences in satisfaction with home care services. A group of 42 severely disabled persons in three age groups (18 through 39, 40 through 64, and 65 and over) rated their satisfaction with the services of the Medicaid-sponsored Nursing Home Without Walls programme, Honolulu, Hawaii, in terms of technical competence, personableness, and access. Overall, respondents reported a high level of satisfaction with all aspects of care. Each patient indicated that the programme was helpful in five or six different ways, with no significant differences by age. The youngest group expressed significantly lower levels of
satisfaction than the other two age groups, however. Younger patients also gave more negative comments, but the content of these comments did not differ by age. Complaints focused primarily on the reliability, attitudes, and training of personal care aides and the lack of promptness of special transportation. Most younger clients had become disabled suddenly through accidents, while older patients tended to have multiple conditions, which resulted in a more gradual disability. Suggestions for program adjustments to increase satisfaction of younger clients are provided. (CM) (AgeLine Database, ©1988, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care - Training/Home Care - All Ages/Home Care/Workers/Quality of Care/Health/Personal Care/Interviews/Home Care Workers/Family/Central/Perception/Employers/Manager/AgeLine: Homecare/Home Health Care/Client Relations/Care Receivers/Interpersonal Relations/Reciprocity/Aging Service Personnel

**Notes:** Examined the nature and quality of relationships between home care clients and their paraprofessional workers—that is, home health aides, homemakers, and personal care attendants. Interviews were conducted with 54 home care clients, 39 home care workers, and 14 family members. Responses suggest that informality—or personal bonding—is a central feature of home care. Most clients and workers described one another in personal terms, as friends or like family. Most clients confided in their workers; and most workers did extra jobs—that is, beyond what they were assigned or paid to do according to perceptions of both workers and clients. Four types of worker-client relationships were identified: Personal, asymmetrical, formal, and collegial. Younger clients were more likely both to have collegial relationships with their workers and to report problems with worker performance. It is suggested that although informality may be necessary for good home care, it may also be a problematic aspect, increasing the risk of worker exploitation and decreasing the client’s control as employer or manager of his/her own care. (WD) (AgeLine Database, ©1991, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care - All Ages/Disabilities/Community/Interview/Aged/Home/Home Care/Homecare Agencies/Disabled/Caregivers/Health/Family/Regulation/Reimbursement/AgeLine: Homecare/Health Status/Costs/Quality Assurance/Workers/Advocacy/Independence/Age Differences

**Notes:** Analyses the differences between the ageing and the disability communities with regard to independent living. Interviews were conducted with 54 clients (aged 27-99) of home care agencies, as well as their paid helpers. These clients included 22 persons, 10 of whom were over age 60, who had been disabled by developmental disabilities or early-onset chronic conditions. All client respondents regularly received two or more visits per week and would need (or
had received) home care for at least six months. Findings in four areas are discussed: The extent of reliance upon paid caregivers, the site and rationale for providing care, the extent of involvement of medical personnel in care arrangements and provision, and the extent to which the disabled person directed and managed his or her services and assistants. Differences between younger and older clients in care arrangements seemed to reflect differences in the clients’ health status, the availability of family members, and regulations regarding the reimbursement of service providers. A preference that was held in common by those in the ageing and disability communities was the belief in allowing for client choice; however, considerations of cost and quality assurance were often more important in determining home care arrangements. Younger clients were more likely to hire their workers directly, while proportionately more older persons obtained agency services. (UH) (AgeLine Database, ©1992, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - All Ages/Home/Home Care/Organizations/Nurse/Physiotherapist/Patients/Environment/Hospitals/Health/MEIN10.MDL (MEDLINE 1966-92)/A:/B:/C:/D:

Notes: 84101077 The home care of the elderly, the physically handicapped, and the terminally ill, as practiced by a non-profit-making organization in southwest France, is described. Peripatetic nurses, nursing aides, and physiotherapists enable patients to remain in their own environments, and also relieve the acute hospital services. Costs are borne by the French health insurance schemes.

Home Care during and following Disasters


Keywords: Disaster/Home/Home Care/South/Nurse/Stress/Community/Work/Caregivers/Family/Environment/MESED5.MDL (MEDLINE 1966-92: MEDLINE 1966-92: PRIMARY RESEARCH)/A:/B:/C:/D:

Notes: 92375904 College of Nursing, University of South Carolina, Columbia 29208. During the course of field observations for an ethnographic study of home care nurses’ job stress, Hurricane Hugo struck the community, causing extensive damage. The nurses’ office building was heavily damaged by wind and water, and their office was not habitable for almost a week. The author had observed the nurses’ work practices over 10 weeks before the hurricane. In the aftermath of the storm, the nurses were simultaneously disaster victims and caregivers for other victims. They experienced grief, anger, and frustration about their losses, as well as conflict between their family- and work-related responsibilities. Their experiences and behaviours were consistent with those described in prior disaster research literature, lending further support to the earlier studies. A major asset for these nurses was their open, supportive work
environment. They were able to accept and affirm one another’s negative feelings and to provide support to each other as they dealt with their losses.


**Keywords:** Disaster/Mortality/Central/Public Health/Health/War/Risk Factors/Surveys/Survey/Death

**Abstract:** Famine and civil war have resulted in high mortality rates and large population displacements in Somalia. To assess mortality rates and risk factors for mortality, we carried out surveys in the central Somali towns of Afgoi and Baidoa in November and December, 1992. In Baidoa we surveyed displaced persons living in camps; the average daily crude mortality rate was 16.8 (95% CI 14.6-19.1) per 10,000 population during the 232 days before the survey. An estimated 74% of children under 5 years living in displaced persons camps died during this period. In Afgoi, where both displaced and resident populations were surveyed, the crude mortality rate was 4.7 (3.9-5.5) deaths per 10,000 per day. Although mortality rates for all displaced persons were high, people living in temporary camps were at highest risk of death. As in other famine-related disasters, preventable infectious diseases such as measles and diarrhoea were the primary causes of death in both towns. These mortality rates are among the highest documented for a civilian population over a long period. Community-based public health interventions to prevent and control common infectious diseases as needed to reduce these exceptionally high mortality rates in Somalia.


**Keywords:** Disaster/Health/Older Adults/Adult/War/Aged/Family/Home/Economic/Community/International

**Abstract:** The high rates of death, disability and illness and the scarcity of resources associated with relief operations for victims of oppression, war and famine have led to some support systems of triage for health and nutritional care in relief. Two vulnerable groups have often been given priority for targeting in health relief—young children and their mothers. This paper reports the findings of a study of the health needs of another vulnerable group—older adults—among those who had been recently displaced to Sudan in 1984-1985 by the war and famine in Tigray region of Ethiopia. The study attempted to determine the extent to which morbidity events and migration affected the life-style of older adults and the socio-economic support mechanisms, which were available to them. The findings indicate that older adults (those over 45 years of age) were a very small proportion of the population and that more than half of those aged 60 years and over (defined as “elderly” in this paper) had been left behind in Tigray. This may well indicate that disability, illness or both, forced many older adults, particularly those most in need, to remain in Tigray. Among older adults living in Sudan, high levels of minor disability, social isolation and total economic dependency indicated
vulnerability, but older adults had not been specifically considered in health policies and plans. Their primary needs were basic - for clothes, food, shelter, transport, seeds, oxen and farming tools. We conclude that priority in relief should be to support individuals, families and entire communities by adequately providing for basic needs. Furthermore, international relief agencies should give equal consideration to those who remain in their homes and those who migrate for assistance. This approach would take into consideration quality of life, not just the number of lives saved among those who reach the camps and shelters, and would assume responsibility for “Health for All”, not just for selected “vulnerable groups”.


**Keywords:** Disaster/Health/Embassy/War/Geriatric Care/Croatia/International Cooperation/Red Cross/Social Welfare/Human/Letter/Priority Journal

**Notes:** CS- S. Lang, Andrija Stampar School Public Health, Zagreb University School of Medicine, Rockefellerova 4, 10000 Zagreb CS- Croatia.


**Keywords:** Disaster/Croatia/Health/War/South/Interview/Volunteers/Social Welfare/Red Cross/Home/Family/Model/Embassy/Europe 0402/Eastern Europe 4022/Therapy 0160/Methodology 0130/Automation, Computers and Data Processing 0530/Economic Aspects 0139/Mammal 0738/Human 0888/Adolescent 0017/Aged 0019/Infant 0014/Child 0022/Adult 0018/Article 0060/Emergency Medicine/Public Health/Elderly Care/United Nations/Army/Police/Follow Up/Population Research/Data Analysis/Income/Pension/Quality of Life/Human/Adolescent/Aged/Infant/Child/Adult/Article/Elderly

**Notes:** CS-Dr. S. Lang, Andrija Stampar School Public Health, Zagreb University School of Medicine, Rockefellerova 4, 10000 Zagreb CS- Croatia AB- Aim. Presentation and analysis of an extensive humanitarian action aimed at saving abandoned, mostly elderly people in a post-conflict situation. SETTING: After almost two years of war in Croatia, the United Nations Protected Areas (UNPA’s) were established in 1992, in the parts of the country under control of the local rebel Serb population and paramilitary forces. On 4 August 1995, the Croatian military and police forces stormed the North and South UNPA zones and regained control of an area covering 10,497 square kilo meters in four days. The Serbian forces, followed by the majority of civilians, fled to Bosnia and Herzegovina and the Federal Republic of Yugoslavia. Immediately after that, it was realized that the remaining population (about 3% of the inhabitants recorded in the 1991 census) consisted mostly of the elderly requiring a substantial external assistance to survive. METHODS: Reconnaissance, follow-up, direct assistance, and interview data regarding 10,594 persons in 524 settlements are presented. The population was interviewed by 136 professionals and volunteers from 28 Social Welfare Centers and 14 Croatian Red Cross branches. Interview data on all 10,594 persons
are analysed. RESULTS: More than 75% of the remaining population were over the age of 60. They were scattered in 524 villages or hamlets, with only one inhabitant in 73 of them. One third had no income, and only about 17% were eligible for pension or welfare. Only approximately one fourth had access to public transportation or supply of goods and food, and half had electricity in their homes. Two thirds considered themselves ill, and some 6% needed emergency assistance, including a change of living conditions. The “Save Lives” operation included a “humanitarian census”, immediate financial, material, medical, and social assistance, increase in security, and a gradual establishment of contacts with families, administrative assistance, and approach to various other needs.

CONCLUSION: The exodus of most of the inhabitants of the area, leaving behind only 3% of the pre-war population, and the fact that most of this remaining population were elderly, has been an un-described phenomenon so far, and thus the “Save Lives” operation presents a unique model of assistance. The military operation, first of low-intensity and long lasting, and then an abrupt defeat of one party caused a total social collapse. The exodus of the inhabitants left behind a selected population of the elderly and helpless. Deprived of their family support network and having to deal with the consequences of the military operations significantly worsened the problems of the elderly. The humanitarian action helped substantially in saving lives, but was unable to increase security or to significantly restore the quality of life for this vulnerable group of people.


Keywords: Disaster/Home/Adult/Health/Urban/Family/Community/Questionnaire/Stress

Abstract: OBJECTIVE: To monitor nutritional status and food security in order to identify nutritionally vulnerable groups. DESIGN: Members of five different household groups (urban and rural residents, displaced people in collective centres and private accommodation, elderly people living without younger family) and all residents of two old people’s homes were prospectively followed. Households were selected from 20 local communities and nine collective centres. SETTING: Monitoring carried out in three besieged areas of Bosnia-Herzegovina (Sarajevo, Tuzla, and Zenica). SUBJECTS: 1739 individuals sampled. INTERVENTIONS: Data collected every month from December 1993 to May 1994. Information on household food security was collected through structured questionnaires. All subjects were weighed and their heights measured. Weight for age Z scores were calculated for children; body mass index was calculated for adults and elderly people. RESULTS: From December 1993 to February 1994, before a temporary cease-fire, access to food was reduced. In February 1994 no significant signs of under-nutrition were detected among children or adults, but elderly people had higher than expected levels of under-nutrition (15.5% with body mass index <18.5), a higher rate of weight loss than adults (1.2 kg over two months), and a higher prevalence of self reported illness. CONCLUSIONS: Elderly people in Bosnia-Herzegovina are at greater risk of under-nutrition than other age groups. Under-nutrition may be precipitated in elderly people by sickness, cold, stress, and problems related to food preparation. The health and welfare of elderly people
during the emergency in Bosnia-Herzegovina requires special attention, and integrated age care programmes are needed.

**Formal and Informal Caregiving:**

Caregiving, and more directly caregivers, especially informal caregivers, account for much of the literature about home care. This is the case, regardless of the focus, whether policy, component services or service delivery, whether freestanding or integrated with other health care sectors and whether research or practice based. Therefore, one of the challenges in constructing this annotated bibliography was determining how to organize the references on caregiving. The decision was made to focus initially on formal caregivers, followed by informal caregivers from the traditional perspective of informal caregivers being unpaid family members and friends, followed by a section addressing the current policy debate on whether or not to pay informal caregivers. Another section discusses the literature about informal caregivers of persons suffering with dementia, which tends to be documented separately from the more general caregiving sources. The last section in this grouping deals with terminal care relative to both formal and informal caregivers.

**Formal Caregivers**


**Keywords:** Home Care - Caregivers/Case Management/Home/Community/Community Care/Health/Frail Elderly/Disabled/Caregivers/Development/Nursing/Nursing Homes/Costs/Assessment/AgeLine: (Community Care NOT Home Care)/Long-term Care/Service Delivery/United States/Other Adults/Home Care/Community Services/Continuum PF Care/Service Planning/Service Needs

**Notes:** Provides an overview of case management in home and community care. Discusses the evolution of long-term care case management service that integrates the health and social support systems of care for the consumer. Reviews the objectives of long-term care case management for frail elderly and disabled populations: Client-oriented objectives such as assuring that services are appropriate to client needs, improving client access to the continuum of long-term care services, supporting the client's caregivers, and serving as a bridge between institutional and community-based care systems; and system-oriented objectives such as facilitating the development of non-institutional services, promoting quality and enhancing the co-ordination of long-term care service delivery, targeting individuals most at risk of nursing home placement to prevent inappropriate institutionalization, and containing costs by controlling client access
to services. Discusses the administration of case management services, qualifications of case managers, and caseload size. Considers six case management functions: comprehensive assessment, care plan development, care plan implementation, monitoring, reassessment, and termination and discharge. Provides advice on staffing a case management agency, discusses for-profit versus non-profit case management, and looks at quality improvement issues. (SW) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care - Caregivers/Female/Caregivers/Employment/Long Term Care/Females/Disabled/Article/Elderly Care/Work/Status/Long-term Care/Care/Survey/Elderly/Analysis

**Abstract:** This article uses data from the 1989 National Long-term Care Survey and its companion Informal Caregivers Survey to investigate how the employment of female primary caregivers (FPCG’s) affects hours of care received by disabled elderly care recipients (CR’s). Multivariate analysis controlling for key FPCG and CR characteristics indicate that when FPCG’s are employed they provide significantly fewer hours of care personally; however, their CR’s also receive significantly more hours of help from other sources. When FPCG’s work more than 17 hours per week, their CR’s receive significantly fewer total weekly hours of care than would otherwise be the case.


**Keywords:** Home Care - Caregivers/Policy Caregivers/Family/England/Costs/Long Term Care/Community/Caregivers/Roles/Home/Disabled/MESED4.MDL (MEDLINE 1993-7:PRIMARY RESEARCH)/A:/B:/C:/D:

**Notes:** 94066925 Institute for Studies on Aging, New England Research Institute, Watertown, MA 02172. The focus on rising costs of long-term care now encompasses community as well as institutional care. Policy makers cite the potential impact of changing social trends on informal caregivers’ availability to continue as the main source of care and the possibility that formal services will then replace this informal care. They fear that families will relinquish their caregiving role if publicly funded home care services are available. Longitudinal data from a sample of disabled elders were used to investigate the substitution of formal services for informal care over a seven-year period. The substitution that was detected could be traced to the limited availability of informal care, and it represented a temporary change in the informal care pattern rather than a permanent replacement for it. Instead, use of formal services has supported the elderly person’s continued residence in the community.

**Lingsom, S. (1992). Home Help and Filial Support. The Effect of Public Services on Adults’ Help to Aging Parents; Hjemmehjelp Og Barna. Invirkning Av**

**Keywords:** Home Care Using Paid Informal Caregivers/Home/Support/Adults/Aging/Norway/Family/Welfare/State/Adult/Adult Children/SOCIOFILE (Paid Home Care)/Elderly/Public Services/Home Health Care/Parents/Dependent Elder Care, Family’s Role Welfare States/Empirical Data/Social Problems and Social Welfare/Social Gerontology

**Notes:** TSMFA4 aja Abstract-of-Journal-Article Norwegian. In Norway, in contradiction to the notion that family care of dependent elders is weakened by the welfare state, evidence from a cross-sectional random national sample of 685 elders age 66+ living at home indicates that public services supplement and support family care. Adult children of both sexes provide parents with more practical assistance in cleaning and shopping when home help services are also used. A possible explanation is that elders using public services need not fear becoming a burden on their families and overcome their reluctance to request and/or accept practical assistance from them. Daughters help more, and in different circumstances, than do sons. 4 Tables, 32 References. Adapted from the source document. (©1993, *Sociological Abstracts, Inc.*, all rights reserved.)


**Keywords:** Home Care - Caregivers/Home/Home Care/Home Care Agencies/Development/South/Health/Training/Workers/AgeLine: Homecare/NewYork/Contracts/Blacks/Wages/Program Description/Home Health Care/Cooperatives/Para-professional Personnel

**Notes:** Describes the development of Cooperative Home Care Associates (CHCA), a worker-owned home care agency in the South Bronx section of New York, N.Y. CHCA began operations in January 1985 and currently provides paraprofessional services under contract to nine certified home health agencies and long-term care programmes. The agency has approximately 160 home health aides and 10 administrative staff, most of whom are black and Hispanic women who live in the area. By offering higher wages, opportunity for advancement, improved working conditions, and an extensive entry-level and in-service training program, CHCA has significantly reduced worker turnover and has fostered a sense of teamwork within the agency. Experience has shown that providing high-quality home care requires adequate job stability, compensation, and respect for paraprofessional workers; selection of workers who are capable of both performing specific tasks and developing personal relationships; a management commitment to support staff and management systems; and an emphasis on satisfying clients’ needs. (LS) (*AgeLine Database*, ©1989, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care - Training/Home Care - Caregivers/Workers/Home/Home Care/Hospitals/Funding/United States/State/Health/Human/Model/ Frail Elderly/
Elderly/Training/Work/Careers/Employment/Interview/AgeLine: Homecare/Models/Home Care Workers/Home Health Care/Para-professional Personnel/California/Home Care Agencies/Program Description/Labor Turnover/Homemaker Services/Program Evaluation/Outcomes/Educational Programs/Career Development/Career Education

Notes: Describes a consortium of home care agencies developed to recruit, train, and place home care workers and to develop retention strategies. In 1992 the Senior Care Network of Huntington Memorial Hospital in Pasadena, California—with funding from the United States Department of Health and Human Services, Administration on Aging—established a consortium that included a diverse group of home care agencies. A major project goal was to develop and test a multiagency model that would provide a pool of qualified workers to serve frail elderly in their homes. The program developed a 3-stage training program that began with a free 60-hour entry-level course focusing on homemaker tasks and skills, followed by a 60-hour block of paid work experience with home care agencies. To extend the career ladder, stage three provided an additional 72 hours of training for state home health aide certification. In return for training, applicants were asked to sign a 6-month commitment to work for the consortium agencies. Eighty percent of those who started the entry-level class completed it. However, between one-third and one-half of the graduates never applied for the paid experience. Out of 120 entry-level graduates, 30 earned certification. Successful strategies for securing employment of new graduates are discussed, including assisting them with applications. The best retention strategy was giving employees as much work as they wanted, although this was difficult for agencies with fewer referral services. The consortium structure proved workable as a way to increase the number of home care workers and improve the quality of home care. Although the attrition rate between interview and graduation was 70%, 44% of those who became employed were still working for their agencies at project end. (TS) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Caregivers/Home/Home Health Care/Health/Home Care/Physicians/Nurse/Workers/Primary Health Care/Patients/Health Care Utilization/Satisfaction/Nursing/Nursing Homes/Costs/MEINT9.MDL(MEDLINE 1966-92)/A:/B:/C:/D:

Notes: 85094720 This report describes the findings of a randomised study of a new team approach to home care for homebound chronically or terminally ill elderly. The team includes a physician, nurse practitioner, and social worker delivering primary health care in the patient’s home, including physician house calls. Weekly team conferences assure co-ordination of patient care. The team is available for emergency consultation through a 24-hour telephone service. The team physician attends to the patient during necessary hospitalisations. This approach was evaluated in a randomised experimental design study measuring its impact on health care utilisation, functional changes in patients, and patient and
caretaker satisfaction. The team patients had fewer hospitalisations, nursing home admissions, and outpatient visits than the controls. They were more often able to die at home, if this was their wish. As expected, they used more in-home services, measured in weighted cost figures; their overall cost was lower than their controls, but the difference was not statistically significant. Their functional abilities did not change differently from the controls, but they, and especially their informal caretakers in the home, expressed significantly higher satisfaction with the care received.

**Informal Caregivers**


**Keywords:** Home Care Informal Caregivers/Elderly/Support/Marital Status/Survey/Income

**Abstract:** This paper describes elderly support and intergenerational transfer by gender, marital status, and place of residence for 150 elderly persons in Zimbabwe. The survey was conducted in September 1988, and includes information on background characteristics, income, and cash support from all sources, non-cash support, and the support of elders to others. Conclusions and implications are discussed.


**Keywords:** Home Care Informal Caregivers/Africa/Elderly/Community/Migration/Roles

**Abstract:** Elders in Africa are seen as a source of wisdom and are regarded as a valuable part of society. A new challenge in Africa is keeping the elderly involved in the community. Modernization, urbanization and migration are seen as factors, which undermine the traditional participatory role of ageing people in this region. Another psychological study has shown that illness in old age is more likely if the elder has been in an unfulfilling role for a long period of time. This reinforces the need to keep elders active in all elements of society.-GH


**Keywords:** Home Care Informal Caregivers/Caregiver/Elderly/South/Relatives/Economic/Economic Factors/Caregiving/Health/Health Status/Caregivers/Status/Determinants

**Abstract:** This study investigated the determining variables of caregiver burden in caring for impaired older relatives in South Korea. Economic factors, daily caregiving hours, and caregiver’s health status emerged as the most important determinants of caregiver burden in Korea. Though not a powerful predictor, caregivers' congruency with the traditional caregiver selection norms remained a statistically significant predictor of certain dimensions of caregiver burden.
Geneva, World Health Organization.

**Keywords:** Home Care Informal Caregivers/Environment/Health/Germany/
Japan/United Kingdom/United States/State/Attitudes/Home/Asians/Caregiving/
Family/Support/Elderly

**Abstract:** Life expectancy is not only affected by heredity and our immediate
environment. Studies on the health and lifestyles of Japanese, Japanese-
Americans, and American Caucasians indicate that cultural environments
influence lifestyles and social networks and therefore may be related to longevity.
An additional study conducted in Germany, Japan, the Republic of Korea, the
United Kingdom and the United States showed extreme differences in attitudes
regarding 3-generation homes. Traditional Asian culture places a greater
responsibility for caregiving on the family, which consequently increases the
likelihood of receiving the support that is needed. Examples of technological
advancements used to provide better care for the elderly are also discussed.-GH

Elderly with Disabilities in Hong Kong. International Journal of Rehabilitation
Research 15[3], 199-207.

**Keywords:** Home Care Informal Caregivers/Elderly/Disabilities/Community/
Community Care/Family/Survey/Disabled/Support/Informal Care/Frail Elderly

**Abstract:** Community care has been a major guiding policy in developing
services for the elderly in Hong Kong. It has been assumed that Chinese families
tend to have a large caring network to render care in the community. However, in
a survey conducted in early 1991, it was found that such caring networks for
disabled elderly people were very small and inconsequential. Quite high
proportions of Chinese disabled elderly are living alone in the community, and
have a small network for emotional support. Effective measures to promote family
care of disabled elderly people are discussed. Two pathways for integrating the
formal and informal care sectors are examined in relation to promoting effective
practice for the frail elderly living in the community.

Takeuchi, F., Takano, T., and Nakamura, K. (1994). Mobility Function of the
Elderly Living With Their Children and its Relation to the Home Health Care
System in Tokyo. Disability and Rehabilitation 16[4], 217-222.

**Keywords:** Home Care Informal Caregivers/Elderly/Home/Home Health Care/
Health/Health Care System/Japan/Questionnaire/Survey/Family/Social Services/
Housing/Parents

**Abstract:** Most elderly in Japan prefer living with their children once their
spouses pass away. In comparison with western countries, home health care
systems have developed quite differently in Japan. The traditional practice of the
elderly living with their children is, however, changing. In 1989 we carried out a
mail questionnaire survey focused on the relationship between mobility functions
of the elderly living in Tokyo and their rate of living with family members. The
subjects for the present analysis were 2368 widows and widowers. Under the
group category 'independent in long walks', 72.8% were living with their families.
With a decrease in mobility functions, this percentage rose to 81.1% and 84.6%, although it decreased to 50.9% in the group with severely impaired mobility functions. The need to develop effective social services for families housing their parents is discussed.


**Keywords:** Home Care Informal Caregivers/Long Term Care/England/60+/Medicare/Disabled/Caregivers/Minority Groups/Ethnicity/Hs1ref.Txt/A:/B:/C:/D:

**Notes:** 97604496 Institute for Studies on Aging, New England Research Institutes, Watertown, MA 02172. USA RESEARCH OBJECTIVES: The objective of this study was to investigate differences between African-American, Hispanic, and non-Hispanic White elders in patterns of long-term care use.

**STUDY POPULATION:** A population-based sample of African-American, Puerto Rican, and non-Hispanic White persons age 60+ was drawn from Medicare beneficiary files and the local annual census of a large north-eastern city. **STUDY DESIGN:** This cross-sectional observational study collected data from a linked sample of functionally disabled older persons and their primary informal caregivers. Both the receipt of informal care and formal services (yes/no) and the amount of help (hours per month) were compared for the three ethnic groups.

**PRINCIPAL FINDINGS:** Elders in the two minority groups were more disabled than White elders, with Puerto Rican elders being the most disabled (p<.001). Puerto Ricans reported having fewer caregivers (p<.05) as well as fewer potential caregivers (p<.001). Ethnicity was not related to either the likelihood of receiving informal care or formal services or the amount of care received. **CONCLUSIONS:** The overall lack of relationship between ethnicity and both patterns of care and amounts of care when controlling for other factors was unexpected. It appears that structural (social) factors may override cultural (behavioural) factors in influencing how informal care is provided and formal services are used, particularly in minority groups. **POLICY RELEVANCE:** Data from this study raise serious questions about future availability of informal care for the highly disabled (predominantly Puerto Rican) elders. It cannot be assumed that traditional family cohesion will outweigh the effects of social changes. (Amended Abstract by: Author)


**Keywords:** Home Care Informal Caregivers/Home/Health/Caregivers/Economic/State/Ethnicity/Family/COSTM2.MDL/A:/B:/C:/D:

**Notes:** 91139000 Department of Economics, Fogelman College of Business Economics, Memphis State University, TN 38152. This paper systematically links and examines two decisions of employed informal caregivers, the allocation of time to care production and to the labour market. Its main contribution is its evaluation of the influence of ethnicity on the family’s decisions about providing health care to meet the impending needs of an elderly family member or friend.
Caregiving production factors, financial resources, and personal characteristics of the informal care providers influence both caregiving hours and the labour market decisions. German-, Irish-, English- and Afro-Americans differ significantly in their decision to provide informal care. Policy and research implications of this analysis are discussed.


**Keywords:** Home Care Informal Caregivers/Employment/Disabled/Health Care Policy/Work/Caregivers/Model/Female/Caregiver/Costs/COSTM2.

**Notes:** 90286656 Agency for Health Care Policy and Research, Rockville, MD 20857. The competing demands of work and elder care are the subject of this study. The employment decisions of the informal caregivers of a nationally representative sample of disabled elders were examined using a nested multinomial logit model. Findings from the work accommodation model demonstrated that primary caregivers and those caring for elders with greater care needs are more likely to take unpaid leave, reduce work hours, or rearrange their work schedules to assume elder care responsibilities. Being female, white, and in fair-to-poor health also increased the likelihood of work accommodation. The model predicting employment of a caregiver revealed that the prospect of having to accommodate work to the demands of caregiving keeps some people from work entirely. However, not all caregivers would choose to work in the absence of caregiving responsibilities. After controlling for the probability of work accommodation, need for care, and availability of others to care, it is more likely that younger, white and more highly educated caregivers will be employed. The self-selection of working caregivers observed in this study should be considered when forecasting changes in caregiving costs associated with changes in the labour force participation of caregivers as a result of deliberate policies or social and demographic trends.


**Keywords:** Home Care Informal Caregivers/Kinship/Lineage/Intergenerational Relationships/Family/Survey/Determinants/Relationships/Parents/Marital Status/Status

**Abstract:** Using data from the second wave of the National Survey of Families and Households, the authors examine the determinants of frequent and infrequent visiting between grandparents and their grandchild sets. A grandchild set consists of all the children of their parent’s household. The 6 significant predictors of frequent or infrequent contact are geographic distance, quality of relationship between grandparent and parent of the grandchild set, number of grandchild sets, gender of grandparent, lineage of the grandchild set, and marital status of the grandparent.

Keywords: Home Care Informal Caregivers/Family/Caregivers/Disabled/Adults/Health/Social Services/Depression/Male/Female/MESED/MDL (MEDLINE 1966-92:(MEDLINE 1966-92: PRIMARY RESEARCH)/A:/B:/C:/D:

Notes: This study examines the efforts and needs associated with family care for disabled and frail adults. A survey of 117 primary caregivers focused on: the health problems associated with caregiving; the existence of informal, family support systems; the use of formal social services, and the need for additional social service programs. Most caregivers report physical and emotional problems due to caregiving ranging from hypertension and back problems to depression and mental exhaustion. The characteristics of caregivers at high risk for health problems are identified. Less than half of the caregivers have family or friends to assist them with caregiving. At least one type of social service was being used by over 80% of caregivers, with utilisation patterns in male and female caregivers. Based on the study findings, several policy implications are reviewed.


Keywords: Home Care Informal Caregivers/Caregiver/ Roles/Health/Long-Term/ Caregivers/Relative/HS2REF.TXT/A:/B:/C:/D:/Policy/Management/Care/Elderly/Caregiving/Long-term Care/Survey/Risk/Risk Factors

Notes: 94338553 Department of Health Policy and Management, Johns Hopkins University, Baltimore, MD 21205. This study focuses on factors related to why people with primary responsibility for providing care to ADL-impaired elderly persons ended their caregiving roles. Data are from the 1982 National Long-Term Care Survey and the Informal Caregiver Survey. Variables reflecting characteristics of care recipients and caregivers, caregiver role responsibilities, and appraisal of the caregiver role are investigated. Of particular interest is the influence of role responsibilities, such as number of ADL tasks, relative to appraisal of the caregiving role. The results indicate that factors other than role responsibilities are important in understanding who ends caregiving, and that risk factor profiles may prove a useful means of targeting caregivers at greatest risk of ending caregiving. (41 References) (Abstract by: Author)(Review).


Keywords: Home Care Informal Caregivers/Caregivers/Chronically Ill/Work/Interview/Home/Home Care/Patients/Social Networks/Satisfaction/Health/Stress/SOCIOFIL.(JMCGOWAN)/A:/B:/C:/D:

Notes: 90W12220 School Social Work U. Michigan, Ann Arbor 48109. Correlational analyses of data obtained via in-depth semi-structured face-to-face interviews with 77 persons providing home care for chronically (some terminally) ill patients, regarding the effect of caregivers' social support networks on their social participation and well-being, support the hypothesis that "robust" social
networks are associated with higher levels of social participation. Social participation, in turn, is related to higher levels of well-being and life satisfaction. Dimensions of social networks are not directly associated with well being. Satisfaction with one's health and higher levels of worry and stress are associated with higher levels of satisfaction with friends and outside activities. Contrasting social network structures and sources of support among caregivers of three types of chronically ill patients served by three different programmes are compared. 4 Tables, 1 Appendix, 15 References. Modified HA (©1990, Sociological Abstracts, Inc., all rights reserved.).


**Keywords:** Home Care Informal Caregivers/Geriatrics/California/Older Adults/Adult/Assessment/Health/Adults/Family/Caregiver/Home/Home Care/Patients/State/MEINT5.MDL (MEDLINE 1966-92)/A;/B;/C;/D;/ Research/Health Care/Care/Relationships/Risk/Risk Factors/Death

**Notes:** 92103599 Geriatric Research, Education, and Clinical Center, VA Medical Center, Sepulveda, California. Elder abuse encompasses physical, psychological, and financial abuse and also includes the violation of an individual's rights, or social abuse. The denial or shame of the abused older adult often obstructs detection of elder abuse and the denial or improper assessment by health care professionals. The ethical struggle professional's face when they suspect abuse may also impede assessment or intervention. Preliminary data on etiologic factors related to elder abuse suggest that misinformation, the caregiver's lack of understanding of the needs of older adults, social isolation, a history of dysfunctional family relationships, and the psychopathologic factors of the caregiver are salient factors for understanding elder abuse. In addition, caregiver burden related to the care of the impaired elder and other external life events are risk factors for elder abuse. Self-neglect is the type of elder abuse most often reported and the most difficult to handle, because older adults have a right to refuse services. Home care providers often face practical and ethical dilemmas in cases of self-neglect. When making an assessment for elder abuse, it is best to use a multidisciplinary approach. In addition to physical indicators (bruises, malnutrition, fractures), attention must be paid to the social, family, and sexual history of the patient. The psychological history of the patient and caregiver is also important. Reporting laws exist in all states, and health care practitioners must become familiar with the laws in their states. Awareness of elder abuse by professionals working in home care is essential, because the failure to detect abuse can interfere with interventions and, in some cases, lead to death. [References: 38] [Review].


**Keywords:** Home Care Informal Caregivers/Family/Caregivers/Dementia/ Nurses/SocialWorkers/Workers/Physicians/Health/Caregiver/Home/Home Care/Article/Roles/MESED2.MDL (MEDLINE 1993-7:PRIMARY RESEARCH)/ A;/B;/C;/D:
Notes: Care plans are developed to meet the needs of persons suffering from a dementia or a chronic, debilitating disease. Nurses, social workers, physicians, physical therapists, and other health care professionals create the care plans, primarily with the care recipient in mind. Yet, often, it is the family caregiver who must provide the majority of home care. Who considers this caregiver's needs? This article focuses on the informal, family caregiver, often untrained, who must follow the care plan, with or without help from the professionals. It offers practical suggestions to help these caregivers carry out their role with productive and satisfying results.

Issues of Paying Informal Caregivers


Keywords: Home Care Using Paid Informal Caregivers/Caregivers/Disabilities/Europe/Care Receivers/Belgium/Canada/Canada/Disabilities/England/France/Germany/Netherlands/Welfare/Regulation/Long Term Care/Family/Disabled/Finland/Sweden/Austria/AgeLine (Paid Home Care)/Informal Support Systems/Financial Assistance/Public Policy/Other Adults/Outside United States/International

Notes: Discusses payments for extra-care activities of caregivers for older people and people of any age who suffer from disabilities in Europe. Three main types of payments for this extra care include direct payments or care allowances; indirect payments or attendance allowances, which are paid to the care receiver and who may use them to pay informal caregivers; or new cash-based schemes of guaranteeing care that operate like attendance allowances but are the main basis for securing rights to care. While Belgium, France, Germany, the Netherlands, and southern Europe have no care allowances, various attendance allowance schemes are found throughout Europe (except for the Netherlands and most southern European countries). Reflecting different streams of thoughts about public welfare, the importance of such regulations may increase as they are part of a restructuring of welfare practices and ideologies and the changing significance of care issues in our societies. Other topics discussed include how the different perspectives on welfare and long-term care affect the design of payments and the impact of payment for care on family care and caregivers. It is recommended that the goals of promoting payments for care as a part of schemes giving more responsibility back to the very frail and disabled and their caregivers should be made mutually dependent with improving the overall status of care by increasing public resources and choices, especially for caregivers. Sidebars provide detailed information on payments for informal care in Belgium, Finland, Sweden, the Netherlands, and Austria. (SW) *AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved*.

Keywords: Home Care Using Paid Informal Caregivers/Policy Europe/Financial Support/Support/Informal Care/United Kingdom/Ireland/Italy/France/Germany/Finland/Sweden/Caregivers/Economic/Models/Development/AgeLine (Paid Home Care)/Older Adults/Outside United States/International/Cross Cultural Studies/Informal Support Systems/Public Policy/Supportive Services/Government Expenditures/Community Services/Service Needs/Service Demand

Notes: Documents existing arrangements for financial support of informal care in seven European countries: United Kingdom, Ireland, Italy, France, Germany, Finland, and Sweden. Considers why various forms of financial support have been introduced and what effects they have had. Outlines existing arrangements for formal service support of informal care and examines how financial support overlaps and interacts with such provision. Investigates the relationship between both financial and service provision and the labour market behaviour of caregivers. Provides information on the demographic and public expenditure context of these issues in Europe. Concludes that all the countries are currently facing growing demands for care services in a time of declining birth rates and economic recession. Describes the different responses to this common set of pressures. Compares the different models of providing financial support that each country’s arrangement seems to reflect and evaluates their adequacy in supporting informal caregiving. Discusses the implications for a range of possible policy developments in the United Kingdom. Includes references. (AR) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


Keywords: Home Care Using Paid Informal Caregivers/Costs/Long Term Care/Family/European Union/United Kingdom/Ireland/Italy/Germany/Home/Economic/Development/Income/Disabled/Elderly/State/AgeLine (Paid Home Care)/Home Care/Older Adults/Outside United States/Europe/Old Age Assistance/International/Income Maintenance/Social Security

Notes: Examines the dimensions that determine whether national social security systems make payments toward the costs of long-term care needs, whether they do so where these needs are met within the family, what kinds of payments are made and to whom, and at what levels these payments are set. Discussion is based on empirical research conducted during 1992 on five European Union countries—the United Kingdom, Ireland, France, Italy, and Germany. The different choices and balances within the various countries between home care services, financial allowances in the form of social security payments, and/or employment-related safeguards to some extent reflect different historical, cultural, and political traditions, as well as different levels of economic development. However, much of the variation in both levels of allowances and their coverage depends on whether cash payments are seen as part of general income maintenance policies at the national levels, as in the United Kingdom, or as part of the responsibilities of local government to provide for the care needs of severely disabled and elderly people, and whether this be via residential care, domiciliary services, or cash allowances. Levels of allowance to meet long-term care needs are most generous in France, followed by Italy and Germany, then by Ireland, and finally the United Kingdom.
Two other factors account for the differences—assumptions of to whom long-term care represents a “risk”, and national principles of subsidiarity and the relationship between the family and the state. Tables and charts illustrate the data. (WD) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Home Care Using Paid Informal Caregivers/Home/Home Care/ Family/Illinois/Financing/Assessment/Quality of Care/Adult/State/Welfare/ Caregivers/Community/Community Care/Aging/Service Delivery/Costs/ Workers/Ageline: Homecare/Adults/Public Policy/Michigan/Home Health Care/Informal Support Systems/Program Evaluation/Reimbursement

Notes: Explores how incentives created by the structure and financing of home care in Illinois and Michigan differentially affect providers’ and clients’ preferences, well-being, and assessments of the quality of care. In Michigan, and Adult Home Help program operated by the state welfare agency pays clients’ informal caregivers, while in Illinois a Community Care Program operated by the state Department on Aging generally pays agencies to provide services. Each program’s origins and context, the structure of service delivery, mechanisms of financing, and impacts on clients are examined. Both care delivery strategies have their strengths. The Illinois approach favours professionalism and high cost and quality, but it also results in high worker turnover and less regard for caregiver-client relationships. Michigan’s approach favours informality, long-term stability of helping relationships, and respect for client preferences and autonomy. (LS) (AgeLine Database, ©1989, American Association of Retired Persons, all rights reserved).


Keywords: Home Care Using Paid Informal Caregivers/Wages/Family/Caregivers/Taxes/Relatives/State/Funding/Community/Michigan/Illinois/Perception/ Costs/Savings/Medicaid/Functional Ability/Assessment/Training/Quality Assurance/Financing/Benefits/Ageline (Paid Home Care)/Public Policy/ Reimbursement/Informal Support Systems/Program Description/Long Term Care/ Service Delivery/Family Relationships/Service Accessibility/Other Adults/Outside United States

Notes: Considers the merits of compensating family caregivers of the elderly. Four main types of programmes encourage family caregiving: tax credits, direct provision of service, legal requirements for family financial responsibility for elderly relatives, and cash grants (the focus of this volume). The first section reviews research findings on compensated family care in selected states and countries, exploring issues of access, equity, quality, and funding, and evaluating various service structures; the second section compares community care
programmes in Michigan and Illinois; and the third section integrates the results and develops policy objectives. The perceptions of affected parties--policy-makers, administrators, families, and consumers--are included in this analysis. It is suggested that approaches that focus on the cost-savings consequences of compensating family caregivers "exploit" rather than support the informal system. The thrust of such policies has been to avoid paying for care that families provide "for free" and to avoid including social care in entitlement programs; concerns are raised about the substitution and "woodwork" effects, in which the establishment of family support systems creates a demand exceeding that which previously existed. An alternative view would place value on community or socialised care, rather than individual care. This approach assumes that the responsibility for care of dependent individuals is one shared by family and government. Family care would be integrated into a continuum of services and programmes, rather than deterred by disincentives such as fees, professional standards, spend-downs, and means testing. The government could guarantee a basic level of support above which families could be free to spend more. A detailed discussion explores various alternatives to implement such a programme. Recommendations are offered in the following areas: eligibility (a Medicaid standard of need, with a functional ability assessment) standards, training, quality assurance, financing (federally-matched state and local funds), allocation, policy objectives, provisions (form of benefit, targeting, and fringe benefits), and delivery strategies. Tables and charts illustrate the data and references are provided. (UH) (AgeLine Database, ©1992, American Association of Retired Persons, all rights reserved).


Keywords: Home Care Using Paid Informal Caregivers/Community/Community Care/Relatives/Caregivers/State/Home/Wages/Welfare/Nursing/Disabled/Nursing Home/Home Care/Relative/Family/AgeLine: (Community Care NOT HomeCare)/Nursing Homes/Reimbursement/Home Health Care/LivingArrangements/Illinois/Program Description/Home Care Agencies/Level of Care/Supportive Services

Notes: Explores the feasibility of a state policy to permit home care agencies to hire kin as caregivers by examining existing data on an Illinois programme that allowed relatives to be hired. The state program, dubbed "310" after the minimum wage paid to caregivers at its inception, began in 1979 when the state legislature shifted responsibility for frail and indigent elderly from the public welfare agency to a community care programme that was designed to provide nursing home services to ill and disabled elderly who otherwise would require nursing home care. Of 444 clients, 22% had kin, mostly daughters, as caregivers. Those cared for by non-kin were almost twice as likely to live alone as those cared for by kin caregivers. Findings showed a relationship between level of impairment and being cared for by either a relative or someone living in the same residence. It is suggested that very high impairment coupled with limited financial resources may lead to family care as the only alternative to inadequate care or nursing home placement since 24-hour care and/or supervision are seldom available through public programmes. The limited number of clients with paid caregivers who were
kin suggests that there may be a natural limit to the demand for such an option. (JM) (AgeLine Database, ©1990, American Association of Retired Persons, all rights reserved.)


Keywords: Home Care Using Paid Informal Caregivers/State/Taxes/Informal Care/Elderly/Caregivers/Frail Elderly/Long Term Care/Financial Support/Support/Article

Abstract: Programmes for informal caregivers of frail elderly can be adopted by States to address some of the problems associated with an expanding and costly long-term care system. In this article, highlights are given from a 3-year study of Idaho and Arizona tax incentive programmes. Characteristics of informal caregivers and elderly participants are described, and elderly participants are compared with elderly non-participants and with the general elderly population. Tax incentives were positively related to the level of service and financial support provided by informal caregivers. Data were inadequate to determine whether the induced informal help substituted for public expenditures.


Keywords: Home/Caregivers/Home Care/Care/Data Analysis/Analysis/Research/Organizations/Family/Caregiving/Support/Support Programs/Female/Care Receivers/Urban/Dependence/Benefits/Stress/Older Adults/Noninstitutionalized Elderly/Canada/Outside United States/Caregiving Burden/Sex Differences/Living Arrangements/Community Services/Informal Support Systems/Supportive Services/Financial Assistance

Notes: Examined the differences between Canadian caregivers receiving financial compensation and those receiving home care or a combination of the two. A secondary data analysis was done of a larger research project, Shared Care: The Organization of Home Care and Family Caregiving. The responses of 136 caregivers (mean age 51) receiving financial compensation (30%), home help services (38%), or a combination of both (32%) under Nova Scotia's Home Life Support and In-Home Support programmes were examined. Paid caregivers were more likely to be female, younger, living with the care receiver, and living in non-urban areas. Caregivers receiving services only were more likely to be sons or spouses and live in urban areas. While few caregivers reported any emotional burden, a time dependence burden was felt across all care groups, with financially compensated caregivers reporting the highest burden. Caregivers cohabiting with care receivers, regardless of the type of programme benefit, reported the highest burden levels. Caregivers receiving home help services experienced positive change over time in more areas, including feeling less tired and anxious, but paid caregivers reported less financial stress. (CN) (AgeLine Database, ©1997, American Association of Retired Persons, all rights reserved).

**Keywords:** Caregiver/Policy/Financial Support/Support/Family/Caregivers/State/Employers/Taxes/Development/Care/Child/Parents/District Of Columbia/Legislation/The Elderly/Elderly/Disabled/Adults/Disabilities/Trends/Welfare/Health/Health Care/Health Care Reform/AgeLine (Paid Home Care)/United States/Older Adults/Public Policy/Financial Assistance/Employee Benefit Plans/Public Sector/Private Sector

**Notes:** Examines the adequacy, equity, and appropriateness of current federal, state, and employer policies regarding financial support for caregivers. Describes the current fragmented array of financial supports for family caregivers, which range from direct payments to tax allowances, dependent-care tax credits, and unpaid leave. Discusses the recently implemented Family and Medical Leave Act (FMLA) of 1993, which represents a step toward the development of a cohesive national family policy; it requires that all private companies with 50 or more employees grant up to 12 weeks of unpaid leave per year for care of a new-born or adopted child, because of the employee’s own serious illness, or in the case of the employee’s seriously ill spouse, child, or parent. Notes that 31 states and the District of Columbia have some type of family and medical leave legislation. Highlights the uneven pattern of supports available to family caregivers of the elderly, the younger physically disabled, and children and adults with mental retardation and developmental disabilities. Discusses the future of financial support policies for caregivers and suggests a slight trend toward increasing public provisions for caregivers, especially through the Clinton administration initiatives in the areas of welfare reform, health care reform, and commitment to the implementation of FMLA. (SW) *(AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved)*.


**Notes:** Dept Social Policy and Social Work U. Tampere, SF-33101 Finland JSSWA9 aja Abstract-of-Journal-Article English United-States. Reviews arguments for and against home care allowances (HCA’s) for the frail elderly, focusing on debates around traditionalist and feminist standpoints. The contextual boundaries of such debates are also considered via analysis of arguments from both the US and Europe. Finland is presented as a special case, because this Scandinavian welfare state has an exceptionally extensive HCA program. 44 References. Adapted from the source document. *(©1994, Sociological Abstracts, Inc., all rights reserved.)* 6127; 6100 SOPODA 94W18051 UMI.

**Keywords:** Home Care Using Paid Informal Caregivers/Financial Support/Support/Finland/Michigan/Home/Organizations/Benefits/Community/Community Care/Home Care/Elderly/Disabled/Chronically Ill/Public Services/Patients/Soc Wk Abst (Paid Home Care)/Informal Care/Support Programs/Financial Assistance/Caregivers

**Notes:** Carer’s allowances are paid to non-professional carers for looking after a person at home. Support systems for informal care date back to the 1940’s, but recent changes in the supply and demand of informal care have resulted in the creation of new administrative organizations in many countries. Carer’s allowances are a peculiar form of social benefit in that they are based both on carrying out a specific assignment and on other criteria. For example, in Britain the primary function of the allowance is to compensate for the carer’s loss of earnings, whereas in Michigan it is a means of rationalising the community care of poor people. In Finland the allowance for children’s home care, and to a lesser extent the allowance for the home care of the elderly, disabled, and the chronically ill, is intended as a compensation for not using communally organized services. In Finland the ideology of financially supporting informal care is grounded in the notion of the priority of public services, which is internationally quite exceptional and which contradicts the principle of subsidiarity. Direct payment to the patient is a common alternative to carer’s allowances. (Journal abstract, edited).


**Keywords:** Home Care Using Paid Informal Caregivers/Costs/Caregivers/England/Support/Disabled/Relative/Interview/Female/Aged/Elderly/Savings/Employment/Financial Support/AgeLine (Paid Home Care)/Older Adults/United Kingdom/Outside United States/Asset/Relatives/Depletion/Economic Resources/Income Loss/Household Composition

**Notes:** Examined the financial circumstances of a small group of caregivers in England who were providing help and support to a very infirm or severely disabled relative or friend, in order to obtain a comprehensive picture of the financial consequences of giving care. Interviews were conducted with 30 caregivers in 29 households in 1986, and the data were analysed to yield both qualitative and quantitative material. Seven of the caregivers were men, of whom five had never married. Of the 23 female caregivers, a similarly high proportion (10 in all) was not currently married. Two thirds of the women were aged 45-64, which is consistent with the national picture that the heaviest and most common caring responsibilities tend to affect working-age women toward the end of their working lives. The majority of the people receiving care were elderly; 22 were over 70, and 13 were aged 80 and older. Altogether, one or more adverse financial consequences of caregiving were apparent in 21 of the 29 households. Three caregivers reported having to draw on the disabled person’s savings and five on their own savings more than they would otherwise have done. One household was
buying more on credit, two delayed paying bills, two caregivers had cashed insurance policies, nine had cut back on other regular patterns of saving, three had had to borrow money, six had cut down or given up specific items of consumption because money was short, and eight caregivers said that they now worried about money more than they used to. Across the sample as a whole, caregivers combining full-time employment with substantial amounts of caregiving were likely to experience high levels of spending on substitute care. The caregivers in two-adult households reported, on average, twice as many adverse effects as those in three-adult households. Findings are discussed in terms of policies aimed at developing financial support for informal caregivers. References are included. (WD) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


Keywords: Home Care Using Paid Informal Caregivers/Family/Home/Home Care/Care Receivers/Caregivers/Manager/Case Management/Nursing/Nursing Home/Questionnaire/Caregiver/Institutionalization/AgeLine: Homecare/United States/Older Adults/Florida/Program Evaluation/Frail Elderly/Financial Assistance/Supportive Services

Notes: Evaluated Florida’s Home Care for the Elderly (HCE) programme from the perspective of care receivers, caregivers, and case managers. The HCE program provides case management services and a financial subsidy of $100 per month to families, friends, and others who provide full-time, in-home care to frail elders who are assessed to be at risk of nursing home or other institutional placement. A total of 151 HCE care receivers (mean age 82.6), 211 caregivers, and 71 case managers from five of the eleven districts in Florida completed a mail questionnaire. Responses indicated that the programme was primarily serving older, low-income elders who were assessed to be at medium to high risk with respect to psychosocial functioning. Their caregivers used caregiving subsidies primarily to pay for the basic necessities of life such as food and medication. A majority of caregivers stated that the subsidy made a difference when considering whether to continue giving care, but less than 10% stated that they might or definitely would stop giving care in the absence of a financial subsidy. The vast majority of care receivers and caregivers were very satisfied with case management services, and 42% of the care receivers named their case manager when asked whom they would contact if they had a problem with their caregiver. Case managers stressed the importance of formal care providers making home visits and referrals to other resources in order to lessen isolation and prevent institutionalization. (AR) (AgeLine Database, ©1997, American Association of Retired Persons, all rights reserved).

Keywords:
Economic/Costs/Caregivers/Relative/Employment/Caregiving/Economic Factors/Female/Canada/Feminism/Interviews/Aged/Family/Workplace/Roles/ Regression/Analysis/Analysis/Caregiver/Policy/Stress/Public Policy/Outside United States/Caregiving Burden/Females/Economic Resources/Workers/Under 65/Young Adults/Adults/Middle Aged/Young Old

Notes: Investigated the relative contributions of employment, caregiving, and economic factors in causing strain among employed female caregivers in Canada, using socialist feminism as a guiding framework. Interviews were conducted with 246 women aged 23-64 (mean age 45.11) who worked at least 15 hours per week (mean 41 hours) and also provided regular assistance (mean 15 hours per week) to a family member aged 60 or over (mean age 77). Participants were first contacted through 37 workplaces in Nova Scotia, Canada, which were stratified on the basis of economic sector, size, geographic location, and unionisation. A total of 20 variables were organized into five conceptual blocks in order to examine their relative strength in accounting for two measures of strain: Role strain due to lack of personal resources and global role strain. Hierarchical multiple regression analysis revealed that the block of variables describing the caregiving situation was the strongest predictor of both measures of strain. The variables representing caregiver characteristics and the economic consequences of caregiving also were significant for both measures, while employee and workplace characteristics were not. When economic factors were introduced into the analysis, the "traditional" caregiving situation variables became less important. Findings suggest that policies and programmes should go beyond the short-term goal of reducing or handling stress in family caregiving; workplace and public policies need to address the long-term consequences of caregiving in women's lives as well. (AY) (AgeLine Database, ©1997, American Association of Retired Persons, all rights reserved).


Keywords: Home Care Using Paid Informal Caregivers/Contracts/Volunteers/Community/Home Care/Work/Community Care NOT Home Care)/Community Services/Motivation/Helping Behaviour/ Great Britain/Volunteer Services/Program Description/Older Adults/Outside United States

Notes: Examines the present and future roles of volunteers in the British community care system. A study was made of the In Safe Hands programme, which exists to help elderly people to continue living in the community and to assist supporters in caring for them at home. Interviews with volunteers, users of the service, and their caregivers were conducted, and office records and other data were examined. The most important feature studied was the volunteers' motivations and rewards. It was found that for most volunteers, the highest reward was the sense of doing something worthwhile, and the satisfaction of seeing other people benefit. They reported being satisfied with the current remuneration scheme (strictly speaking, they are not volunteers but are paid a nominal sum). There was
strong aversion to increasing the remuneration, the feeling being that then their work would become more like a job and less satisfying. It is therefore concluded that a “contract culture” focusing more on formal agreements and financial compensation would erode rather than enhance the contribution by volunteers to community care services. (CB) (AgeLine Database, ©1991, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care Using Paid Informal Caregivers/Models/Personal Care/Medicaid/Benefits/Income/Older Adults/Adults/Disabled/Surveys/State/Perception/Roles/Satisfaction/Survey/Consumers/Informal Support Systems/Support/Costs/Independence/Ageline (Paid Home Care)/United States/Home Care/Service Delivery/Service Needs/Supportive Services/Public Policy

**Notes:** Assessed alternative approaches to administering programmes financed under the Medicaid Personal Care Services (PCS) optional benefit. This benefit makes attendant services available to low-income older adults and disabled persons in need of help with activities of daily living. Descriptive data on the administrative features of Medicaid PCS were drawn from surveys of attendant services programmes in all 50 states conducted in 1984 and 1988 and subsequent in-depth case studies in six states based on site visits carried out during 1990 and 1991. Client perceptions of their role in directing services, as well as their satisfaction with care, were drawn from a 1990 survey of older PCS clients in three states. Most Medicaid PCS clients reported high satisfaction with their aides, and less than 10% reported being not very satisfied or not at all satisfied with their aides. Multivariate analyses of data found strong associations between indicators of consumer choice and indicators of consumer satisfaction. Consumer choice and satisfaction were maximised when a public program encouraged clients to hire their own attendants directly and hire whomever they wished. Data suggest that when given the choice, consumers favour persons already known to them--family members, neighbours, friends-- resulting in an integration of their formal and informal support systems. States have found these consumer-directed models of personal care to curb costs and produce greater satisfaction, independence, and empowerment among clients. (AR) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).


**Keywords:** Home Care Using Paid Informal Caregivers/Caregivers/Disability/Home/Home Care/Perception/Aged/Pension/Questionnaire/Benefits/Housebound/Community/Ageline: Homecare/Disabilities/Financial Assistance/Veterans Administration/Veterans Benefits/Disabled/Noninstitutionalized Elderly

**Notes:** Assessed caregivers’ perceptions of the helpfulness of financial assistance in the form of a disability allowance as a support for in-home care. A total of 155 caregivers of veterans aged 65 and older, receiving a Veterans Administration (VA) pension and allowance, completed self-administered questionnaires. A number of variables were examined for an association with perceived helpfulness:
The amount of the benefit, spending pattern, caregivers’ emotional strain, financial strain, and programme knowledge. The veterans were receiving Aid and Attendance, a supplemental allowance that is added to a veteran’s pension if the veteran is determined to be in need of the “regular aid and attendance” of another person or is permanently housebound. The vast majority of caregivers reported that the VA financial benefits were helpful in maintaining the veterans in the community. Moreover, financial assistance was the type of support most desired by these caregivers. Over half of the caregivers indicated that the benefit amount was not enough. Those caregivers who reported lower emotional and financial strain were more likely to report that the benefit program was helpful, although it was not possible to ascertain a causal relationship. (WD) (AgeLine Database, ©1991, American Association of Retired Persons, all rights reserved).

Informal Caregivers to Persons Suffering with Dementia

**Keywords:** Home Care With Informal Caregivers Of Dementia Sufferers/Careers/Caregivers/Survey/Patients/Dementia/Roles/Stress/Care-giver/Institutional Care/ Institutionalization/Intervention Strategies/Public Policy/AgeLine (Paid Home Care)/United States/Older Adults/Alzheimer’s Disease/Caregiving Burden/Longitudinal Study/Instructional Materials/Gerontology  
**Notes:** Provides practical information on caregiving for teachers and students of caregiving, as well as caregivers, using research from a longitudinal survey of caregivers of patients with Alzheimer’s disease or a related dementia. Traces the experiences of husbands, wives, daughters, and sons in the caregiving role, identifies common stress factors, and discusses how stress affects the caregiver’s physical and emotional well-being. Examines the five major phases of caregiving: Acquisition of role as caregiver, in-home care, institutional care, bereavement, and social reintegration of the caregiver. Conceptualises caregiving as a multistage career with an impact on the caregiver that continues after institutionalization. Identifies caregivers who are most at risk for adverse adaptation to the caregiving role, describes preventive and clinical intervention strategies, and identifies post-care risks and issues. Considers public policy implications and provides an overview of caregiving careers. (SW) (AgeLine Database, ©1995 American Association of Retired Persons, all rights reserved).

**Keywords:** Home Care With Informal Caregivers Of Dementia Sufferers/Home Care/Caregiver/Roles/Disabilities/Adult/Child/Dementia/Disabled/Caregivers/Home/Interviews/Income/Employment/Institutional-ization/AgeLine: Homecare/Adults/Adult Children/Dependent Parents/Stress/Household Composition/Activity Patterns/Caregiving Burden

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Notes: The relationship between household size, composition, and temporal variability in household activity patterns and indicators of caregiver and elder well-being is examined with a focus on the role of different types of disabilities in this relationship. Two groups of adult child caregiver/elder pairs were studied: 20 pairs in which the elders were cognitively impaired but physically well (the dementia group) and 20 pairs in which the elder was physically disabled but cognitively unimpaired. Mean age of caregivers was 50 and mean age of elders was 81. Caregivers and elders were assessed in home interviews and caregivers completed a three-day log of caregiving activities. When the elder was cognitively impaired, greater household size, higher income, employment of the caregiver, and lesser variability in household activity patterns were all associated with a lesser degree of caregiver strain. When the elder was physically disabled, the same variables (except income) were associated with a greater degree of caregiving strain. In addition, caregivers of dementia victims perceived more strain and considered institutionalization more frequently. The two groups were similar in the amount of time spent in caregiving and in the types of caregiving provided. The utility of a social-ecological framework for research on home care is discussed. (LS) (AgeLine Database, ©1987, American Association of Retired Persons, all rights reserved).


Keywords: Dementia/Caregiver/Home/AgeLine: (Community Care NOT Home Care)/Great Britain/Caregivers/Community Services/Language/Terminology/ Older Adults/Outside United States

Notes: Examines the problem of defining the terms used in Great Britain to discuss community care of dementia sufferers. Although it must be acknowledged that some degree of generalisation about client groups is necessary and unavoidable in order to effectively provide a service, it must also be conceded that certain terms are, by their nature, complex and variable, and these complexities and variations must be taken into account. In particular, the terms “community”, “care”, “carer”, and “dementia sufferer” are not unambiguous concepts, and need to be carefully defined and used. For example, the term “community” can, depending on the circumstances, be used to represent various entities and relationships ranging from a closely knit locality of people supporting each other to simply the presence of a child or spouse as sole caregiver. Problems of stereotyping, labelling, and misperception are addressed, and examples are presented from a study of the home support of dementia sufferers. (CB) (AgeLine Database, ©1991, American Association of Retired Persons, all rights reserved).


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Family/Perception/Adolescent/Health/Minnesota/Interviews/Home/Home Care MED92-2.(JMCGOWAN)A:/B:/C:/D:

Notes: 95129687 Division of General Pediatrics and Adolescent Health, University of Minnesota, Minneapolis 55455. The purpose of this study was to
identify the major themes that 38 multigenerational families emphasised in their conversations about living with Alzheimer's disease. Interviews were conducted with families that were providing home care in the early stages of the disease. Family perceptions were analysed with the aid of a computer content analysis program. Families emphasised four themes: 1.) The awareness that something was "wrong"; 2.) the uncertain nature of the diagnosis; 3.) excluding a family member; and 4.) the ambiguous nature of family life with Alzheimer's disease.


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Family/Japan/Nursing/Caregivers/Elderly/Parents/Dementia/ Home/Long Term Care/Organizations/Interviews/Interview/Motivation/ Development/Mesityl.Mdl (MEDLINE 1993-7:PRIMARY RESEARCH)/ A:/B:/C:/D:

Notes: 97356064 Department of Family Nursing, Faculty of Medicine, University of Tokyo, Japan. noriko-ty:umin.u-tokyo.ac.jp. The purpose of this study was to develop concepts that facilitate our understanding of why family caregivers of demented elderly persons can continue caregiving despite various difficulties of care. Twenty-six Japanese daughter or daughter-in-law caregivers of elderly parents with dementia who lived at home or in long-term care facilities were recruited through various senior service organizations in Japan. The caregivers underwent unstructured interviews, and the interview data were analysed using the constant comparative method. Three categories emerged as reasons for care continuation: value of care, maintainers of value, and re-enforcers of care continuation. Value of care came from societal norms and attachment, and was the basis of caregivers' motivation to continue care. Several maintainers of value and re-enforcers of care continuation also emerged from the analysis. The contents and some longitudinal changes in these categories were explained. The findings highlight the need to assess these categories separately in order to develop appropriate interventions and they have implications for future research and policy development.


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/ Dementia/Patients/Family/Home/Japan/Work/Aged/Home Care/Support/Roles/ Human/TerminalCare/Nursing/Community/Welfare/MEINT6.MDL(MEDLINE 1966-92)/A:/B:/C:/D:

Notes: 91013185 Japan College of Social Work. Present problems concerning home care for the aged including the following three points: 1.) The extent of the period during which care is needed has been prolonged as the aged live longer than in previous times. 2.) The range of need for home care has increased. 3.) As a result of the increase of the individual-dependent "life support infrastructure" due to the decreased role of the family-dependent "life support infrastructure", the aged, who were more self-supporting in past, have become more dependent on
care both in quality and quantity. In particular, dementia patients gradually worsen, therefore care for them becomes increasingly difficult with time. This report attempts to clarify the actual conditions of care for dementia patients by long-term stay, short-term stay and day care. At present it is difficult to ensure sufficient human terminal care. To overcome this problem, some families caring for dementia patients have formed "self-help groups" and give mutual support while attempting to approach to professional aid groups. While the family is the core of the home care system, it is not necessarily home care per se. Medical and nursing systems should improve home care by creating a system by which professionals are able to approach to families caring for dementia patients through two ways of "waiting" and "visiting" community programmes, and by building closer connections with the welfare service.


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/ Home/Home Care/Model/Patients/Nursing/Taiwan/Hospitals/China/Family/ Self Care/Nurses/Social Workers/Workers/Roles/Support/Manager/Caregiver/ Caregivers/Home Care Agencies/Community/Health/Follow Up/MEINT2.MDL (MEDLINE 1993-7)/A:/B:/C:/D:

Notes: 96261122 Graduate Institute of Nursing, Chang Gung College of Medicine and Technology, National Taiwan University Hospital, Taipei, Republic of China. The purposes of this research project were to establish an integrated home care model and understand the influence of an integrated home care model on demented elders and their families. The changes in cognitive function and self-care ability of demented elders were also explored longitudinally. The disciplines involved in the integrated home care model included doctors, home care nurses and social workers. The integrated home care model was developed according to the functions and roles of different disciplines in their actual working process. Services provided included home nursing care, telephone consultation and a support group. Home care nurses played the role of case manager in this model. Twenty-five families participated in the study. Among them, 22 received home care service, and 20 of them participated in a caregiver support group. The cognitive function of the demented elders did not significantly decrease over the 6-month period. Among their self-care ability, grooming and eating dependency were found significantly increased during this period. Overall, 81% of families reported that home nursing care services could help them to develop care skills, care knowledge and provided emotional support. However, the caregiver burden did not significantly decrease after the home nursing care services. Seventy percent of caregivers reported that telephone consultation could support them emotionally and provided them with information concerning care. Over half of the caregivers reported that getting related information and receiving emotional support was helpful. The integrated model developed from this research project can be adapted and used in networking home care agencies, the community and health care resources. The small and convenient sample was one of the limitations of this
study. The insignificance of some of the findings might be due to the short time period (6 months) and some effects of the model might appear later than 6 months. For further research, larger and random samples and a longer period of follow-up with more health disciplines involved were suggested.


**Keywords:** Home Care With Informal Caregivers Of Dementia Sufferers/Family/Patients/Dementia/Home/Elderly/Relative/Relatives/Nursing/Support/Community/Community Care/Disability/Falls/Institutionalization/PatientCare/Female/Economic/Japan/MED66-1.(JMCGOWAN)/A:/B:/C:/D:/Disabilities

**Notes:** 91367900 Department of Neuropsychiatry Yamanashi Medical College. Although it has been stressed that patients with dementia should be cared for at home, family care seems to break down sooner or later. On the other hand, the number of demented patients is now increasing at a far greater rate than can be handled by institutions for the elderly. For these reasons, the appropriate use of social resources is now being emphasised. As early as 1960, Macmillan pointed out that the emotional relationship between an elderly patient and the relative responsible for him determines whether family care will breakdown, and stressed the importance of troublesome behaviour in this relationship. Since then, researchers have studied the problem of troublesome behaviour in demented patients and the burden that this creates for relatives nursing them. Such studies have stressed that the support of caring relatives is indispensable for the community care of demented patients. In the present study an attempt was made to analyse in detail the breakdown of family care for demented patients. To facilitate systematic study, we compiled a pair of check lists containing criteria of troublesome behaviour and care burden, adapted from the Disability and Handicap criteria of the WHO. For the purpose of the study, we regarded troublesome behaviour as Disability, and care burden as Handicap. The subjects were 40 demented patients and their respective main carers, who had requested institutional care. Before the breakdown, the author had been in charge of all of the patients. The mean period of patient observation was 12 months. At the point when the decision of institutionalization was made by family members, visits were made to each patient-carer pair, and the check lists were used to assess troublesome behaviour and care burden. In order to clarify the features of the subject group, the author also visited and examined another 30 patient-carer pairs, who still lived in their home communities, between June and September, 1990. The mean period of observation for these patients was 18 months. There were no significant differences in sex, diagnosis, duration of illness, cognitive function, or number of physical complications between the two groups. No significant difference was found in the total score for the behaviour check list between the two groups. In contrast, however, there was a significantly higher score for the burden check list representing those caring for the patients in the study group. Furthermore, it was revealed that social activity, individual free time and familial interaction, as well as many emotional and physical aspects, were more severely affected in the subject carers. This result appeared to confirm that the care burden itself, rather than
troublesome behaviour is responsible for breakdown. In all of the 70 pairs
analysed, a significant correlation was found between the total score for the
behaviour check list and that for the burden check list. The result of this study
highlighted several new emerging problems. One serious problem is that of
patients driving by themselves. In addition, many of carers reported recurrent falls
by the patients. As to the problems faced by carers themselves, an appreciable
number had been forced to give up their jobs to devote themselves to patient care.
In general, female carers with husbands younger than 65 years reported economic
distress. Additionally, unlike the situation in most western reports, as many as
43% of the main carers in this study were daughters-in-law. These problems faced
by carers seem to be common in Japan, and are perhaps characteristic of Japanese
society. (ABSTRACT TRUNCATED AT 400 WORDS).

of People With Dementia. Expressed Emotion, Strain and Coping. British Journal
of Psychiatry 157, 221-227.

Keywords:  Home Care With Informal Caregivers Of Dementia Sufferers/
Dementia/Emotions/Health/Hospitals/Parents/Community/Follow Up/
RESEARCH)/A:/B:/C:/D:

Notes:  91028521 Redbridge Health Authority, Goodmayes Hospital, Ilford,
Essex. Twenty-five women who were the primary carers for a parent with
dementia rated for expressed emotion (EE) and then divided into two groups: 11
with low-EE ratings and 14 with high-EE ratings. Although there were no
differences between these groups in the levels of their parents’ cognitive
impairment, when such impairment was taken into account, high-EE subjects were
found to report higher levels of strain and distress. More efficient coping
strategies were reported by subjects who made fewer critical comments and more
positive remarks. High-EE subjects more frequently had no living siblings, and
were more likely to have had a respite break from caring. EE status was not
associated with continuing care in the community at a nine-month follow-up.

Problems of Caregiving Spouses of Patients With Dementia. Patient Education
and Counseling 25[2], 143-149.

Keywords:  Home Care With Informal Caregivers Of Dementia Sufferers/
Patients/Dementia/Netherlands/Caregivers/Health/Roles/Social Networks/
MED92-1.(JMCGOWAN)/A:/B:/C:/D:

Notes:  95388625 Twenty-six caregiving spouses of patients with dementia in the
Netherlands were interviewed to better understand their problems and needs.
Special attention was paid to the information the caregivers received from their
general practitioner. Nineteen caregivers indicated that they received little or no
information about the disease and its possible consequences. Furthermore, they
experienced many problems, because of the disease and the daily care they
provided; eleven caregivers indicated a decrease in social contact, which resulted
in further problems. Caregivers who sought professional help at an early stage
experienced fewer problems in providing daily care. The results of this project
suggest that in future health education policy, special attention should be paid to
the role of the general practitioner and to the importance of a caregiver’s social
network.

Demented Elderly]. [Dutch]. Tijdschrift voor Gerontologie en Geriatrie 14[4],
149-156.

**Keywords:** Home Care With Informal Caregivers Of Dementia Sufferers/
Support/Relatives/Patients/Dementia/Elderly/Death/Depression/Family/Home
Care/Relative/MEIN10.MDL (MEDLINE 1966-92)/A:/B:/C:/D:

**Notes:** 84046086 Relatives of patients suffering from senile dementia have to
deal with multiple changes and difficulties. Emotional problems as well as the
continuing care for the elderly demented patient may be a cause of progressive
social isolation. The co-operation with professional helpers is often a source of
considerable conflicts. These conflicts may still aggravate once the patient has
been admitted into a specialised psycho-geriatric ward. Conceptually some
reactions of the relatives may be interpreted as manifestations of a mourning-
process, where not only real losses play an important part, but also anticipated loss,
e.g. the prospect of imminent death. The characteristics of anticipatory grief are:
Denial, depression, feelings of guilt and aggression. After an inventarisation of the
problems, the professional helper can provide the family with information
concerning the disease and with advice about the home-care. In group meetings
relatives may support each other. Psychotherapeutic intervention may be necessary
for the mourning relative.

Bereavement: Chronic Stress Isn't Over When It's Over. Psychology and Aging
9[3], 372-380.

**Keywords:** Home Care With Informal Caregivers Of Dementia Sufferers/
Caregiver/Depression/Stress/Ohio/State/Health/Relative/Dementia/Caregivers/
Longitudinal Study/Symptoms/Social Support/Support/MESED3.MDL
(MEDLINE 1993-7:PRIMARY RESEARCH)/A:/B:/C:/D:

**Notes:** 95092264 Department of Psychiatry, Ohio State University College of
Medicine. Although the adverse mental health consequences of caregiving for a
relative with a progressive dementia are well documented, little is known about
caregivers’ adaptation after bereavement. This longitudinal study examined
changes in three groups: Continuing caregivers, who had been caregiving across a
4- year period (n = 98), bereaved caregivers, whose impaired relative died between
years 1 and 4 (n = 49), and controls (n = 107). Although a mean of 19.8 months
had elapsed since bereavement by year 4, bereaved and continuing caregivers did
not differ on syndromal depression or depressive symptoms; both groups were
significantly more depressed than controls. Time since bereavement was unrelated
to depression or social support. Those caregivers who ruminated more about
caregiving after bereavement reported more depression, greater stress, and greater
social isolation.

**Keywords:** Home Care With Informal Caregivers Of Dementia Sufferers/Support/Caregivers/Nurses/Home/Home Care/Long Term Care/Roles/Family/Health/Social Networks/Demographic Characteristics/Socioeconomics/Social Support/Nursing/Assessment/MESED2.MDL (MEDLINE 1993-7:PRIMARY RESEARCH)/A:/B:/C:/D:/Health Status/Care/Long-Term Care/Caregiving/Research/Status/Relationships/Demographics/Risk

**Notes:** Nurses in home care and long-term care settings play an important role in assisting family caregivers of elders who are cognitively impaired to sustain personal support while caregiving. Research has shown that such support is associated with positive health status. The characteristics of the caregiver’s social network provide information about the potential for support. The purpose of this study was to describe and compare the social networks of men and women caregivers in terms of the composition of the social network and the size of the available, utilised and conflicted social networks. The possible relationship between the demographic characteristics of caregivers and the size and composition of their social networks was also examined. In comparison to men, the conflicted social networks of women were larger and comprised of more family members. For women, age, years of caregiving and socio-economic status were not significantly related to the size of their social network. However, younger men and men of higher socio-economic status reported significantly larger available social networks than other men. Knowledge of the gender differences in network size and composition that were identified in this study contributes to nurses’ ability to identify caregivers who may be at risk for inadequate social support. In conjunction with the findings from related studies these results have implications for nursing assessment and intervention in home care and long-term care settings.


**Keywords:** Home Care With Informal Caregivers Of Dementia Sufferers/Case Management/Management/Home/Home Care/Medicare/Nursing/Nursing Home/Patients/Caregiver/Adjustment/Institutionalization/Stress/Falls/Caregivers/Educational Programs/Review/AgeLine: Homecare/Ohio/Nursing Homes/United States/Older Adults/Alzheimer’s Disease/Dementia/Medicaid/Noninstitutionalized Elderly/Nursing Home Placement/Caregiving Burden/Program Evaluation/Outcomes

**Notes:** Reviewed the Cincinnati site of the national Medicare Alzheimer’s Project (MAP) to determine whether the project effectively delayed nursing home placement of patients with Alzheimer’s disease. The Cincinnati intensive case management approach included monthly contact with the primary caregiver, at least bimonthly home visits, and ongoing reassessment and adjustment of the care plan. Data were examined from the case records of 154 MAP participants who had relocated to a nursing home by May 1992 to determine factors that affected length
of time in the project and primary reasons for institutionalization. Results showed that only two characteristics were statistically significant in predicting nursing home placement: The patient's education level and the caregiver's number of children. The most prominent reasons for nursing home placement were behavioural problems, caregiver stress, physical problems, caregiver frailness, and patient falls. Caregivers who attended five or more educational programs continued to provide home care for an average of five months longer than those who did not attend educational programs. The results of this mid-project review indicate that frequent use of services and caregiver education delayed nursing home placements of individuals with Alzheimer's disease. (PH) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).

Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Home/Home Care/Dementia/Patients/Caregivers/Community/Physicians/Institutionalization/Death/Caregiver/RespiteCare/Costs/Medicaid/Nursing/Nursing Home/Family/Training/Manager/Ethnicity/Consumers/Benefits/AgeLine: Homecare/Nursing Homes/Service Utilization/Home Health Care/Alzheimer's Disease/Caregiving Burden
Notes: Reports low utilisation of a dementia-specific in-home respite service by caregivers of dementia patients, identifies factors that may have interfered with its timely and effective use, and offers suggestions for overcoming these barriers. Less than one-fourth of caregivers who participated in community studies conducted by Duke University used any formal services other than physician care, and most of the use was concentrated in the year preceding institutionalization or the death of the patient or caregiver. The study found that neither documentation of positive effects nor caregiver knowledge of service availability ensured caregivers would use in-home respite care. Cost and time were partially responsible for low utilisation rates. Caregivers feared future Medicaid spend-down rules for nursing home care rather than the actual cost of the services. In addition, 50% of the respite clients died or were institutionalized within 8 months. However, several features of the program design were partially successful in overcoming family barriers: Matching of respite providers with clients based on client preferences, specialised training, provision of a nurse/case manager, word of-mouth referrals, providers who reflected the ethnicity of the community, training for providers and consumers, service flexibility, and an emphasis on patient rather than caregiver benefits. (AW) (AgeLine Database, ©1990, American Association of Retired Persons, all rights reserved).

Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Home Care - Training/Development/Dementia/Family/Health/Benefits/Job Satisfaction/Satisfaction/Occupational Therapist/Personal Care/Functional Ability/Management/Training/AgeLine: Homecare/Alzheimer's Disease/Respite Care/District Of Columbia/Program Description/
Occupational Therapy/Home Health Care/Homemaker Services

Notes: Describes the development of an in-home activities programme for the demented home care client. AL-C*A*R*E is a programme in Washington, D.C., that provides comprehensive home care services to individuals with Alzheimer’s disease and other forms of dementia, and their families. The homemaker-home health aides’ primary responsibilities are to provide supervision and companionship to clients whose responsiveness may be quite limited but who often have few personal care needs. Consequently, the professional staff found it necessary for the aides to develop new skills in order to utilise their time to the benefit of clients and to their own job satisfaction. An occupational therapist was selected to introduce the concept of an in-home therapeutic activities program that included dancing, playing music, engaging the client in reminiscence, and exercising. However, staff resistance was strong, as they were oriented toward performing traditional personal care tasks. Therefore, monthly meetings were held with the aides, at which time staff elaborated on the three potential benefits of the programme: To help maintain functional abilities, to improve care management by offering a pleasant distraction, and to develop positive relationships. Once resistance was overcome, it was possible to proceed with the actual training portion of the programme. So far, responses from clients and families to the programme have been favourable. (WD) (AgeLine Database, ©1984, American Association of Retired Persons, all rights reserved).


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Family/Caregivers/Nursing/Interviews/Adjustment/MED92-1.(IMCGOWAN)/A:/B:/C:/D:

Notes: 96031179 MS Nursing Program, University of Northern Colorado, Greeley, CO 80639, USA. The purpose of this exploratory study was to examine and compare communication processes used by family members and formal caregivers to manage behavioural problems such as fearfulness, agitation, and wandering, that commonly occur when caring for persons with Alzheimer's Disease (AD). Two groups of caregivers of persons with AD (formal and family) comprised the sample for the study. Two themes emerged from the focus group interviews: Environmental adjustments and reassurance. Results suggest that interventions must be individualised. Enhancing the caregiver’s skills to manage disruptive behaviour may prolong his or her ability to provide in-home care for the family member with AD.


Keywords: Family/Caregivers/Caregiver/Whites/Aging/Workers/Support/Consumers/Long Term Care/Care/Caregiving/AgeLine (Paid Home Care)/United States/Older Adults/White House Conference on Aging/CaregivingBurden/Service Needs
Notes: Presents a report from four public forums sponsored by California's Caregiver Resource Centers (CRC's) on the needs of family caregivers. The free public forums were offered 28 February-3 March 1995 in preparation for and as officially recognized events of the 1995 White House Conference on Aging (WHCOA). California's CRC's serve families and caregivers of persons with adult-onset brain diseases and disorders such as Alzheimer's, Parkinson's, Huntington's diseases, stroke, and traumatic brain injury. The half-day public forums were held in San Diego, Fresno, Sacramento, and San Francisco. A total of 464 persons attended the four events, of whom 39% were family caregivers and 44% were older persons. In addition to family caregivers, participants included professionals in ageing and allied fields, public officials, legislative staff, government workers, media, and advocates. Background information is provided, followed by a discussion of the four major topics: Caregiver support services, consumer and family choices involved in long-term care, legal and financial concerns, and needs of an ethnically diverse caregiving population. Recommendations adopted by the forums are presented, and a list of discussion group facilitators is appended. (SW) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Home Care - Technology/Support/Home/Caregiver/France/Nursing/Ohio/Home Care/ Elderly/Nurses/Caregivers/MED66-1.(JMCGOWAN)/A:/B:/C:/D:

Notes: 91282421 Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, Ohio. Computers have become ubiquitous in contemporary society, as has the demand for home care for the elderly. Caregiving is recognized as a normal experience across the life span, and nurses must develop innovative responses to support caregivers. Computer networks offer caregivers access to a wide range of services such as communication, information, and decision support. Presented here is an interim report of a randomised field experiment demonstrating the feasibility of computer networks as a mechanism for delivering nursing services to caregivers of persons with Alzheimer's disease. Caregivers can and do use the computer network in home care.


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/ Model/Nursing/Nursing Home/Nursing Home Placement/Home/Health/Family/ Caregivers/Caregiver/Health Status/Support/Health Care Delivery/Workers/ Community/Funding/Community Care/HEALTH95.(JMCGOWAN)/ A:/B:/C:/D:/Nursing Homes

Notes: 97604519 Center for Health Systems Research and Analysis, University of Wisconsin, Madison 53705, USA. RESEARCH OBJECTIVE: The decision to place a family member in a nursing home is a hard decision often made in a crisis.
The effectiveness of decision AIDS are limited by the ability of the professional to identify which families are contemplating placement. The aim of this research was to develop a model to predict the probability a person with Alzheimer's disease (AD) would be placed in a nursing home within three months. STUDY POPULATION: Families providing community-based care for someone with AD. The informants were selected to represent a broad range of caregivers. STUDY DESIGN: The model was developed using the experiences of 24 caregivers, who identified thirty factors which influence placement decisions. An expert panel, composed of six experienced family caregivers, was convened to create the Baysian Model. PRINCIPAL FINDINGS: The most predictive factors were caregiver health, amount of sleep and privacy received by the caregiver, and his/her health status, subjective burden, and the amount of disruptions to daily activities. CONCLUSIONS: The predictions of the model were found to be marginally correlated to those of experienced professionals; however by considering the influential factors identified, the professional is able to consider the perspective of the caregiver regarding their future need for placement decision support. RELEVANCE TO POLICY AND HEALTH CARE DELIVERY: This model allows a case worker to either intervene with a factor and allow the person to remain in the community or assist the family in identifying appropriate placement alternatives. The model can also help prioritise funding supporting community care. (Abstract by: Author).

Jerrom, B., Mian, I., Rukanyake, N. G., and Prothero, D. (1993). Stress on Relative Caregivers of Dementia Sufferers, and Predictors of The Breakdown of Community Care. International Journal of Geriatric Psychiatry 8[April], 331-337. Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/ Stress/Relative/Caregivers/Dementia/Community/Community Care/Assessment/ Hospitals/England/Follow Up/Aged/Caregiver/Patients/Health/Questionnaire/ Relatives/AgeLine: (Community Care NOT Home Care)/Health Status/Caregiving Burden/Longitudinal Study/Institutionalization/Risk Factors/ Older Adults/Outside United States

Notes: Studied stress levels among caregivers of people with dementia referred to an assessment day hospital in England and investigated predictors of the breakdown of community care during a one-year follow-up period. The sample consisted of 63 consecutive referrals to the day hospital who had a clinical diagnosis of dementia, who were aged 65 and over, and whose primary caregiver was a relative living with the patient or in daily contact. Measures were administered within one week of admission and were repeated 12 weeks or later or at discharge if this was earlier. Caregivers were interviewed and assessed using the General Health Questionnaire (GHQ), the Relatives Stress Scale, the Social Interaction Scale, and the Health Self-Rating scale. Patients were followed up at 3, 6, and 12 months after discharge to investigate the type of care they were receiving at the point of follow-up. At admission, 48% of caregivers scored above the threshold for “caseness” on the GHQ. The primary variables influencing stress levels were the caregiver’s own health self-rating and a measure of behaviour and mood disturbance in the patient. At 12 months, caregiver’s “caseness” on the GHQ was a highly significant predictor of the breakdown of community care. Findings
provide further evidence of raised levels of distress among the principal relative caregivers of people suffering from dementia. They also suggest that part of the initial assessment of the multidisciplinary team should include an evaluation of the relative's own health and psychological status. (WD) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Health/Development/Model/Geriatrics/Depression/Home/Home Care/Caregivers/MED66-1.(JMCgowAN)/A:/B:/C:/D:

Notes: 90369133 Philadelphia Geriatric Center. This study modelled the causal relationship between physical health and depression among a sample of 315 people providing home care for a spouse who had been diagnosed as having Alzheimer’s disease. In addition to significant stability paths and co-relations among variables at any one point in time, significant lagged paths were found in which depression (1) predicted physical health (2), depression (2) predicted physical health (3), and depression (1) predicted burden (2). Contrasting the overall model for husband and wife caregivers over a six-month period indicated that the model was significant for wives but not for husbands.


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Stress/Elderly/Caregivers/Nursing/Survey/Home/Home Care/Parents/Perception/MED92-2.(JMCgowAN)/A:/B:/C:/D:

Notes: 93388003 Duke University Medical Center, School of Nursing, NC 27710. A daily experience survey instrument was used to distinguish patterns of stress in a group of elderly individuals providing home care to a spouse or parent with Alzheimer’s disease and a comparison group of elderly noncaregivers. It was found that life circumstances influenced stress perception in daily life. Caregivers and noncaregivers differed in the types of experiences they endorsed as routines, uplifts, challenges, and hassles, and in the impact ratings associated with them in consistent and interpretable ways.

Providing Care to the Terminally Ill


Keywords: Home Care Terminal/Home Care European/Patients/Italy/Symptoms/Quality of Life/Physicians/Nurses/Social Workers/Workers/Volunteers/Family/PSYCG84.(JMCgowAN)/A:/B:/C:/D:
**Notes:** 81-03140 Ospedale Buccheri La Ferla FBF, Palermo, Italy. Describes a home therapy service for the pain and symptoms of patients with advanced cancer, established in Palermo, Italy, in 1988. The goal of the service is to help these patients maintain an acceptable quality of life and to enable them to remain at home. The service staff includes physicians, nurses, a social worker, and volunteers, and the service cares for about 350 people yearly. The strong structure of the family in Mediterranean society reinforces the likelihood of successful home care for these patients. (PsycINFO Database ©1994, American Psychological Assn, all rights reserved).


**Keywords:** Home Care Terminal/Health/Caregivers/Patients/Home/Hospitals/Family/Caregiver/MEINT3.MDL (MEDLINE 1993-7)\}A:/B:/C:/D:/Home Care

**Notes:** 94251736 Health caregivers working with palliative patients in the home are able to establish closer relationships with these patients than in the palliative hospital setting. Since a familiar and comfortable setting helps set the stage for effective communication, it is not surprising that home care patients and their families often share intimate thoughts and feelings with visiting caregivers. Yet that same closeness can make it more difficult for a home caregiver to accept a patient's denial of impending death. While agreeing that, in theory, denial is a normal defense mechanism, the home caregiver may have become too emotionally involved to appreciate denial as a particular patient's choice.


**Keywords:** Home Care Terminal/Home/Mortality/Survey/Aged/Health/Model/Risk Factors/Home Care/Adult/Activities of Daily Living/Family/Caregivers.AgeLine: Homecare/Models/United States/Older Adults/Home Health Care/Long Term Care/Noninstitutionalized Elderly/Service Utilization/Frail Elderly/Functional Ability/Under 65/65+

**Notes:** Examined the relationship between functional status and the provision of formal home care to persons with chronic illness during their last year of life. Data were obtained from the 1986 National Mortality Followback Survey, a nationally representative sample of 18,733 persons aged 25 and older who died in 1985 and 1986. A survey mailed to informants 6 months after the death occurred obtained information on decedents’ health, functional status, and use of health services. A total of 14,728 decedents (mean age 70.4) who had not been institutionalized for at least 11 months during the previous year and for whom a completed survey was available were included in the study. A multivariate, epidemiologic logistic regression model was developed to identify risk factors for formal home care use for the following age groups: Under age 65, 65-74, 75-84, and 85 and older. Results indicated that 60% of adult decedents in 1986 had experienced some functional impairment in activities of daily living (ADL) during their last year of life, and 50% had received some form of home assistance (formal or informal). The primary risk factor for receiving formal home care was level of functional
impairment; persons with moderate and severe levels of dysfunction were most likely to receive formal home care. Having two or more family caregivers with greater involvement lowered the use of formal home services, except among persons with severe impairments. Other attributes positively related to use of formal home care included being older, having more health problems, and living in a metropolitan area. (PH) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).

Issues with Specific Diseases:

The fourth grouping in this annotated bibliography documents a varied collection of sources that relate to single illnesses, rather than dealing with the more generic home care issues characteristic of the rest of this bibliography. For example, they generally integrate formal and informal care within the same source because the disease, not caregiving or service organization, is the focal point of this material. There are three sections in this group. The first section is, in some ways, a miscellaneous category within which home care that is provided to victims of several different diseases are discussed. Within the general criteria for this annotated bibliography, much of the known literature that is relevant to home care for persons with these diseases is included, even if that is only one article. The second section again deals with dementia, but in this section, unlike the section in the previous grouping the disease is the focal point, not the caregiving or caregivers. This is, in part, reflected in the titles of these sources, which tend to refer to Alzheimer' disease rather than dementia. The final section in this grouping deals with home care for persons with HIV/AIDS. This is a large and diverse section because very few of these sources were able to be categorized, elsewhere, precisely because the disease, not the organization or delivery of formal and informal home care services, is the focal point even in those sources related to policy concerns.

Home Care with Specific Diseases Other than Dementia and HIV/AIDS


Keywords: Home Care By Illness/Patients/Home/Home Care/Relatives/ Community/Community Services/MEIN11.MDL (MEDLINE 1966-92)/ A:/B:/C:/D:/Care/Management/Relationships

Notes: 78248549 The first year of running a new continuing Care Unit for patients with malignant disease demonstrated the importance of continuity of care in their management after curative measures have ceased to be appropriate. This was achieved by regular home visiting by Unit staff, liaison with home care services and the promise of readmission whenever necessary. As a consequence good relationships with patients, relatives and community services were built up,
the average duration of in-patient stay was reduced to 19.6 days and more effective
episode care was possible, this being integrated with an understanding of the
overall problem.

Tolerance and Diabetes Mellitus in a Suburban Sri Lankan Community.
Postgraduate Medical Journal 70, 347-349.
Keywords: Home Care By Illness/Community/Patients/Aged/Survey/Health
Abstract: The prevalence of impaired glucose tolerance and diabetes mellitus
was studied in a suburban Sri Lankan community using 1985 WHO criteria. Oral
75g glucose tolerance tests were performed on 633 subjects aged 30-64 years. The
age-standardised prevalence rate for diabetes mellitus were 5.02 (95% CI 3.59-
6.43) and impaired glucose tolerance 5.27 (95% CI 3.74-6.78). A total of 21% of
diabetic patients were not known to have diabetes and were diagnosed for the first
time during the survey. Obesity was more common (P<0.05) in diabetic patients
(21%) when compared to non-diabetic subjects (10.5%). Diabetes mellitus is a
common health problem in Sri Lanka, and there is a need for developing national
policies for its prevention and control.

Swai, A. B., Kitange, H. M., Masuki, G., Kilima, P. M., Alberti, K. G., and
Tanzania? British Medical Journal 305[6861], 1057-1062.
Keywords: Home Care By Illness/Rural/Aged/Survey/Outcomes/Roles
Abstract: OBJECTIVE: To investigate the relation between under-nutrition and
diabetes. DESIGN: Survey of glucose tolerance in rural Tanzania. SETTING:
Eight villages in three widely separated regions of Tanzania. SUBJECTS: 8581
people aged 15 and above: 3705 men and 4876 women. MAIN OUTCOME
MEASURES: Oral glucose tolerance, body mass index, height, and low
haemoglobin and cholesterol concentrations. RESULTS: In the eight villages
42.7-56.9% of all men and 30.0-45.2% of all women had a body mass index below 20
kg/m2: The lowest quintile was 18.2 kg/m2 in men and 18.6 kg/m2 in women. The
prevalence of diabetes did not change significantly from the lowest to the highest
fifths of body mass index in men (lowest 1.6% (95% confidence interval 0.8% to
2.9%) v highest 1.3% (0.7% to 2.5%)) or women (1.1% (0.6% to 2.1%) v 0.5%
(0.2% to 1.2%)). In men and in women prevalence of impaired glucose tolerance
was greater in the lowest fifths of height (8.2% (6.3% to 10.6%), and 11.1% (9.2% to
13.3%)) respectively and body mass index (9.6% (7.5% to 12.1%, and 8.4%
(6.7% to 10.5%)) than in the highest fifths (impaired glucose tolerance 4.7% (3.4% to
6.5%); and 5.1% (3.9% to 6.7%); body mass index 5.1% (3.7% to 7.0%), and
7.7% (6.2% to 9.6%). CONCLUSION: Rates of diabetes were not significantly
associated with low body mass index or height, but overall rates were much lower
than those in well nourished Western populations. Increased impaired glucose
tolerance in the most malnourished people may reflect the larger glucose load per
kilogram weight. The role of under-nutrition in the aetiology of diabetes must be
questioned.
Notes: Clinical Research Edition

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**Keywords:** Home Care By Illness/Patients/Health/Treatment/Caregivers/Social Workers/Workers/Adjustment/Rehabilitation/Work/MED66-I.(JMCGOWAN)/A:B:C:D:/Care/Policy/Analysis/SocialSupport/Support/Screening/Socio-economics/Status

**Notes:** 90273026 Department of Medicine, SUNY Health Science Center, Brooklyn 11203. Diabetic nephropathy is now the leading cause of renal failure in patients referred for uremia therapy. The diabetic patient is a complicated treatment problem from the first detection of microalbuminuria, at which time decisions regarding choice of antihypertensive and strictness of metabolic control assume increasing importance. At present, our policy is to advocate strict control of blood pressure, aiming for a systolic blood pressure of less than 140 mm Hg and a diastolic blood pressure of less than 80 mm Hg. We attempt to maintain haemoglobin Alc levels at less than 8%, if the patient does not develop frequent episodes of hypoglycemia. We extend these recommendations to the patient with frank proteinuria, nephrotic syndrome and early uremia, understanding that strict metabolic control may be impossible as patients lose GFR. In addition, we recommend avoidance of a high protein diet in the early nephropathic diabetic, with diet of approximately 1 gm/kg/d. As renal failure progresses, we embark on an analysis of the patient's abilities, lifestyle, and social support. At a GFR of approximately 10 mL/min, we initiate preparations for uremia therapy. If a willing and appropriate living related kidney donor is available, the patient is referred for cardiovascular evaluation and kidney transplantation performed subsequently. If no donor is immediately available, we refer the patient for vascular access placement and/or insertion of a Tenckhoff peritoneal catheter, if preferred. Most of these predialysis patients also undergo screening for placement on the cadaveric kidney transplant list, including cardiac work-up as is done for the patients who receive living-related renal transplants. Because of the long waiting list in Brooklyn, and the universal shortage of organ donors, many of these patients eventually end up on dialysis for some period of time. Other extrarenal problems (urologic, ophthalmologic) are addressed at initial referral and followed up, in hopes of maintaining the patient in optimal physical shape as uremia progresses.

The care of the diabetic patient with ESRD ideally involves a consortium of caregivers. We include a nurse-educator familiar with options for uremia therapy, a podiatrist, a cardiologist, and often a urologist, an endocrinologist, and a gastroenterologist. In addition, a social worker is helpful to assess psychologic difficulties in adjustment to uremia, socio-economic considerations, and rehabilitation status. Finally, the nephrologist, as co-ordinator of this team works with the vascular or transplant surgeon, to facilitate the transition to ESRD and its therapy. [References: 65] 9009 [Review].


**Keywords:** Home Care By Illness/Patients/Treatment/Asians/Community/Health/Roles

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Abstract: Diabetes and hypertension are much more prevalent among Britain’s 2.5 million Asian and African-Caribbean population than among the white population and are major contributors to end stage renal failure. Asians and African-Caribbeans have threefold to fourfold higher acceptance rates on to renal replacement therapy than white people, and in some districts they comprise up to half of all patients receiving such treatment. Their greater need for renal replacement treatment is accompanied by difficulties of tissue matching in cross racial transplants and a shortage of donor organs. The ageing of ethnic minority populations will increase local need for renal services significantly. Measures to control diabetes, hypertension, and secondary complications in Asian and African-Caribbean communities will contribute both to safeguarding health and to economies in spending on renal services. Education about diabetes and hypertension, modification of behavioural risk factors, early diagnosis, effective glycaemic and blood pressure control, and early referral for signs of renal impairment are essential preventive measures. Primary and community health care professionals have a critical role to play here.


Keywords: Home Care By Illness/Treatment/Health/Embase/Ethnic or Racial/Traditional Medicine/Non Insulin Dependent Diabetes Mellitus/Foot Ulcer/Negro/Home Care/Human/Male/Female/Clinical Article/Aged/Adult/Article/Priority Journal

Notes: CS- K.K. Parry, Program in Physical Therapy, 11300 Northeast, 2nd Avenue, Miami CS- USA.


Keywords: Home Care By Illness/Aged/Patients/Welfare/Relative/Quality of Life/Model/Family/Economic/Development/MED92-1.(JMCGOWAN)/A:/B:/C:/D:

Notes: 97392144 Department of Social Welfare, Hallym University, Chunchon Kangwon-do, Korea. Among the most prevalent disabling diseases of old age, stroke is the leading chronic condition in Korea. The physical and psychosocial complications of a stroke can result in serious limitations on all aspects of one’s life that affect overall quality of life. This study examines the relative importance of and interactions among factors which affect the quality of life of 119 stroke patients 65 and older in Korea. The model uses family support, personality (specifically hardness), economic status, and physical functioning as independent variables, and quality of life as a dependent variable. The results of this study suggest that physical functioning and physical care by the family are important factors influencing quality of life of the aged stroke patients. Hardy personality is negatively associated with financial support and physical care by the family. These findings have several implications for policy development, clinical practice, and future research in this area 9712. Entry Week: 97124.

**Keywords:** Home Care by Illness/Family/Patients/Home/Home Care/ Health/Caregivers/Nursing/Nursing Homes/Follow Up/Caregiver/Stress/ Risk Factors/MESED7.MDL (MEDLINE 1966-92:(MEDLINE 1966-92: PRIMARY RESEARCH)/A:/B:/C:/D:

**Notes:** 86279369 Elderly stroke patients and their families were studied to determine the health effects of providing home care on family caregivers, whether or not caregivers actually providing care in the home experience different effects than caregivers whose family members live in nursing homes, and factors associated with any observed deleterious effects of caregiving. One hundred forty-seven stroke patients were eligible for study. Of these, 101 were available for follow-up; 89 family caregivers were interviewed (88%). Caregivers reported both positive and negative effects of providing home care. When actual home caregivers were compared with potential caregivers (those with family members in institutions), no differences in effects were seen. The relationship between each of three health effects (general, social, and emotional) and patient and caregiver attributes was explored. No factors were found to be related to poorer perceived general health. Dependent patient functional status and additional life stress were both associated with diminished social activity and emotional ill-health. In the latter instance, insufficient social activity and help from family were additional risk factors. If policy is going to advocate home care, its consequences for family caregivers must be known.


**Keywords:** Home Care by Illness/Quality of Life/Caregivers/ Health/Community/ Canada/Disabled/Questionnaire/Satisfaction/ Home/Demographic Characteristics/ Disability/Symptoms/ Home Care/Institutionalization/MED92-1.(JMCgowan)/ A:/B:/C:/D:

**Notes:** 97161240 Department of Community Health and Epidemiology, Queen’s University, Kingston, Ontario, Canada. For those with a chronic illness, suffering may result not only from physical limitations, but also from the psychosocial consequences of having a chronic condition. Few studies have described the psychosocial characteristics of the physically disabled. Even more rare are population-based studies of quality of life (QOL) among persons with multiple sclerosis (MS) and their caregivers. We conducted a large survey of persons with MS and their caregivers in Ontario using self-completed mailed questionnaires. The objectives included describing satisfaction with QOL and determining relationships between QOL as a whole and several other factors, such as demographic characteristics and measures of physical disability. Response rates were 83% for those with MS and 72% for their caregivers. Based on 697 respondents with MS, mean age was 48 years, 70% were women, and 75% were married. While 24% experienced no mobility restrictions, the majority required some type of aid or a wheelchair for getting around. Health received the lowest satisfaction rating among the six components of QOL, while finances received a
relatively low satisfaction rating from the 345 caregivers. Less satisfaction with several QOL components was evident for those with MS compared with the disabled in the Canadian general population, and for caregivers compared with the able-bodied general population. Poorer QOL as a whole among those with MS was associated with unemployment, MS symptoms of moderate or worse, fatigue, mobility limitations on stairs, a disease course other than stable, and was most strongly related to interference by MS in social activities. Among caregivers, poorer QOL as a whole was associated with being a spouse, longer duration of caregiving, moderate or worse MS symptoms in the care recipient, and most strongly related to a care recipient's current MS disease course of other than stable. Through an understanding of the satisfaction with QOL of persons with MS and caregivers, and the relationships with other important factors, autonomy and home care may be supported and prolonged, while preventing unnecessary institutionalization 9705. Entry Week: 97051.


**Keywords:** Home Care by Illness/Family/Caregivers/Nurses/Patients/Home/ Disabilities/Community/Caregiver/Community Care/Health/Satisfaction/ Roles/Public Policy/Nursing/Work/COSTM2.MDL/A:/B:/C:/D:

**Notes:** Neuroscience nurses are most likely to encounter multiple sclerosis (MS) patients in outpatient clinic situations or during their usually brief admissions to acute care facilities. In the early stages of their disease, most people with MS are able to live normal lives in their own homes. Then disabilities (weakness, loss of control of limbs and of bowel and bladder function, sensory and visual impairment) become permanent, the possibility of remaining in the community is usually made feasible only by the presence of a family caregiver in the home. Although community care of persons with MS is socially and economically desirable, many literature sources discuss the "burden" of family caregiving. This study examined the impact of caregiving on 61 MS family caregivers in British Columbia. The report of the study will include information regarding the caregiver's physical and mental health, health behaviours, participation in and satisfaction with preferred activities, and financial resources. In spite of marked health deficits in all domains, most caregivers reported their desire to remain in the role. Study findings will be used to describe how health professionals such as neuroscience nurses can support caregivers even with limited contact. Areas in which specific improvements in community resources and public policy are needed will also be discussed. OBJECTIVES: 1.) Describe deficits in well-being reported by this group of caregivers. 2.) Describe nursing interventions that will support the family member in the caregiving role. 3.) Identify potential changes in public policy and adjunctive services that could facilitate the caregiver's work.


**Keywords:** Home Care by Illness/Treatment/Rehabilitation/Home Care/Welfare/ Croatia/Attitudes/Follow Up/Home
Abstract: In order to fully review the problems and needs of handicapped persons, the Republic Institute of Social Welfare compiled a report about the social activities and general conditions of rehabilitation and welfare of handicapped children and youth which was presented to the Government of Croatia. A programme for the prevention, early detection and rehabilitation of handicapped children and youth was suggested. The programme anticipates solving all problems in accordance with the norms of all professions included in the rehabilitative process and attitudes of our “self-managing” society for all groups of handicapped, including those with progressive muscular dystrophy (PMD). As one of the possible solutions, the authors suggest the foundation of a centre for treatment of persons with PMD. The centre should organize its activity through outpatient treatment, half-and whole-day treatment in the centre, and so-called “total” inpatient treatment. Primarily it should have the following organizational units: Prevention and detection unit, unit for elementary education, unit for social rehabilitation and recreation, and a unit for follow up, patronage and home care activities. In the meantime, until the creation of some regional centres, the treatment of persons with PMD can be organized within existing institutions for elderly people.

Miles-Tapping, C. (1994). Home Care for Chronic Obstructive Pulmonary Disease: Impact of the Iqaluit Program. Arctic Medical Research 53[4], 163-175. Keywords: Home Care by Illness/Home/Home Care/Community/Health/Manitoba/Canada/Interview/Hospitals/Economic/Quality of Life/Long Term Care/Family/Language/MED92-2.(JMCGOWAN)/A:/B:/C:/D:

Notes: 95160871 Department of Community Health Sciences, University of Manitoba, Winnipeg, Canada. The Iqaluit home care programme, which began in February 1987, has a five-year history. Data about hospitalisation of five elderly persons with chronic obstructive pulmonary disease (COPD) are available for the five years before and the five years after the programme. Data for some of these years are available for four other COPD clients who joined the programme in 1987 and for seven others who joined the programme after its inception. The health histories of these 16 people presented an excellent opportunity to demonstrate the effects of Home Care programmes in the Northwest Territories. Home care in Iqaluit was evaluated by interviews with clients and care givers, by analysing the trend in admission to hospital and hospitalisation days for each client. The study showed that home care 1.) improved health and reduced the economic impact of COPD by reducing the average number of days in hospital for each episode of hospitalisation; 2.) allowed clients with COPD to experience a better quality of life than they would if in hospital or institutional long-term care; 3.) allowed people to live in their homes, with their families, taking part in their usual age and role-appropriate cultural activities, language and daily life.

Abstract: The broad relationship between the extent and pattern of sickness in a south Indian rural community, attendance at the Area Health Centre and service rendered to the sick at the Centre were studied. The point prevalence of sickness in the area was 9.5%; cough, pain and fever, in that order were the three cardinal symptoms that accounted for 68% of the total sickness in the community. Only 1.3% of the sick, at any point of time, had attended the Area Health Centre but the attendance by the sick persons residing in the village where the health centre is located was 9.2%. The composition of the out-patients attendance was significantly different from that of the sick in the community in respect of age, sex and symptoms. Thus, women and the elderly persons who also constitute a major reservoir of tuberculosis, tended to disregard their symptoms while younger persons, in the productive age group had availed the health centre facilities more freely. Among symptoms, cough was the most ignored. Of the out-patients, 71% had attended only once, 18% twice and 11% three times or more for any particular episode of sickness. Only 9.7% were offered laboratory examination and an insignificant number were referred to better equipped health institutions.


Keywords: Home Care -Training/Patients/Treatment/Home/Reimbursement/Physicians/Training/Home Care/MEIN12.MDL(MEDLINE 1966-92)/A.:B.:C.:D:

Notes: Data are presented on the characteristics of all patients with end-stage uremia who were treated in Connecticut haemodialysis programmes over a 7-year period. Of the total of 353 patients, 103 patients died, 37 had successful transplants and discontinued dialysis, no information was available for one patient, and the remaining 212 patients continued to receive treatment in 1 of the 12 haemodialysis programmes. The mean age of active chronic haemodialysis patients was 43.6 years; about 83% of all active patients were under age 55. Twenty-two percent were non-white; the non-white caseload appeared high in relation to the percentage of non-white population. Of the 212 active patients, 78% were dialysed at in-centre programmes and 22% at home; one patient obtained dialysis from a new limited-care programme. The largest group (28%) of active patients had been in dialysis less than 7 months, about one-fourth had been dialysing for 7-12 months, and about 13% of the total active population had been in dialysis between 19 and 24 months. The average period for active patients to be in dialysis was 17 months. The advent of Federal reimbursement for haemodialysis, as well as changes in the criteria for the selection of patients and increased physician awareness, can result in significant increases in the future population of patients receiving dialysis. To prevent overburdening of existing in-centre programmes, expansion of training facilities state-wide for home care dialysis is suggested.


Keywords: Home Care by Illness/Patients/Male/Treatment/Rehabilitation/
Abstract: There were an estimated 1.66 million hip fractures world-wide in 1990. According to the epidemiologic projections, this world-wide annual number will rise to 6.26 million by the year 2050. This rise will be in great part due to the huge increase in the elderly population of the world. However, the age-specific incidence rates of hip fractures have also increased during the recent decades and in many countries this rise has not levelled off. In the districts where this increase has either slowed or levelled off, the change seems to especially concern women's cervical fractures. In men, the increase has continued unabated almost everywhere. Reasons for the age-specific increase are not known: increase in the age-adjusted incidence of falls of the elderly individuals with accompanying deterioration in the age-adjusted bone quality (strength, mineral density) may partially explain the phenomenon. The growth of the elderly population will be more marked in Asia, Latin America, the Middle East, and Africa than in Europe and North America, and it is in the former regions that the greatest increments in hip fracture are projected so that these regions will account for over 70% of the 6.26 million hip fractures in the year 2050. The incidence rates of hip fractures vary considerably from population to population and race to race but increase exponentialy with age in every group. Highest incidences have been described in the whites of Northern Europe (Scandinavia) and North America. In Finland, for example, the 1991 incidence of hip fractures was 1.1% for women and 0.7% for men over 70 years of age. Among elderly nursing home residents, the figures can be as high as 6.2% and 4.9%. The lifetime risk of a hip fracture is 16%-18% in white women and 5%-6% in white men. At the age of 80 years, every fifth woman and at the age of 90 years almost every second woman has suffered a hip fracture. Since populations are ageing world-wide, the mean age of the hip fracture patients are increasing rapidly, too. Between 1970 and 1991, the mean age of male Finnish patients increased dramatically from 52.9 years to 69.0 years. In women, the corresponding figures were 71.6 and 78.9 years. This change is likely to cause increasing problems in the treatment and rehabilitation of the patients. In 1990, 72% of the hip fractures world-wide occurred in women. All over the world, the hip fracture incidences are about two times higher in women than in men. Women's overrepresentation has been explained by women's lower bone mass and density and higher frequency of falling. Epidemiologic studies show that trochanteric fractures are an increasing problem since compared with cervical fractures their relative number increases progressively with age in women after the age of 60 years and since their incidence has been shown to increase in both sexes and all age groups during the recent decades. This may have direct public health implication since mortality, morbidity, and costs caused by trochanteric fractures are higher than those of the cervical fractures. Reduced bone density (strength) by age and over the recent decades has been the most frequently mentioned reason for the increase of trochanteric fractures. Also, the fall characteristics of the elderly may have changed during the recent decades resulting in increasing numbers of this type of hip fractures since the type of the hip fracture (cervical or trochanteric) also depends on the impact angle of the greater trochanter at the moment of the floor contact.

**Keywords:** Home Care by Illness Patients/Home/Home Care/Nursing/Disability/Family/Caregivers/Treatment/Assessment/MESED6.MDL (MEDLINE 1966-92: (MEDLINE 1966-92: PRIMARY RESEARCH)/A:/B:/C:/D:

**Notes:** 89027999 School of Nursing, McMaster University, Hamilton, Ontario, Canada. We conducted a 1-day survey to determine the prevalence of urinary incontinence among patients in four home care programmes in southern Ontario and the characteristics of incontinent patients. Of the 2801 patients for whom the continence status was known, 22% were assessed as incontinent. The mean age of the incontinent patients was 74 (extremes 18 and 101) years, and 65% were women. A total of 89% had at least one functional disability in cognition, mobility, transferring in and out of bed or chair, or undoing garments. The incontinence was moderate to severe in 41% of the patients, and 95% of the family caregivers living with these patients viewed the incontinence as a problem. Palliative rather than remedial treatment was used most frequently; only 5% of the patients had undergone a urodynamic assessment in the previous year. Future research should emphasise the assessment of remedial interventions.


**Keywords:** Home Care by Illness/Depression/Home/Home Care/Patients/Roles Home Care Workers/Workers/Assessment/Treatment/AgeLine: Homecare/Older Adults/United States/Noninstitutionalized Elderly/Symptoms/RiskFactors/Suicides

**Notes:** Discusses the role of home care workers in observing symptoms and risk factors for depression and suicidal behaviour among home care patients. Home care workers are in an excellent position to recognize the changes in personality, speech patterns, and energy levels that indicate depression—and to maintain a necessary objectivity in care. Demographic profiles for elderly most at risk for depression overlap with those of the majority of home care recipients, including women, those living alone, and those without adequate support networks. The basic indicators of depression are described, as are the symptoms of bipolar disorder, seasonal affective disorder, and warning and risk factors for suicide. Advice is given on how home care workers can help in the assessment and treatment of depression. Common responses to medication and psychotherapy are described so that the home care worker can know what to expect over the course of treatment. (TS) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


**Keywords:** Dementia/Family/Aged/Economic/MED92-1.(JMCGOWAN)/A:/B:/C:/D:/Elderly/Health/The Elderly/Care/Review/Demographics/War/Policy/Research
Notes: 96100893 Department of Social Medicine, Harvard Medical School, Boston, MA 02115, USA. Growing numbers of elderly in countries of the developing world presage an increase in those affected by organic, age-related mental diseases such as dementia. A simultaneous rise in the burden of non-organic mental disorders in elderly populations is likely because stressors in many countries are affecting the mental health of the elderly directly and/or indirectly by altering the ability of families to provide care for them. This paper reviews studies on the disease burden of mental health problems of the aged in the developing world. It examines evidence on how demographic change, economic change, education, urbanisation, war and displacement, and widowhood influence elderly mental health. A look at policies and programmes improving the condition of elderly mentally ill throughout the developing world emphasises positive options for policymakers. Recommendations for future research both identify areas in which investigation would be particularly useful and highlight current methodological problems. [References: 178] 9604 [Review].


Keywords: Home Care by Illness/Patients/Home/Home Care/Home Care Workers/Workers/Health/Institutionalization/Rehabilitation/Independent Living/
AgeLine: Home care/Home Health Care/Visually Handicapped/Community Services

Notes: Offers guidance to home care providers on caring for elderly visually impaired patients. There are approximately 1,391,000 severely visually impaired, non-institutionalized persons in this country, 71% of whom are elderly. Home care workers and homemaker-home health aides will serve growing numbers of visually impaired elderly patients. The elderly home care patient with vision loss may very well have other physical and psychological losses. Home care providers should be aware of existing resources for the visually impaired so that some independent functioning can be restored in the hopes of avoiding premature institutionalization. Although there are many obstacles to obtaining services for older visually impaired persons, in-home rehabilitation services are becoming more available. The home care provider can help by recognizing the onset of vision loss, establishing initial linkages with services for the ageing and services for the visually impaired, and reinforcing independent-living skills taught by the rehabilitation teacher. Provides 20 hints to help the home care worker to become more comfortable and effective in working with elderly, visually impaired patients. (LS) (AgeLine Database, ©1988, American Association of Retired Persons, all rights reserved).

Home Care with the Dementing Diseases


Keywords: Home Care - Nursing/Dementia/Nursing/Family/Health/MED92-1.
Notes: This paper explores the early experience of dementia when the veil of uncertainty that surrounds the diagnosis of this condition is lifted. Consideration will also be given to the impact of dementia on carers and the service demands that are created. In the UK alone there are estimated to be 636,000 people living with dementia, with this figure rising to just under 900,000 by the year 2021. In the USA the projected number of people with Alzheimer’s disease is expected to be 9,000,000 by the year 2040. Despite a wealth of social and gerontological research on the impact of dementia upon family carers, service responses and policy initiatives are fragmented because dementia is excluded from some important recent initiatives, such as the Mental Health Task Force. Current services and interventions focus predominantly on the later stages of dementia, when a meaningful perspective of the person with dementia is difficult to obtain. Nursing has a relatively long history of caring for people with dementia and their family carers. The paper will also consider the contribution of nursing and nursing research to the field and explore additional avenues for service intervention and education. [References: 207] 9702 [Review].


Keywords: Dementia/Hospitals/Patients/Interview/Physicians/Community/Community Care/Roles/Family/Organizations/MED92-2.(JMCGOWAN)/A:/B:/C:/D:

Notes: 96382789 Centre for Health Services Research, University of Newcastle upon Tyne. BACKGROUND: Pre-senile dementia of Alzheimer type is a rare condition, and a report drawn from a large population may be useful to general practitioners. AIM: A study was undertaken in the Northern Regional Health Authority area to investigate general practitioner referral practice, hospital investigations and diagnosis in cases of pre-senile Alzheimer’s disease. METHOD: Reviews of 186 sets of case notes of patients diagnosed between 1985 and 1989, and follow-up interviews with the principal carer in a sub-sample of 73 surviving patients were undertaken. RESULTS: In 63% of cases, formal diagnosis of pre-senile Alzheimer’s disease was made by a neurologist, in 27% of cases by a psychiatrist and in 9% by a physician. Symptoms of depression had been noted in 45 patients (24%) and 21 had been prescribed antidepressant drugs prior to specialist referral. Computerised tomography scans were requested significantly more frequently by neurologists than other specialists and lumbar puncture was virtually only done by neurologists, but there were no significant differences between specialists regarding other clinical investigations. Domiciliary care or day centre attendance were more likely to be arranged at hospital discharge by psychiatrists than other specialists, but at follow-up interview no differences in community care provision were found according to initial specialty. Interviews with relatives of surviving patients revealed that at initial contact with general practitioners, 48% of patients were unaware that they had any problem. Only 13 relatives (18%) felt they had been given sufficient
information at diagnosis concerning the chronic and progressive nature of the disease, and at follow up 26% remained unaware of the existence of the Alzheimer's Disease Society. CONCLUSION: These results reinforce the importance of the role of general practitioners in arranging and co-ordinating appropriate support for patients and their relatives, in providing continuity of care and in advising the families of the existence of voluntary organizations.


**Keywords:** Dementia/Family/Patients/Roles/Physicians/Assessment/Home/Community/Caregivers/Home Care/Nursing Homes/MED66-1.(JMCGOWAN)/A:/B:/C:/D:/Care/Relationships/Nursing/Nursing Home

**Notes:** 88189937 School of Primary Medical Care, University of Alabama in Huntsville 35801. The various approaches to the patient with Alzheimer's disease are receiving much attention, but relatively little has been written about the important role physicians can serve in helping the patient's family deal with the disease. In managing Alzheimer's disease, the physician's relationship with family members may be as important as or even more important than his or her relationship with the patient. Establishing and maintaining a successful relationship involve early assessment of family function, periodic home visits, coordination of available community resources, regular assessment of caregivers' coping skills, and regular discussions about the limits of home care and the possibility of placement in a nursing home. When nursing home care is chosen, the physician can, by continuing his or her involvement, help assure provision of the highest quality care possible.


**Keywords:** Dementia/Caregivers/Family/Perception/Hospitals/Assessment/Physicians/Community/Questionnaire/MED92-1.(JMCGOWAN)/A:/B:/C:/D:

**Notes:** 95291476 Department of Family Practice, University of Iowa, Iowa City, USA. OBJECTIVES: To document caregivers' perceptions of the deterioration in functional ability of persons with dementia over time, to identify the most problematic behaviour for caregivers at two stages of dementing illness, and to compare the perceived informational needs of caregivers at diagnosis and 3 years later. DESIGN: Single cohort. Surveys were mailed at time 1 and respondents were followed up after 3 years (time 2). SETTING: Midwestern hospital dementia assessment clinic with a family physician director. Continuing care was by community physicians. SUBJECTS: Thirty elderly patients with dementia who were evaluated at the dementia clinic. Data were provided by their caregivers. RESULTS: Patients' scores on the Activities of Daily Living section of the questionnaire declined (bath self, P = .03; transfer from bed or chair, P = .03; and groom self, P = .06). Significant deterioration in behaviours over time was found
in incontinence (P = .04). Fewer patients were depressed at time 2 (P = .02). The patient behaviours found most troublesome at time 1 were worrying about memory loss, losing or hiding things, feeling blue, experiencing restlessness, having difficulty calculating, experiencing a lack of interest, and having false ideas. At time 2, the greatest problems were having a short attention span, failing to recognize persons or things, experiencing a lack of interest, experiencing restlessness, repeating himself or herself, forgetting where he or she is, speaking incoherently, and being incontinent. Questions caregivers most wanted answered at time 1 concerned possible treatment, the future course of illness, and the cause of the symptoms. At time 2, the concerns were the future course of illness, possible treatment, and disease inheritance. There was significantly more interest in family agreement about care (P = .004) and the need for legal guardianship (P = .001) at time 2. CONCLUSIONS: Caregivers’ perceptions of the most frequent and troublesome behaviours of patients with dementia were documented at different stages of the disease. The importance caregivers attached to their requests for information reflected changing but continuing needs for reassurance about the patient’s diagnosis and treatment and for help with the psychosocial consequences of dementia. Physicians must be aware of caregivers’ needs at different stages of the disease process and be equipped to help them appropriately.


**Keywords:** Dementia/Caregivers/Health/Health Services/Community/Environment/Development

**Abstract:** This study reports the Italian data of a collaborative project between the Health District of Piacenza and the Lewisham and North Southward Mental Health Service in London. The aim of the project is to confront opinions and ongoing strategies of the local communities with respect to the services for demented patients. A rapid appraisal evaluation was conducted, based on semi-structured interviewing of "key informant" and "caregivers". Environment, services and health policies were discussed, highlighting differences between professional and lay informants and gathering suggestions that should find an answer to guarantee a participated development of the program.


**Keywords:** Dementia/Family

**Abstract:** The elderly population of the People’s Republic of China is increasing rapidly. Yet few studies of dementia have been carried out outside of the large cities. Prevalence rates are approaching those in the West. Influences on the system of care for demented old people include the growth of one-child families; decreasing levels of filial care; changing levels of residential care provision; a low level of specialist medical care and other welfare services; a low level of public awareness of dementia; and the weakening of the extended family, associated
especially with urbanisation and the increasing mobility of labour. These trends may create a difficult situation for dementia sufferers and their carers.

Home Care with HIV/AIDS


Keywords: Home Care - AIDS/HIV

Abstract: OBJECTIVE: To determine the incidence of infection with HIV-1 and the risk factors associated with seroconversion in three geographical strata of a rural Ugandan district. DESIGN: Serological, socio-demographic, and behavioural surveys of everyone aged 13 or more in 21 randomly selected communities at baseline and one year later. SETTING: Rural population of Rakai district, southwestern Uganda, residing in main road trading centres, secondary trading villages, and agricultural villages. SUBJECTS: In 1989, 1292 adults provided a blood sample and interview data; one year later, 778 survivors (77%) who had been seronegative at baseline provided follow up data. MAIN OUTCOME MEASURES: Incidence of HIV infection in relation to individual characteristics and risk factors, including place of residence. RESULTS: Incidence of HIV infection in all adults was 2.1/100 person years of observation (SE 0.5 (95% confidence interval 1.1 to 3.1)); in people aged 15-39 the incidence was 3.2/100 person years. Incidence was highest in men and women aged 20-24 (9.2/100 person years (3.9) and 6.8/100 person years (2.9) respectively. Risk factors significantly associated with seroconversion were age 24 and under and two or more sexual partners. Between the surveys the proportion of all respondents reporting high risk behaviour (two or more partners) significantly increased from 8.9% to 12.3%. CONCLUSIONS: Despite preventive programmes and substantial knowledge about AIDS the incidence of HIV infection remains high in this rural population. Prevention aimed at vulnerable rural communities is urgently needed to contain the HIV epidemic.


Keywords: Home Care - AIDS/HIV/Urban/Migration/Males/Aged/Employment/Africa/Females/Male/Rural/Female/Economic/Roles/Health/Health Promotion/Public Policy/Policy/Work

Abstract: The population pyramid in most African countries is symmetrical with a broad base. However, in urban areas, one finds a prominent one-sided bulge caused by the migration of young males (aged 18-35) into the cities for employment. The prevalence of HIV infection in urban populations in Africa is
highest in the 25-35 year old age-group in males and in the 15-25 year old age-group in females. This difference is due to the fact that on average, sexual partnerships are formed between older men and younger women. The distortion of the urban population profile caused by male migration results in an overall 1:1 female:male prevalence ratio of infection. However, as the epidemic spreads into the larger rural population, the absolute size of the most severely affected younger female population is larger than the size of the older male population, which eventually results in a higher number of infections in women. This excess of female morbidity from HIV infection has important implications for the social and the economic role of women in society. It also adds fuel to an emerging epidemic of paediatric AIDS. Health promotion strategies to address this issue should include: 1.) Public policies designed to narrow the male:female age-gap of sexual partnership formation; 2.) policies addressing the economic migration patterns of the male work force and; 3.) policies to narrow the base of the general population pyramid.


**Keywords:** Home Care - AIDS/HIV/Economic/Canada

**Abstract:** HIV is spreading in Canada’s marginalised populations, and the populations at high risk for infection have changed. In order to prevent new infections, Canada must stay as close as possible to the leading edge of this elusive epidemic. We need to improve techniques for monitoring an epidemic that is largely hidden from view at the peripheries of society, and to target high-risk populations for prevention programmes at a time of low HIV prevalence. Previously successful prevention strategies are not effective for the populations (injection drug users, young gay men, Aboriginal people and vulnerable women) who are most at risk in this “third wave” of the epidemic.


**Keywords:** Home Care - AIDS/HIV/Aid1.Mdl/A.:B.:C.:D.:Rural

**Notes:** 92403027 Our Lady’s Hospital AIDS Project, Chilonga Mission, Mpika, Northern Province, Zambia. ISSUE/PROBLEM: Community rejection of a newly started AIDS program in rural Zambia due to the stigmatisation of discharged AIDS patients and their families during hospital counselling sessions and while being visited by our home care team. DESCRIPTION OF PROJECT: Our Lady’s Hospital at Chilonga addresses the AIDS issue in three main areas; health education, pre-and post-test counselling and home-based care. Upon initial implementation community trust was lost because of lack of confidentiality and fear of being labelled an AIDS patient upon being visited by the “AIDS team” at home. The new approach was to do away with detrimental AIDS committee members and train reliable, motivated medical staff as counsellors. Health education was continued in the villages and seminars were held for village headmen. Home care was improved by bringing patients to their homes upon discharge from hospital and a date set for the following visits. The visiting team was limited to only three constant-committee members and the home care service was also made available to patients suffering from cancers, hemiplegia and other
terminal illnesses. Home visits sometimes continue after the death of our patients, funerals are attended and some small support is rendered to the orphans left behind. RESULTS: One year later, the hospital administration has received no more complaints about the program and, contrary to how we were received initially, patients willingly accept us in their homes. LESSONS LEARNED: AIDS has many social implications. In order to evoke a positive response from the community towards AIDS activities, it is imperative to involve only motivated reliable staff, to convince influential community leaders of the need and to integrate the care for AIDS patients and those suffering from other diseases.

(Abstract by: Author).


**Keywords:** Home Care - AIDS/HIV/Meint2.Mdl (MEDLINE 1993+)/A:/B:/C:/D:

**Notes:** 95359259 British Columbia Centre for Excellence in HIV/AIDS, Vancouver, Canada. A retrospective chart review of all in-patient deaths in 1992 was undertaken to examine patterns of care in advanced HIV disease at St Paul’s Hospital, Vancouver, Canada. St Paul’s Hospital cares for approximately 75% of the Province of British Columbia’s AIDS caseload. This represents about 18% of Canada’s caseload. Data were collected on demographic characteristics, the utilisation of home care and community services, income and social support, symptom presentation at terminal admission and the utilisation of acute hospital care and hospital based palliative care. A total of 126 deaths were reviewed. All but two subjects were homosexual/bisexual men. The median age at death was 39 years (range 24-67). Four patterns of care at death were identified: 1.) Aggressive therapy with resuscitation 24 (19%), (resuscitation was initiated in 58%); 2.) aggressive therapy with a no resuscitation order 49 (39%), in which the palliative period was a median of three days; 3.) death on the palliative care unit 33 (29%), with a median survival once palliative of 20 days; and 4.) death on the palliative care unit following respite admissions 16 (13%), with a median survival once palliative of 64 days. Despite a well known and respected Palliative Care Unit and community palliative care programme, there is a marked trend towards death occurring during aggressive therapy with a 200% increase in the initiation of resuscitation compared to the previous three years. No one has been discharged alive from hospital following the initiation of resuscitation since 1988. This study illustrates the need for providers and persons infected with HIV to reconsider expectations about treatment outcomes in advanced HIV disease.


**Keywords:** Home Care - AIDS/HIV/Aidl.Mdl/A:/B:/C:/D:/Care

**Notes:** 96925896 Asociacion Mexicana De Servicios Asistenciales En Vih/Sida I.A.P., Mexico City, D.F. Mexico. Fax: (525)5331774. ISSUE: We recognize that many patients have very real concerns for the daily management of their illness, specially where finances are concerned. PROJECT: It is to create a medical care model, non profit, low rate and low cost operating, working professionals with
experience attending people with HIV/AIDS. Actually, most of these people do not have social medical assistance, are unemployed, or other. This model has all what that is necessary for a person who lives with HIV in a medical area: Treatment orientation and medical support for HIV/AIDS including a physician directory with specialists as dermatology, psychology, dentistry, gynaecology, etc; support on laboratories specialised; discounted medicine bank and support medicine; conferences and workshops on HIV/AIDS related topics; periodical reference library for information related to HIV/AIDS with treatments, therapies, nutrition, home care, etc., consulted by specialists. All this work is co-ordinated by a staff of administrators volunteers with a group of professional health care volunteers, who are donating their work through low rate costs from patients to maintain operating the clinical and workplace. We have entered into agreements with other organizations, laboratories, and private business to provide discounted laboratory analysis and pharmaceuticals. The equipment was donated by particulars or government. this project has been working for about eighteen months and the services are increasing. RESULTS: Installations: 3 consultories, 1 dentistry area, 1 administrative area, Nursery and reception area. Medical Staff: 2 physicians, 2 psychologists, 2 dentists, 2 nurses, 1 proctologist, 10 collaborating physicians to the clinical, 8 administrative volunteers. Rates and recuperation costs (approximately): 7.5-10 US Dollars per consultation; 2-10 US Dollars nursery applications; 20-50% laboratories specialised discount and medicine discount. The average obtained by month for clinical operation is US Dollars 1,500 from recuperating costs. In addition, there are US Dollars 13,000 of investment to initiate operations, equipment and installations. Average Services: 1585 consultations, 840 laboratories practices, 382 open label medical patients histories, 2931 medicines interchanged, 470 nursery services in eighteen months. Lessons Learned: It is possible to create a low rate, non profit, medical clinical service unit co-ordinating the human resources and the financial resources available, by new government organizations, with professionalism and efficient operation. We do not expect that social, economic and scientific conditions will permit a final solution for HIV/AIDS patients to continue living longer lives. Unfortunately, many people will die in following months and years out of ignorance. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV/AIDSLINE.(JMCgowan)/A:/B:/C:/D:/ Rural

Notes: 96920918 Concern Worldwide, Masaka, Uganda. Fax: 256-481-20514. In Rakai District, Uganda, most families with sick people due mainly to HIV/AIDS cannot afford the high cost of Western Medicine and are often reluctant to use the cheaper local herbal medicine due to uncertainty about their effectiveness. Health facilities in health centres are unavailable to the majority of the population. OBJECTIVE: To identify and promote the possible alternatives to Western Medicine that can be used effectively in the treatment of opportunistic infections and to find ways of improving accessibility to treatment at no or minimum cost. METHOD: A study group of 73 people with knowledge and
experience of local herbs was identified for Community Based Research. AIDS related diseases also identified and the commonly used herbs for their treatment. The most effective and easily available ones were selected and samples collected for scientific analysis. Individual interviews were carried out with the study group on preparation, administration and other uses. The results of the scientific analysis and individual interviews were fed back to the study group and the community. This included recommendations for the selection, preparation, administration and side effects if any. RESULTS: 25 different types of herbs have been recommended and made available to the patients at no cost by a network of community-based home care volunteers who have also set up herbal gardens and First Aid Boxes. Patients interviewed reported relief and consolation. There is improved and shared knowledge of the herbs, improved access to the herbs and appreciation of their effectiveness by the community. CONCLUSION: Given the constraints outlined above, and donor fatigue, it is important to start looking at how best the local resources can be utilised in developing countries for the improvement of the quality of life. (Abstract by: Author).


**Keywords:** Home Care -AIDS/HIV/AIDS

**Notes:** 9692123 Communication Disease Centre, Republic of Singapore. Fax: 286-5801. E-mail: lynn@pacific.net.sg. OBJECTIVES: 1.) To reduce patients’ hospitalisation to save cost and patients can return home to be with family. 2.) To create an affordable and conducive day treatment centre which is easily accessible. 3.) To have a one-stop outpatient facilities. ISSUE: Patients’ were fearful of the disease and feel insecure staying at home, slightest discomfort, they want to be admitted. Some patients were not able to come daily for treatment without assistance and financial support. METHOD: Upon first diagnosed, patients were referred to Infectious Disease physicians. Counsellled by medical social workers and screened by health advisers. Patients were educated on how to cope with the disease, progressive counselling on personal issues and advice on safer sex. Patient and family members were advised to practice universal precautions. Patients were introduced to the support services available and encouraged to read up on resources to update themselves. Training programmes for support groups and community care providers were conducted to reduce fear and stigma. At the day treatment centre patients could come back daily for their drug therapy, Pentamidine aerosol therapy or any short procedures. These will help to reduce the cost and they can spend more time with their families. It is also a gathering centre for people living with AIDS. At the outpatient, confidentiality is maintained. The experienced nurse continues to give the holistic support. RESULTS: Data collected from January to June 1994 showed that most of the 70% of repeated admissions were due to: 1.) Fear of disease progress and death. 2.) Worries about the future. 3.) Family and friends not supportive. After initiating the comprehensive programme and follow through there was a reduction of repeated admissions to 30%. CONCLUSION: Patients were knowledgeable and competent in self care. They were able to provide support for and among themselves. (Abstract by: Author).

**Keywords:** Home Care - AIDS/HIV/Aid1.Mdl/A:/B:/C:/D:/Satisfaction/ Caregivers/Home/Home Care/Care

**Notes:** 96922350 Enfermedades Infecciosas, Hospital Ramon y Cajal, Madrid, Spain. **OBJECTIVE:** To evaluate the level of satisfaction experienced by the primary care giver (PCG) of advanced AIDS patients after receiving home care assistance (HCA). **METHODS:** A specific questionnaire was designed and sent to 167/191 (87%) PCG; we can confirm the address of 141/167 (84%). Ten questions were made to assess the programme, and two to ascertain family problems with regard to patients' care. HCA was created at our institution in 1990 as an alternative to hospital care. **RESULTS:** Data were obtained after one week and a half of fieldwork. We analysed 83/167(50%) answers. Patients received HCA after family/patient request (23%), or (73.8%) after being offered the assistance; 3% of patients were compulsory sent home. (Table: see text) **CONCLUSIONS:** HCA created as a tertiary hospital initiative, with voluntarily admitted patients, high degree hospital integration, and well trained and motivated personnel results in a very high satisfaction level. (Abstract by: Author).


**Keywords:** Home Care - AIDS/HIV/AID1.MDL/A:/B:/C:/D:

**Notes:** 97153788 Silver Chain Nursing Association, Osborne Park, W. A. Silver Chain Nursing Association has been providing care and support to people living with HIV disease in Western Australia for over ten years. As early as 1989, Silver Chain recognized that accommodation for this client group was a concern. In 1992 Respite House was established to provide short term respite care for clients with HIV disease and their carers, thus bridging a gap in HIV/AIDS service provision in Western Australia. The aim of the service is that clients and carers will be assisted to plan their respite, thus empowering clients and maintaining the service's policy of independent living and promotion of health. Respite House is a home designed to meet the needs of residents. The house can provide accommodation for up to three people at any one time. It is staffed by a Respite Co-ordinator and 80 volunteers on a 24-hour, 7-day a week basis. Volunteers are provided with a comprehensive orientation and in-service training programme which equips them with the skills required to fulfill their role as carers. Nursing care and support is provided by the Silver Chain Special Services nursing team, ensuring continuity of care from hospital to home, to respite to home again. The purpose of this poster is to provide information on the development, service and success of Respite House in the provision of HIV/AIDS care in Western Australia. (Abstract by: Author).

**Keywords:** Home Care - AIDS/HIV/AIDSLINE (JMCGOWAN)/A:/B:/C:/D:

**Notes:** 92403032 AIDES Federation Nationale, Paris, France

**ISSUE/PROBLEM:** PWA who are very sick want to stay at home as long as possible as no special care is required. They want professional services. AIDES, a community-based organization, had to deal with the Ministry of Health to implement the first home care program available in France for young people.

**DESCRIPTION OF PROJECT:**

1. The project aims to give PWA a greater autonomy.
2. AIDES co-operates with existing home care services dealing with old people.
3. AIDES trains the home care services on the specific care to give PWA and provides the services psychological support.
4. The services provide PWA with mAIDS and nursing help.
5. Each PWA was allowed to have 1,080 hours of help every year. The PWA who has not used the 1,080 hours can give the extra hours to another.

**RESULTS:** After a one year experience, AIDES helped 175 persons living in Paris, Nice, Marseille or Strasbourg. These persons needed a daily help of an hour and a half (average) in order to clean the house, to do the shopping and the cooking. 60% of them lived alone. 80% needed only a maid and about 10% needed both a maid and a nurse help but this demand increased during the last term of 1991.

**LESSONS LEARNED:** The home care service increases its activity during the year. As a consequence more and more people want to stay at home as long as possible, therefore new funds are needed in order to provide extra nursing help. Will it be necessary to start palliative care at home which at the moment is not available in France? (Abstract by: Author)


**Keywords:** Home Care - AIDS/HIV

**Abstract:** The study investigated knowledge, beliefs, practices, and experiences of traditional healers in relation to sexually transmitted diseases (STD’s), HIV and AIDS. Traditional healers see about 70% of the African patients, with all kinds of ailments. The advent of HIV/AIDS and the introduction of home-based care in most African countries has increased the case-load of many traditional healers and increased the risk of contact with people living with HIV/AIDS. To protect themselves and their clients they need the right information on HIV/AIDS. Most traditional healers use their bare hands as a diagnostic tool and to apply topical medicine. Many traditional healers also utilise their mouths to suck blood from their patient’s body as part of disease management. Most of the patients who are discharged from hospitals on home-based care usually end up at the traditional healer as relatives seek a second opinion or simply because they disagree with the diagnosis of incurable disease. This exposes traditional healers to HIV/AIDS. The study showed that traditional healers have some practices and beliefs, such as the use of the mouth for sucking blood (blood-letting), use of sharp instruments which is risky behaviour and the belief that HIV/AIDS is not a new disease. Further most of the traditional healers did not have adequate and in some cases correct information on HIV/AIDS. A few even believed they could cure AIDS as it has always been a disease they have been dealing with and were adamant it is not a new disease. Rapport between traditional healers and scientific medical personnel

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is essential for an effective and successful HIV/AIDS prevention and control programme.


**Keywords:** Home Care - AIDS/HIV/AIDSLINE.(JMCROWAN)/A:/B:/C:/D:

**Notes:** 30082490 AIDS Bureau, NSW Dept. of Health, Sydney, Australia.

**OBJECTIVE:** To develop a comprehensive state-wide 5 year strategic plan for meeting the health care service needs of people with HIV/AIDS. **METHOD:** A planning team addressed the following: analysis of epidemiological and utilisation data (including projections and scenario analysis); hospital services (scatter bed versus cluster, day care, discharge planning); institutional services (intermediary care, nursing home, hostels); community based services (home care, STD clinics, general practitioners); palliative care (institutional and community); mental health services (neuro-psychological assessment, rights of clients, management of long-term patients); psychosocial support (testing and counselling); services for IVDU (methadone, crisis housing, pain management); health workforce issues (range, numbers, training, support mechanisms); minimal level requirements in lower prevalence regions; prison medical services; identifying health service research needs (cost implications of different models of care); resource implications; establishing performance indicators. This service planning was achieved by extensive consultation with service providers and consumers, combined with epidemiological and utilisation data, literature review and a patient satisfaction survey. **RESULTS:** Strategies, policies and guidelines have been developed to ensure that service delivery enhances quality of life and is responsive to the medical and psychosocial needs of clients, while being cost effective. Mechanisms have been put in place to minimise the use of inappropriate specialised acute inpatient care. Increased emphasis has been placed on community and ambulatory care models. Co-ordination within the extended health system has been developed and strengthened to ensure a continuum of care. **CONCLUSION:** This approach to long-term service planning will ensure that care provided to people with HIV/AIDS is of high standard, co-ordinated and responsive. (Abstract by: Author).


**Keywords:** Home Care -IDS/HIV/AIDSLINE2.MDI/A:/B:/C:/D:/Home/Home Care/Care/Patients

**Notes:** 10090290 Hospital Na Sa de Aranzazu. Servicio Vasco de Salud-Osakidetza. San Sebastian, Spain. **OBJECTIVE:** To evaluate the first programme in Spain of a home care scheme for AIDS patients. **METHODS:** The programme of home care for AIDS patients was set up in February of 1988. It involves a team of one doctor and a nurse who are part of the Infectious Diseases Unit of the hospital. They provide home care to AIDS patients who cannot be attended in hospital due to their terminal state. **RESULTS:** During these two years the team has attended 26 patients, the majority being drug addicts, and have carried out 265
visits. The team provides medical care, psychological support and sanitary education. CONCLUSIONS: 1.) The psychological support and education of the patient and his or her family is as important as the medical care provided. 2.) This work can be carried out by nursing personnel, as long as there is always medical back-up available. 3.) Psychological support for the home care team itself is fundamental, due to the stressful nature of the situations which they have to confront. 4.) A fundamental aspect of their work is co-ordination with and education of primary care teams. (Abstract by: Author).

Garde, C., Arrizabalaga, C., Arrizabalaga, J., Iribarren, J. A., and Zulaica, D. (1994). At-Home Care Of Terminal AIDS Patients. 1994. Keywords: Home Care - AIDS/HIV/AID2.MDL/A:/B:/C:/D:/Care/Patients Notes: 00179489 Hospital Nuestra Senora de Aranzazu. Servicio Vasco de Salud. Osakidetza. San Sebastian, Spain. OBJECTIVE: Evaluation of the problems of this new form of care of AIDS patients. METHOD: The hospital team included a physician and a nurse who were charged with at-home care of AIDS patients, particularly terminal cases. The number of visits was determined by the patient's individual needs, and the objective of each visit was to offer the necessary medical care, education for health care, education for health care and disease prevention, and any psychological support required by the patient or his/her family. RESULTS: From February to December 1988, 16 patients were attended, 9 of whom died, with different diseases: cerebral toxoplasmosis, PML, KS... The number of visits made to each patient was 2-3 per week, of an approximate duration of an hour. CONCLUSIONS: 1.) If the domestic circumstances of the terminal AIDS patient present the necessary sanitary conditions and there are persons willing to care for him/her, in our opinion it is preferable that the patient spend his/her last days at home, since this situation is more conducive to the patient's sense of well-being and the family is more satisfied as to having done everything possible for the patient. 2.) Prolonged hospital stays can be considerably reduced, which represents an economic savings for public institutions. (Abstract by: Author).

Ghirga, P. and Aliberti, L. (1993). AIDS Patients Home Care: One Year Experience. 522. Keywords: Home Care - AIDS/HIV/Aidsline.(JMCGOWAN)/A:/B:/C:/D:/ Patients/Home/Home Care/Care Notes: 93335956 Ospedale L. Spallanzani Rome, Italy. 19 patients (11 men and 8 women) with an age range between 23 and 47 years (mean value 32) were followed in home care program over a period of one year (7/1/92-7/1/93), for a total of 498 medical visits. Home care medical team is composed of 6 doctors and 14 nurses of the hospital. METHOD: All the patients followed in the home care program were discharged from the hospital. They were notified for AIDS (according CDC criteria) and had a Karnofsky index of less than 70%. EPIDEMIOLOGY: Five women were drug addicts and 3 were heterosexual, amongst the men, 8 were drug addicts and 3 were homosexual. During a one year period 5 men and 8 women died. Eight people died in the hospital and 3 at home. During the period of home care assistance the patients had 398 days of
hospitalisation. DISCUSSION: Ninety percent of the patients who answered questionnaires indicated that the level of the home care assistance program was very good. The cost of the home care was considerably lower than hospitalisation. (Abstract by: Author).

Orofini, G. C., De Agostini, M., Busso, M., Bonasso, M., and Pellegrini, W. (1994). Home Care Service for AIDS Patients in Turin Area. 20. Keywords: Home Care -AIDS/HIV/AIDSLINE.(JMCGOWAN)/A:/B:/C:/D:/ Home/Home Care/Care/Patients Notes: 96923181 HCS, Amedeo di Savoia Hospital of Turin, Torino, Italy. Fax: 039117761757. ISSUE: Home Care Service (HCS) for AIDS patients and evaluation of its development in the future. PROJECT: In 1992 we established a HCS of AIDS patients in our hospital of I. D. in Turin. The access to this service was only for patients living at home or in community in the city limits of Turin. Patients' eligibility was verified by a team composed by: I. D. specialist, senior nurse of I. D., social worker. Patients' eligibility criteria were: 1.) The conclamation of AIDS disease, 2.) the severe improvement of illness, 3.) familiar assistance during the intravenous therapy, 4.) patients' personal approval, 5.) minimal life conditions. RESULTS: Since January 1992 up to December 1995, 200 patients have been enrolled (175 M. 25 F.) aged between 21-69 (median age 37.7). A total 130 were followed until death. Their average stay in HCS was 67.2 days (range 1=285). The most frequent diseases included: CMV (22.5%) HIV-related neurological diseases (13.5%) MAC+TBC (11. 2%) S.Kaposi (9.8%). LESSONS LEARNED: The Home Care Service for AIDS patients in Turin is feasible in all the clinical situations of AIDS up to death, except with emergency. Further studies will be done to better define if it's possible to improve the quality of life and survival rate of these patients. (Abstract by: Author).

Butters, Higginson, George, and McCarthy. (1993). Palliative Care for People With HIV/AIDS: View of Patients, Carers and Providers. Special Issue: The Family and HIV Disease. AIDS Care 5[1], 105-116. Keywords: Home Care - AIDS/HIV/PSYCG84.(JMCGOWAN)/A:/B:/C:/D: Notes: 80-30868 U London University Coll and Middlesex Hosp School of Medicine, England. Compared views of palliative care reported by 19 patients, 8 informal carers and the Community Care Team (CCT), a multidisciplinary team caring for people with late stage HIV/AIDS illness. Patients and their carers were interviewed at home, 3-4 weeks after referral to CCT. They rated 9 items of the Support Team Assessment Schedule (STAS), a standardised measure of palliative care. Satisfaction with health services was also recorded. CCT separately recorded the severity of 17 STAS items as part of a continuing audit of care. Patients and CCT identified continuing problems with symptom control, pain control, patient and family anxiety, and communication from professionals. Patients’ and CCT ratings were significantly correlated. However, patients rated pain as significantly more severe than did CCT. All patients and 7 carers rated the care given by CCT as good or excellent. (PsycINFO Database ©1993, American Psychological Assn, all rights reserved).

Keywords: Home Care - AIDS/HIV/Aid2.Mdl/A:/B:/C:/D:/Roles/Hospitals/Home/Home Care/Care

Notes: 30081790 Principal Medical Officer, London Lighthouse, London, England. OBJECTIVE: To enable people with HIV infection to access existing community care structures in London in co-operation with an acute hospital unit. METHODS: A multi-disciplinary home support team complementing the role of primary carers was designed to provide comprehensive domiciliary care for people with HIV infection. All patients lived within the Greater London area and reasons for referral included medical nursing, socio-emotional and liaison with community resources. RESULTS: An analysis of the 250 patients admitted to the programme within the first 18 months demonstrates the mean length of time over which input is provided is 5 months per patient. Eighty percent had an involved primary care physician, 25% had a community nurse and 23% had a social worker. This input enabled 30% of those terminally ill to die at home (twice the national average). CONCLUSION: This model of care may be adopted for use in large urbanised areas where community carers already exist but require education and support in order to care for individuals with HIV infection. Costing and individual acceptability remain unexplored areas. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV/AID1.MDL/A:/B:/C:/D:/Home/Care

Notes: 94370763 Department of infections diseases, Hvidovre Hospital. OBJECTIVE: To create on alternative to hospitalisation for the AIDS patients in periods where intensive treatment is not necessary, and to make is possible for these patients to die in their homes. METHODS: Two nurses have been responsible for the successful management of the AIDS home care project. Paid helpers have been utilised for direct home care of AIDS patients. These helpers have not necessarily been educated as social workers but have experience in many different professions. RESULTS: After six years, 195 AIDS patients have been connected to the project. 170 have died in their homes. The project has been a success and is now permanent. The budget a year is 2 million Danish Kroner, and 10 patients can be home at the same time. CONCLUSION: It's possible to create on alternative to hospitalisation, and to make it possible to take care of the patients who want to die in their home. The price for one patients is three times cheaper than a bed at the hospital. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV/AIDSLINE.(UMCGOWAN)/A:/B:/C:/D:/: Nursing/Care/Model

Notes: 92403470 Federal University of Goias. OBJECTIVE: Validate the Model of Nancy Roper for nursing care of clients infected with HIV or AIDS; identify factors which interfere in nursing care; analyse nursing care given in the out-patient clinic, hospital and home. METHODS: Research was a case study
descriptive in nature with a qualitative approach. This research was developed from the theoretical-philosophical reference of Nancy Roper using her Model of Nursing Care, at the Unit of Infectious and Parasitic Diseases of the University Hospital of the Federal University of Minas Gerais. The model was applied to eight clients in the hospital, clinic or at home for seven months with emphasis on: Nursing history, client’s life style, treatment plan and evaluation of the dependence-independence “continuum” for each daily activity. RESULTS: The use of the model permitted a holistic, individualised approach in addition to showing the necessity of participation of the client and his family group in the care process. The perception about clients infected with HIV or with AIDS or their way of life shows dichotomies not yet resolved in nursing care. The model led to the perception of the client as a human being and contributed to establishing positive interaction between the nurse, client and family. CONCLUSIONS: The model of Nancy Roper offers systematised nursing care at the levels of primary, secondary and tertiary care and rehabilitation of health. Its application in home care is facilitated because the care occurs in the natural environment of the client, including his social group. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV/AID1.MDL/A:/B:/C:/D:/Roles/Care
Notes: 96925488 AIDS Control Programme, Uganda. Fax: 20608. ISSUE: With the increasing number of people with HIV/AIDS and ARC, hospitals are overcrowded. Although hospitals and health units are equipped with medical workers, counsellors and counsellor assistants respectively, patients discharged are left in uncoordinated suspense which calls for a dignified home care and referral service. This gap has been filled with Community-based Counselling Aides (CCA’s). Through their services, emphasis on traditional system of care and support has been rejuvenated to absorb this vacuum. PROJECT: NACP puts in place six trainers at the district. The district selects one sub-county where one person per village is selected by the Community leaders. This one is trained in basic counselling skills for 14 days to become a CCA. The CCA acts as a complement for continuum care and is in constant touch with the dispensary and community. The initial sub-county is an example to the rest and the DMO is encouraged to continue training and supervise in other sub-counties using existing local funds. LESSONS LEARNED: CCA’s in each village are an important referral link for continuum care. They are a good source of information and they distribute educational materials. Traditional systems of care and support through CCA’s is being rejuvenated. CONCLUSION: Complementing continuum care right from hospitals through health units to the community is possible. CCA’s are a realistic source of support as they promote and strengthen rejuvenation of cultural response to epidemics and terminal diseases like HIV/AIDS. (Abstract by: Author).

**Keywords:** Home Care - AIDS/HIV/MDL/A:/B:/C:/D:/Family/Care

**Notes:** 94371605 AIDS Support Organization, Kampala, Uganda.

**INTRODUCTION:** The AIDS Support Organization (TASO), an indigenous Ugandan NGO, is conducting a participatory evaluation of its care activities. Among the key actors in the evaluation are family members who look after bedridden patients. **OBJECTIVES:** To identify who provides family care, their source of support, knowledge and the difficulties encountered. **METHODS:** As part of an evaluation exercise of TASO services, family caregivers looking after bedridden PWA were interviewed within their homes using a standard questionnaire. Convenience sampling was used to select the families from the seven TASO centres. Data were collected from caregivers of 232 patients.

**RESULTS:** The majority of caregivers are women (86% female; 14% male). TASO was the most frequently cited source of care related information (81.5%) and emotional support (82.8%); neighbours were the next most frequently mentioned source of information (31.9%) and emotional support (41.7%). Whereas medicines/treatment were considered to be the most important type of care (28.1%), emotional support was mentioned as the most difficult patient’s need to cope with (31.3%). When challenged as to who should take the main care of a PWA, 53.6% said that it should be the mother of the client or a spouse (10.7%).

More results to follow. **CONCLUSION:** The burden of home care lies heavily on women, either as mothers or spouses. Neighbours are an important source of information and support; programs teaching family caregivers in home care of PWA should also train neighbours in basic AIDS information and home care.

(Abstract by: Author)


**Keywords:** Home Care - AIDS/HIV/Home Care - Training/Rural/MDL/A:/B:/C:/D:/Care

**Notes:** 96924050 Nairobi. Fax: 254-2-243164. **ISSUE:** Community in Homa Bay and Suba District don’t have knowledge about caring/counselling for HIV/AIDS. **PROJECT:** A home care counselling workshop was organized by WOFAK members to gauge their understanding in taking care of people with AIDS who are usually taken from urban areas to rural homes to die there when they are already weak. The training was carried out in the Homa Bay town of Kenya. The trainees were women group leaders drawn from the surrounding districts. They were mainly nurses, teachers, church leaders and farmers. These women were already working in their communities in various groupings. After a five-day training, we asked the participants to demonstrate what they had learned in those five days in their own ways and they chose to do this in role plays. **RESULTS:** One month after the training we had already received encouraging response from the community leaders who took responsibility of the groups. They informed us that they were already working with the community closely. After 3 months when we
went for our follow up, each group had trained at least 500 people or more. People with AIDS were by this time included in the groups and the fear and stigma which was associated with AIDS was history. The only problem they had was the training materials and caregiver items like gloves and disinfectant. LESSON LEARNED: In HIV/AIDS care, we need to work closely with the community for they are the ones who know their people in terms of culture and customs well. Care should not be left to doctors alone. Training materials should also be translated into local languages. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV/AIDSLINE.(JMCGOWAN)/A:/B:/C:/D:/ Care/Community/Health/Africa

Notes: 94372310 Southern African AIDS Training Programme, Canadian Public Health Association. OBJECTIVE: To develop a programmatic approach to the amplification of community health structures capable of responding to AIDS in Southern Africa. METHODS: The actual structures of community care comprise the pattern of agents, acts and resources available in the community to produce and protect the health of its members. The method employed by the Southern African AIDS Training Programme to identify, support and amplify these structures is described here as one example of such a mechanism. RESULTS: Mechanisms can be devised to support and augment the actual structures of care which communities deploy to cope with the AIDS epidemic, and to inter-link these with government services. Relatively small financial inputs, if accompanied by appropriate non-financial supports, such as local NGO skills-building and mentoring linkages, can achieve impressive results. DISCUSSION: In the experience of the SAT Programme and its project partners, “who cares?” is a fundamental question which must be asked in order to achieve the broad community involvement needed in countries with an escalating burden of AIDS illness and death. Otherwise, community involvement remains a “black box”, desired but not understood. Caring is shown to be an integral health-producing act based on respect for fellow human beings which at community level renders the distinction between “prevention” and “care” artificial: All good care incorporates elements of prevention; all sound prevention is caring. SAT’s experience indicates that the structures of community care are an effective and sustainable entry-point into affected communities, and that responses grounded in care antidote the threat which communicable illness poses for human rights. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV/Home Care - Training/AID1.MDL/A:/B:/C:/D:/Home/Home Care/Care/Volunteers

Notes: 92401137 Norwegian Red Cross, Oslo. PROBLEM: Families all over the world care for people with HIV disease in the home. Where access to health services is limited, palliative care in the home is often the only care available. Teaching families to provide basic nursing care in the home increases the quality
of life in people with illnesses such as chronic malaria, tuberculosis and HIV disease. PROJECT: Two Rwandan nurses train Red Cross volunteers to teach families basic nursing skills. In the five-day course they teach skills in nursing care, hygiene, and HIV prevention. After the course volunteers return to their villages to teach these skills to their families. RESULTS: Seven Red Cross volunteers attended the first training. All seven passed the skills evaluation at the end of the course. In the three months after the course they visited a total of 56 families to teach about home care. Evaluation indicates that families feel they benefited from the volunteers’ training. The nurses continue to train new volunteers and provide follow-up visits for old volunteers. LESSONS LEARNED: Volunteers can be trained to teach about nursing skills to families caring for people with HIV disease in the home. This presentation will provide the course content, information about the impact of the volunteers in their communities and identified unmet needs of the families. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV

Abstract: In Africa, AIDS is called the grandmothers’ disease because the burden of caring for the sick and the survivors falls on older women. The two abstracts which follow report an overview of research on the social and economic effects of the HIV/AIDS epidemic in Southern Africa and a case study of an intervention among older women in a Botswanan village.


Keywords: Home Care - AIDS/HIV/MED66-1.(JMCGOWAN)A:/B:/C:/D:

Notes: 92223148 Institute for Social Studies in Medical Care, London, UK. Despite calls for a shift from hospital to community based care for people with HIV infection there has been some speculation about whether the facilities will actually be available. One central element of community care is informal care. Structured interviews with 125 people who were supporting gay men with HIV related illness including AIDS (hereafter PWA) provide information about the characteristics of people who were helping on an informal basis, what they did, and what support they needed for themselves. It was mostly male friends and partners who were offering support. Half the carers were carrying out specific physical tasks, though much of the support was more general, particularly emotional support. Where both people had experienced symptoms, some reciprocity of caring was taking place. Resistance to being labelled a “carer” was evident. Carers felt themselves inadequately supported both practically and emotionally and were specific about what could be done to change this.


Keywords: Home Care - AIDS/HIV/AID1.MDL/A:/B:/C:/D:
Notes: 93335898 Medical Policlinic, University Hospital, Berne, Switzerland.

OBJECTIVE: To assess social support needs of HIV/AIDS patients.

METHODS: We reviewed the charts of all the 319 patients who visited our HIV/AIDS out-patient clinic in 1992. RESULTS: 121 (38%) of the 319 patients (28 women, 93 men) requested social support in addition to medical care. Forty-one and one-half percent were homosexuals (HS), 41.5% IVDU and 17% heterosexuals, haemophiliacs and others. Out of a total of 518 visits, 43% of patients attended 2-5, in 35% more than 5 times. Of those requesting counselling 63% were patients in CDC IV, 37% were asymptomatic HIV-patients. The table shows the reasons for counselling (more than one reason possible): Tabular Data, See Abstract Volume. There were no sex differences. CONCLUSIONS: There is considerable need for social support. Insurance and legal problems dominate. IVDU's more frequently require help related to financial problems and housing. HS's need more psychological support and home care, reflecting more advanced disease in this group. In our experience, social support is a crucial element in the care of people with HIV/AIDS. The social worker should be integrated in the HIV/AIDS outpatient clinic team. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV/AIDS1.MDL/A:/B:/C:/D:/Needs Assessment/Assessment/Caregivers

Notes: 92401166 Faculty of Nursing, University of Montreal. OBJECTIVES: To assess the needs of natural caregivers of seropositive or PWA for services to be offered to these caregivers by the Pierre-Henault Center (a centre created by and for them). METHODS: In-depth interviews with 18 natural caregivers: parents, spouse, siblings, friends (4 of seropositive individuals, 9 of AIDS diagnosed individuals, 5 of individuals already dead from AIDS). They were recruited through clinics and announcements in local newspapers. A standard pre-tested interview guide with open and closed questions was used. Data were analysed according to the classical thematic analysis method. RESULTS: The announcement of seropositivity or AIDS creates a great impact on all caregivers, expressed in anger, powerlessness and mainly in deep sorrow. Facing the hostility of those close to them and society at large, many deny their own needs, particularly at the last stages of AIDS, withdrawing from social activities or leaving their previous jobs (4/18). This situation generates anxiety, lost of appetite and sleepiness. However, the experience of being a caregiver offers profit to half of the sample. While the family is the cornerstone of natural caregiving, friends become more involved when the PWA has found the links cut with the family. The most important needs reported were “to be listened to” and “to share experience” with other natural caregivers (15/18), “to be prepared for the death of PWA” or “to deal with death” (12/18), “to receive support in home care” (12/18). Results clearly indicate that caregivers are highest in the PWA situation because of both social stigmatisation and the youth of the PWA. CONCLUSION: The operation of the P.-H. Center has proven the adequacy of the needs assessment, 6,000 services being delivered to 600 natural caregivers in the sixteen months following the study. Caregivers come very late to the Center, because they do not respect their
own needs. It demonstrated also the appropriateness of services offered directly to natural caregivers in a centre managed by natural caregivers. (Abstract by: Author).


**Keywords:** Home Care - AIDS/HIV/AIDS2.MDL/A:/B:/C:/D:/Stress/Caregivers

**Notes:** 00387189 University of California, San Francisco, USA. OBJECTIVE: To identify the dimensions of stress experienced by gay men caring for friends or lovers with AIDS. METHODS: Qualitative interviews were conducted with 20 informal caregivers. Interviews were taped, transcribed and analysed for stress-related content. Structured questionnaires were administered to an additional 30 respondents. RESULTS: Three broad dimensions of stress were identified: 1.) Primary Caregiver Strains that arise directly out of the demands and responsibilities of the caregiver role; 2.) Secondary Strains that develop in other areas of the caregivers’s life because of the intrusion of caregiving demands; and 3.) Intrapsychic Strains resulting from the caregiver’s own fear of contracting AIDS, the attenuation of his social network because of AIDS-related deaths, and the anticipated loss of an intimate relationship. Several sub-components within each of these general dimensions of stress have been identified. The types of coping strategies used to deal with these stressors will also be presented. CONCLUSION: While caring for the AIDS patient in the community has humanitarian benefits for the patient and economic advantages for society, it is not without costs. The informal caregiver is often left to contend with a great number of intense stressors. The importance of incorporating the needs of informal caregivers into public health policy is evident. (Abstract by: Author).


**Keywords:** Home Care - AIDS/HIV/Survey/Support/Support Programs/Organizations/Attitudes/Rural/Data Analysis/Aged/Family/Intervention Strategies

**Abstract:** The John Hopkins University. HAPA Support Program (HSP) provided technical assistance to Save the Children (SC), a U.S.-based non-governmental organization, to conduct a survey of knowledge, attitudes, beliefs, and practices (KABP) related to AIDS among rural Zimbabweans. The objectives of the HSP technical assistance were to field test a rapid KABP survey methodology and to assist SC to provide data that would contribute to their final project evaluation. The entire process of planning, implementation, preliminary data analysis, and preparation of a draft report of survey results was completed in a four-week period. A total of 660 respondents, aged 18-45 years, selected by a modified 30-cluster sampling method, were interviewed in two SC project areas. Although knowledge about HIV/AIDS was high, a number of misconceptions about HIV transmission and unfavourable attitudes to people with AIDS were noted. Of five knowledge and attitude variables that could be compared with the baseline survey results, four showed favourable changes and one showed an unfavourable trend. Comparing responses from those who were educated by SC
with those who had other sources of information about HIV/AIDS, higher levels of knowledge were seen in the SC-educated group and, in one area, somewhat greater willingness to care for family members with AIDS. However, there were no differences seen in other attitudes, beliefs, or in practices regarding condom use. The rapid KABP survey approach was successful in providing, with a relatively modest investment of resources, quantitative data useful for project evaluation, and for developing HIV/AIDS intervention strategies.

Nfila, B. F. (1994). Home Based Care, A Viable Option for the Care of AIDS and Other Terminally Ill Patients in Botswana. 80.

**Keywords:** Home Care - AIDS/HIV/AIDSLINE.(JMCGOWAN)/A:/B:/C:/D:/Care/Home/Support/Community

**Notes:** 96923496 Nfila BF. ISSUE: Botswana is in the grip of an HIV epidemic. It is estimated that there are currently about 3,110 AIDS patients and 125,000 people living with HIV infection in Botswana. It has been noted that 50% of hospital beds are now being occupied by patients with HIV related illnesses. PROJECT: Ten AIDS patients for home based care and their family members were interviewed to determine their attitude towards home based care. RESULTS: Almost all of the patients and their family members showed an initial negative attitude toward home care. Reasons aired included lack of capability both material and skills for the care of the critically ill patients and fear of infection spreading to the rest of the family members on account of inevitable contact. Denial and stigma associated with the disease were also factors associated with the negative attitude. The initial attitude was reversed in a high proportion of the families after adequate counselling. A small proportion, about 25%, resisted entirely the responsibility of caring for their sick at home. These were mostly families of low social economic status, urban based and with limited extended family relationship. LESSONS LEARNED: With adequate involvement and counselling of the family, acceptance and accommodation of AIDS patients can be high. Determining factors are the existence of traditional extended family support system, socio-economic status, effective continuous family and client counselling and early involvement of the family. In spite of problems encountered, home based care remains a viable option. In fact the concept fits into the primary health care strategy already adopted by the Government. (Abstract by: Author).


**Keywords:** Home Care - AIDS/HIV/AIDSLINE.(JMCGOWAN)/A:/B:/C:/D:/Care/Home/Support/Community

**Notes:** 96921023 National AIDS/STD/TB and Leprosy Programme, Lusaka, Zambia. OBJECTIVE: To determine factors influencing the adequacy of care of chronically ill/HIV disease at household level. METHODS: Chronically ill patients (CIP, sick 30 + days) were identified by interviewing head of households. Households were sampled by 1.) Arbitrary selection of communities and 2.) systematic sampling of households. Personal interviews were conducted with identified CIP’s and their respective immediate care provider (ICP). RESULTS:
The proportion of households (N=3047) with an adult CIP was 6.5%. Most patients presented symptoms or diseases indicating HIV infection. The majority of CIP’s (77%) and ICP’s (71%) preferred the care to be home based. A high proportion (73%) of CIP’s perceived received care as rather restricted and frequently inadequate. Despite the willingness of relatives supporting in various ways, most ICP’s experienced critical problems related to provision of food and proper hygiene. Access to professional health care was hampered by high user fees and shortage of drugs. Except for significant outreach of churches (21% received support recently), the coverage of other types of support services appeared marginal in most communities. CONCLUSION: The findings reflect the current economic situation in Zambia (76% extremely poor); very limited coping capacities regarding basic needs. Patients’ preference was to be cared for at home, but in most cases particular support from outside own family will be vital prerequisite adequate care. The coverage of this type of support services seems still seriously low, despite being long established in Zambia, and access to medical treatment appeared significantly hindered by the government policy transferring more of the burden of financing health care to patients. (Abstract by: Author).

Notes: 93112315 Infectious Diseases Department, San Bortolo Hospital, Vicenza, Italy. OBJECTIVE: To evaluate the costs and cost- effectiveness of home-care assistance (HCA) as an alternative to hospital-based care only for patients with AIDS (PWA). DESIGN: A six-month prospective study. Use of resources by a control group of PWA receiving ordinary hospital-based care (OC group) was compared with that by a random group of PWA who, in addition to hospital care, were also receiving home care (HC group). SETTING: Home- and hospital-based care for PWA in Vicenza, Italy. PATIENTS: HC group selection was based on eligibility criteria for severity of illness, home location and economic and family support. Ten of the PWA satisfying all eligibility criteria were randomly allocated to the HC group. The control group consisted of 32 PWA lacking one or more of the eligibility criteria. INTERVENTION: HCA involved the provision of palliative care for PWA by a multidisciplinary team of caregivers. Hospital-based services covered inpatient and outpatient services. MAIN OUTCOME MEASURE: The health benefits for HC and OC groups using a quantitative quality of life measure (the Quality of Well-Being Scale). RESULTS: Overall health-care cost savings of 6-7%, relative to the OC group, were predicted for the HC group. Costs per well week were estimated at US Dollars 482 for the HC group and US Dollars 791 for the OC group. CONCLUSION: Home-care assistance appears to be a cost-effective strategy for the treatment and care of PWA if strict eligibility criteria are adhered to.

Keywords: Home Care - AIDS/HIV/AIDS. MDL/A:/B:/C:/D:/Home/Home Care/ Care/Analysis/Economic/Costs/Patients

Notes: 03405591 Department of Infectious Diseases, San Bortolo Hospital, Vicenza, Italy. OBJECTIVE: To compare economic costs and benefits of Home Care (HC) with Ordinary Care (OC). METHODS: A group of 29 OC patients (Pts) was compared in all use of resources with an HC of 9 Pts. Data collection was performed according to the DRG cost model for a period of six months for each individual subject. Enrollment criteria in HC were: 1) Adequate economic and family support and 2) stage 2 or 3 of Severity Classification System for AIDS Hospitalization. When death was to occur at home, special medical and nursing support was given. Based on palliative care principles, our approach aimed to improve the quality of life by good symptom control. Costs are in Million Italian Lira. RESULTS: Total number of nursing days (ND) for OC was 990 with an average length of stay (LOS) of 22.5 days (d). Of 29 Pts, 19 died. In the HC group, the total number of ND was 87 with a LOS of 9.5; 4 Pts died and 2 dropped out. For the OC group, the average outpatient cost was 2,792 and as inpatient, 16,600. Costs were 2,297 and 8, 596 respectively for HC group. The average cost per patient for health home care was 2,981. The total cost per patient was 19,392 in OC and 13,874 in HC. CONCLUSION: Preliminary data confirm a great difference in the economic costs for equivalent care. In our study, given the choice, 2 out of 9 Pts enroled preferred to die at home. This clearly demonstrates that by integrating OC and HC real benefits can be gained both in terms of economic cost and compliance of the patients. (Abstract by: Author).


Keywords: Home Care - AIDS/HIV/Home Care - Nursing/Aidsline. (JMCGowan)/A:/B:/C:/D:/Outpatients/Model/Treatment/Patients

Notes: 93335895 Sunnybrook Health Science Centre, University of Toronto, North York, Ontario, Canada. OBJECTIVE: To describe outpatient management of CMV disease in HIV infected patients. PROJECT DESCRIPTION: When a diagnosis of CMV is made, the implications are discussed with patient. After the patient agrees to treatment, and home care (provincially funded visiting nurses) is arranged, medication (ganciclovir or foscamet) with intravenous supplies are delivered to the patient’s home. The first dose is infused at the clinic to observe for any potential reactions and introductory teaching is done. Peripheral IV’s or Landmark catheters are used until Port-a-cath or Hickman insertion. Blood work is done twice weekly, in the home, for the induction period then once weekly for maintenance therapy. Subsequent infusions are provided in the patient’s home with the support of visiting nurses. Weekly Port-a-cath access can either be done in the home, by visiting nurses, or in the clinic. With total outpatient treatment our experience has shown a relatively low infection rate with indwelling catheters. (Abs. PoB 3889, 1992) RESULTS: Patients with CMV disease (retinitis, colitis, esophagitis) can be successfully treated at home, with intermittent visits to an
outpatient clinic, and the support of visiting nurses. CONCLUSIONS: Patients with CMV disease, dependent on intravenous medications, can be managed at home, maintaining a normal lifestyle and improved quality of life. (Abstract by: Author).

**Home Care Staffing:**

The sources in this group deal primarily with issues that arise from or relate to staff of home care services. Many of these sources relate to training issues and some to compensation. However, as this group has been divided, the first section primarily addresses itself to training, both pre-employment and continuing education of staff, training of informal caregivers and clients. The second section deals with the special staff-related concerns in Adult Day Care and Respite Care that are treated as components of home care throughout this bibliography. The third and fourth sections address the concerns of Nurses and Physicians, respectively. In the case of nursing, the label is restricted, almost exclusively, to registered or licensed nurses. Both sections address the roles of these professionals in home care, especially in the case of physicians. The final section deals with technology, largely the use of “high” technology, in home care. Included in the latter section are citations that deal with information technology as a tool for home care but one that places different demands on staff as well as on clients and caregivers.

**Havens, B.** (1995b). Long-Term Care Diversity Within the Care Continuum. *Canadian Journal on Aging* 14[Summer], 245-262.

**Keywords:** Home Care Canada/Long-Term Care/Continuum of Care/Canada/Financing/Funding/Health/Health Care/Model/Universal Health Care/State/Older Adults/Outside United States/Health Services/Public Policy

**Notes:** Discusses four major issues that are part of the diversity of long-term care within the continuum of care in Canada. Separate sections are devoted to each of the four issues: Identifying the continuum of care and placing long-term care within that continuum; characterising the diversity of long-term care; organising systems of care to maximise both diversity and universality; and discussing organizational, utilisation, and financing implications for this system. Long-term care owes its form, function, and funding to the principles and values inherent in the Canada Health Act, especially to the principle of universality; it also spans a broad range of very diverse services and occupies a pivotal location within the overall continuum of health and health care. Health care may be characterised as a dynamic series of interdependent processes and persons, with changes in one component of care affecting all other components. Long-term care is set in a social model of universal health care, which not only respects diversity but thrives on it. The current state of Canadian health care in general, and long-term care in particular, demands the skillful juggling of universality and diversity to maximise both without sacrificing either. In an atmosphere of reform and fiscal restructuring, the organizational, utilisation, and financing implications for this system are substantial. The challenges are to maintain a balance while securing a future.
system that is efficient, efficacious, equitable, effective, and empowering. (SW) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).

**Training Issues in Home Care**


**Keywords:** Home Care - Training/Training/Elderly/Elderly Care/Developing Country/Models/Funding/Roles/Workers/Social Workers/International/Family/ Human/Health/Physicians/Nurses/Aging/Model

**Abstract:** Developing countries are facing multiple problems in establishing and funding socio-medical services for the elderly. This study outlines the need for such services especially in the transitional stage of urbanisation, changes in the structure and role of families, and the inadequate resources for establishing community-based elderly care programmes. The study focuses on the analysis of human resource needs for training of the different categories of health workers, both educational degree and non-degree training for elderly care programs. It proposes an integrated approach for short-term training of physicians, nurses, and social workers. This concept was accepted and adopted by the Expert Group Meeting of the International Institute on Aging in Malta, 1989. The study also presents applications of this model in Romania, Barbados, and Kuwait.


**Keywords:** Home Care - Training/Physiotherapy/Roles/Elderly/Elderly Care/ Quality of Life

**Abstract:** The World Confederation for Physical Therapy has identified roles for physiotherapy in the care of older people. However, most African countries, like Nigeria are yet to come up with well-defined programmes for elderly care. A picture of the present status of older people in Nigeria is presented, based on available information. A few approaches are suggested towards getting physiotherapy to play a role in improving the quality of life of the elderly in Nigeria.


**Keywords:** Home Care - Training/International/Training/Elderly/Elderly Care/Embase/Therapy 0160/Economic Aspects 0139/Education and Training 0143/Priority/Geriatric Care/Physiotherapy/Developing Country/United Nations/International/cooperation/Health Promotion/Social Behavior/ Priority journal/Conference Paper

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Notes: AB- The World Confederation for Physical Therapy (WCPT) and the International Institute on Ageing (INIA), United Nations Malta, brought together for the first time 32 physical therapists, from 23 countries (of whom about a third came from the developing countries) in a training course in 1993.


Keywords: Home Care - Training/Geriatrics/Aged/Economic/Health/Health Care Need/Article/Health Care/Care

Abstract: In Malaysia the steady rise in the proportion of people aged 60 or more, and an awareness of their complex psychosocial, economic and health care needs, have led medical faculties to introduce geriatrics as an essential subject in their curricula. The efforts made in this field by the School of Medical Sciences of the Universiti Sains Malaysia are outlined in the present article.


Keywords: Home Care - Technology/Technology/Home/Home Care/Frail Elderly/Elderly/Training/Environment/Treatment/Home Health Care/Health/ Patients/Family/Assessment/AgeLine: Homecare/Home Care Agencies/Life Sustaining/Treatment/Medical Ethics

Notes: Examines implications of the use of life-prolonging technologies in home care for the frail elderly. Rapid expansion in the range of in-home technologies has served to both alter the home environment and the nature of treatment provided to the homebound elderly. Medical and communications technologies have been miniaturised and made portable. These technologies are becoming increasingly commonplace in the home, and in the province of concern and responsibility of staff employed by home care programmes. These staff are providing services to people who are older, more deteriorated, and increasingly dependent on others for life maintenance. Staffing, training, and organizational design issues for home health care providers are set forth. It is suggested that these providers must develop guidelines for dealing with potential ethical issues or conflicts, and that they may need to utilise ethics committees or similar governing bodies. In addition, the in-home personnel must enlighten patients and their families regarding access to and refusal of medical technology. An agenda for assessment and research is developed. (UH) (AgeLine Database, ©1991, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Training/Home/Home Care/Training/Home Care Agencies/New York/Elderly/Social Workers/Workers/Manager/Service Needs/Family/Case Management/Geriatrics/Community/Health/Assessment/Work/

Keywords: Home Care - Training/Roles/Home/Home Care/State/Aging/Workers/Home Care Workers/Wages/Employment/Benefits/Training/Support/Funding/Costs/Massachusetts/New York/Advocacy/AgeLine: Homecare/Careers/Service Delivery/State Agencies on Aging/Area Agencies on Aging/Para-professional Personnel/Labor Turnover/Productivity/Older Adults/United States

Notes: Reviews factors affecting worker availability in the home care field, discusses findings from efforts to address worker retention and recruitment, and considers the roles of state units on ageing in encouraging improvements in worker retention and recruitment. National labour estimates and reports from providers and state units on ageing (SUA's) point to a growing shortage of paraprofessional home care workers at prevailing wage rates. Five factors are consistently reported as affecting the employment decisions of home care workers: Low salaries, part-time employment leaving workers vulnerable to sudden cutbacks in hours, lack of fringe benefits, inadequate training and supervision, and poor career advancement opportunities. Several demonstrations have shown the effectiveness of improving worker retention and recruitment by increasing salaries, fringe benefits, and training, but few organized efforts have been made to increase productivity. Without the support of funding sources, agencies cannot afford the cost of increased salaries, improved benefits, special training, and other career incentives. There have been several successful initiatives to improve salaries and working conditions for home care workers. In Massachusetts and New York, broad coalitions of agency administrators, workers, unions, elder advocates, state
agencies, and elected representatives worked together to successfully pressure funders for increases in wages. Other approaches include training supervisors to be supportive of workers, improving the provision of field supervision to provide on-the-job support, and worker recognition efforts in the form of awards and recognition banquets. Options and roles of SUA’s and area agencies on aging are described, including such activities as advocacy efforts to help interested parties understand the effect of worker availability problems on service delivery. (WD) (AgeLine Database, © 1992, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Training/Aged/Developing Country/Training/ Costs Caregivers/Health Promotion/Caregiving/Health/Elderly/Quality of Life/Management

Abstract: At the start of the 21st century, 60% of the people aged 65 and over will live in developing countries. Consequently, training must be provided as quickly as possible to individuals who will be involved with caregiving activities, particularly for non-professional primary caregivers. This will contribute to the reduction of health care costs for the elderly and hence an increase in quality of life. Three main areas of focus are health promotion and disease prevention, acute care, and management of chronic diseases. Recommendations for this training program are discussed.-GH.


Keywords: Home Care - Training/Home/Home Care/Aged/Costs/Nurses/Nurses Aides/Nursing/Nursing Homes/Community/Workers/Family/Training/AgeLine: Homecare/Activities of Daily Living/United States/Older Adults/50+/Females/Middle Aged/Home Care Workers/Home Care Agencies/CostEffectiveness/Recruiting

Notes: Discusses one home care agency’s experiences employing middle-aged women as personal assistants to provide home care to individuals needing help with one or more activities of daily living (ADL’s). The high cost of other care options, such as live-in nurses aides, nursing homes, and retirement communities, is compared to the relatively low cost of hiring a personal assistant, at about $11-12 per hour, for as many hours as needed. Catalina In-Home Services in Tucson, Arizona, has found that women in their 50’s make the best personal assistants, in that they are usually prepared to stay with a client longer than a younger, more mobile worker, and that they often have a lifetime of homemaking and family management skills to draw upon. To ensure the availability of a reliable pool of qualified home care aides, Catalina created its own 150-hour training programme for certified nurses aides and a 60-hour training programme for personal assistants. (MM) (AgeLine Database, © 1996, American Association of Retired Persons, all rights reserved).

**Keywords:** Home Care - Training/Work/Home/Home Care/Workers/Sweden/Health/Relative/Risk Factors/Female/Support/MED92-1.(IMCGOWAN)/A:/B:/C:/D:/Relatives/Females

**Notes:** 96096337 National Institute of Occupational Health, Division of Work and Environmental Physiology, Solna, Sweden. **OBJECTIVES:** To describe the nation-wide occurrence of work related musculoskeletal injuries among all home care service workers in Sweden, and to identify relative risks and risk factors of the injuries. **METHODS:** The study was based on work related injuries reported to the Swedish occupational injury information system in 1990-1. The work related musculoskeletal injuries were divided into overexertion accidents and musculoskeletal diseases. The incidence of the injuries in female home care service workers was compared with those in nursery school workers and all other employed women in Sweden. **RESULTS:** In home care service workers, the annual incidence of injury from overexertion accidents and musculoskeletal diseases were 19.2 and 15.1 per 1000 workers, respectively, which was higher than those in nursery school workers and all employed women in Sweden. For five injury locations including the back, all the age standardised relative risks (SRR) of overexertion accidents exceeded 4.0, and most of those for musculoskeletal diseases were 1.5 or more in home care service workers compared with all other employed women in Sweden. Total duration of sick leave due to overexertion accidents was 7.7 times, and musculoskeletal diseases 3.5 times, longer than in nursery school workers. National loss due to sick leave resulting from only musculoskeletal injuries in home care service workers was about 8.2% of the total work related sick leave in all employed women in Sweden, although the number of home care service workers represented only some 5% of this population. Lifting other people was most frequently reported as the main risk cause of overexertion accidents in both kinds of workers. **CONCLUSIONS:** The results support the hypothesis that home care service workers have higher annual injury incidence of musculoskeletal injuries than nursery school workers due to physically stressful tasks that are far less common in nursery school workers.


**Keywords:** Home Care - Training/Home Care - Caregivers/Workers/Home/ Home Care/Hospitals/Funding/United States/State/Health/Human/Model/Frail Elderly/Elderly/Training/Work/Careers/Employment/Interview/AgeLine: Homecare/Models/Home Care Workers/Home Health Care/Paraprofessional Personnel/California/Home Care Agencies/Program Description/Labor Turnover/Homemaker Services/Program Evaluation/Outcomes/Educational Programs/Career Development/Career Education

**Notes:** Describes a consortium of home care agencies developed to recruit, train, and place home care workers and to develop retention strategies. In 1992 the
Senior Care Network of Huntington Memorial Hospital in Pasadena, California—with funding from the United States Department of Health and Human Services, Administration on Aging—established a consortium that included a diverse group of home care agencies. A major project goal was to develop and test a multi-agency model that would provide a pool of qualified workers to serve frail elderly in their homes. The programme developed a three-stage training programme that began with a free 60-hour entry-level course focusing on homemaker tasks and skills, followed by a 60-hour block of paid work experience with home care agencies. To extend the career ladder, stage three provided an additional 72 hours of training for state home health aide certification. In return for training, applicants were asked to sign a six-month commitment to work for the consortium agencies. Eighty percent of those who started the entry-level class completed it. However, between one-third and one-half of the graduates never applied for the paid experience. Out of 120 entry-level graduates, 30 earned certification. Successful strategies for securing employment of new graduates are discussed, including assisting them with applications. The best retention strategy was giving employees as much work as they wanted, although this was difficult for agencies with fewer referral services. The consortium structure proved workable as a way to increase the number of home care workers and improve the quality of home care. Although the attrition rate between interview and graduation was 70 percent, 44 percent of those who became employed were still working for their agencies at project end. (TS) (AgeLine Database, © 1994, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Training/Home/Home Care/Aging/Training/Health/South/Follow Up/Support/Workers/Patients/AgeLine: Homecare/United States/ Older Adults/Ageism/Home Care Workers/Age Stereotypes/Attitudes Toward Aging/Knowledge of Aging/Knowledge Level

Notes: Investigated the facts, myths, and biases about ageing held by home care aides (HCA’s) before and after a 1-hour training session on ageing issues. A sample of 103 HCA’s (mean age 45.3) from four home health agencies in upstate South Carolina completed the 25-item Palmore Facts on Aging Quiz 1 (FAQ1) prior to a 1-hour training session on ageing issues and the 25-item Palmore Facts on Aging Quiz 2 (FAQ2) at the end of the session. The mean score on FAQ2 was significantly higher than on FAQ1, and frequent misconceptions were identified on 11 FAQ1 items and 3 FAQ2 items, indicating a significant improvement in knowledge concerning ageing issues as a result of the training session. The age bias measure decreased from FAQ1 to FAQ2, but the resulting net score indicated a net anti-age bias. Sixty-one of the HCA’s attended a follow-up discussion group and indicated a need and desire for increased training in specified areas as well as a need and desire for more supervision. Results support the need to assess health care workers’ knowledge and beliefs about older patients and the value of training to correct misconceptions. (MM) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).

Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Home Care - Training/Development/Dementia/Family/Health/Benefits/Job Satisfaction/Occupational Therapist/Personal Care/Functional Ability/Management/Training/AgeLine: Homecare/Alzheimer’s Disease/Respite Care/District of Columbia/Program Description/Occupational Therapy/Home Health Care/HOMEMAKER Services

Notes: Describes the development of an in-home activities program for the demented home care client. AL-C*A*R*E is a program in Washington, D.C., that provides comprehensive home care services to individuals with Alzheimer’s disease and other forms of dementia, and their families. The homemaker-home health aides’ primary responsibilities are to provide supervision and companionship to clients whose responsiveness may be quite limited but who often have few personal care needs. Consequently, the professional staff found it necessary for the aides to develop new skills in order to utilise their time to the benefit of clients and to their own job satisfaction. An occupational therapist was selected to introduce the concept of an in-home therapeutic activities programme that included dancing, playing music, engaging the client in reminiscence, and exercising. However, staff resistance was strong, as they were oriented toward performing traditional personal care tasks. Therefore, monthly meetings were held with the aides, at which time staff elaborated on the three potential benefits of the programme: to help maintain functional abilities, to improve care management by offering a pleasant distraction, and to develop positive relationships. Once resistance was overcome, it was possible to proceed with the actual training portion of the programme. So far, responses from clients and families to the program have been favourable. (WD) (AgeLine Database, ©1984, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Training/Home/Home Care/Roles/Inteviews/Home Care Workers/Workers/Health/New York/Female/Satisfaction/Family/Work/Home Care Agencies/Development/Training/Support/AgeLine: Homecare/Females/Job Satisfaction/Interpersonal Relations/Paraprofessional Personnel/Caregivers/Attitudes/Older Adults/United States

Notes: Studied the role of interpersonal relationships in paraprofessional home care. Interviews were conducted with 487 home care workers (both health aides and attendants) working with agencies in New York City. The workers (mean age 45.3, 97.1% female) discussed the characteristics of their clients, their jobs, and the nature and extent of both job satisfaction and job-related strain. A six-item Worker-Client Affectivity Scale was used to measure the degree of positive affectivity in the caregiving dyad and the extent to which workers felt accepted by their clients. Family-worker relationships and overall job satisfaction were also assessed. The respondents rated the degree of compatibility with their clients very highly. More than three-quarters of respondents indicated that they were able to
spot problems before they became serious for the client. Almost three-quarters of
the workers favourably described their relationships with the clients' families, and
more than 80% found families to be very or somewhat helpful. One-third of
respondents indicated that they worked extra hours without pay for reasons such as
lateness of a relief worker, reluctance to leave work unfinished, or sympathy for
the client. A chronic complaint emerged in small group discussions: many
workers felt clients’ families treated them as maids. It is concluded that the
relationships that home care workers develop with their clients and their families
are a rewarding part of their day-to-day work experience. Positive relationships
enhance both client care and job satisfaction. Home care agencies should foster the
development of these relationships through appropriate training, supervision, and
support. (UH) (AgeLine Database, ©1993, American Association of Retired
Persons, all rights reserved).

Clients and Their Workers: Implications for Quality of Care. Gerontologist
31[August], 447-456.

Keywords: Home Care - Training/Home Care - All Ages/Home Care/Workers/
Quality of Care/Health/Personal Care/Interviews/Home Care Workers/Family/
Central/Perception/Employer/Manager/AgeLine: Homecare/Home Health
Care/Client Relations/Care Receivers/Interpersonal Relations/Reciprocity/
Aging Service Personnel

Notes: Examined the nature and quality of relationships between home care
clients and their paraprofessional workers—that is, home health aides,
homemakers, and personal care attendants. Interviews were conducted with 54
home care clients, 39 home care workers, and 14 family members. Responses
suggest that informality—or personal bonding—is a central feature of home care.
Most clients and workers described one another in personal terms, as friends or
like family; most clients confided in their workers; and most workers did extra
jobs—that is, beyond what they were assigned or paid to do according to
perceptions of both workers and clients. Four types of worker-client relationships
were identified: Personal, asymmetrical, formal, and collegial. Younger clients
were more likely both to have collegial relationships with their workers and to
report problems with worker performance. It is suggested that although informality
may be necessary for good home care, it may also be a problematic aspect,
increasing the risk of worker exploitation and decreasing the client’s control as
employer or manager of his/her own care. (WD) (AgeLine Database, ©1991,
American Association of Retired Persons, all rights reserved).

Kaye, L. W. (1986). Worker Views of the Intensity of Affective Expression
During the Delivery of Home Care Services for the Elderly. Home Health Care
Services Quarterly 7[Summer], 41-54.

Keywords: Home Care - Training/Workers/Home/Home Care/Elderly/Health/
Dependence/Home Care Workers/Support/Training/AgeLine: Homecare/
Management/Personnel/Emotions/Emotional Dependence/Homemaker Services/
Interpersonal Relations/Statistical Data
Notes: The intensity of home health worker-client affective relations was investigated from the perspective of home health agency staff. Twenty-four indirect service staff (e.g., programme supervisors and directors) and 67 direct service staff (e.g., homemakers and chore workers) from three home care programs were surveyed. Elderly clients were perceived by respondents to display greater degrees of emotional dependence on workers than workers displayed toward clients, although workers did express a certain amount of feeling for clients which did not diminish over time. Direct service staff demonstrated more expressive feeling than indirect service staff. Regardless of the nature of the service package the home care worker had been engaged to perform, elderly clients presented an intense set of additional expectations for affective and emotional support. Dealing with client-centred personal problems and family-related problems posed the greatest difficulties for both direct and indirect service staff. Implications for training home care personnel are discussed. (LS) (AgeLine Database, ©1987, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Training/Policy Middle East/Home/Home Care/ Elderly/Health/Health Status/Family/Costs/Relatives/Community/Organizations/ War/Training/Volunteers/Caregivers/Primary Health Care/Workers/AgeLine: Homecare/International/Egypt/Outside United States/Lebanon/Cyprus/Developing Nations/Older Adults/Health Services/Home Health Care

Notes: Discusses home care provisions and the health status of the elderly in eastern Mediterranean countries. The major concerns for the vast majority of families in the region are financial- the inability to bear the day-to-day living expenses and costs of medical care for the elderly. A number of countries in the region are exploring a system of providing financial assistance to families with elderly relatives to help them acquire part-time helpers from the community. The complementary efforts of governments, non-governmental organizations, religious bodies, and communities in the region strengthen the age-old tradition of keeping elderly relatives at home. For example, in Beirut, even in the midst of war, feeding programmes for the elderly and outdoor clinics continued to provide services. The concept of training community volunteers as informal caregivers for the elderly in individual homes is receiving increasing attention in the region. Primary health care is viewed as a powerful approach in bringing health care for the elderly to individual homes. The eastern Mediterranean regional office of the World Health Organization is incorporating its “Manual for Primary Health Care Workers in Health Care of the Elderly” into the training course of workers in these countries. (SW) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Training/Training/Support/Home Care/Aging/Elderly/
Replicated a previously developed American Indian home-care training programme at an American Indian college, as part of the National Eldercare Campaign to enhance services to American Indian elders. The National Eldercare Campaign, initiated by the Administration on Aging in 1991, is designed to increase public awareness of vulnerable elderly through educational efforts, organizational outreach, and coalition building at local, state, and national levels. A college-level home-care training programme originally developed during 1991-1992 at Salish Kootenai College in Pablo, Montana, was designed to provide students with occupational skills necessary for the direct provision of home care services to American Indian elders and to prepare them to take the Medicare certification exam. This curriculum replication effort extended the training programme, with some modifications, to the Fond du Lac Tribal and Community College (FDLTCC) in Cloquet, Minnesota. The FDLTCC curriculum included 100 hours of nursing assistant/home health training and 10 additional hours of cultural awareness workshops. On successful completion of this combined programme, each student had to pass State of Minnesota exams to be certified in both capacities. The replication effort at FDLTCC was documented through a post-training survey of programme participants at the end of the fall semester, 1994. Of the 76 students enrolled in the program, 72 successfully completed it. A majority of the respondents were satisfied with the programme. Most respondents (85%) are currently employed as home health care aides, long-term care aides, or both; of these, 81% found the work satisfying enough to continue working in the field. Overall, the FDLTCC programme made substantial progress in developing and extending gerontological curricula at American Indian colleges, and it is easily transferable to other community colleges. (SW) (AgeLine Database, ©1997, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - AIDS/HIV/Home Care - Training/Rural/AIDS/MDL/A:/B:/C:/D:/Care

Notes: 96924050 Nairobi. Fax: 254-2-243164. ISSUE: Community in Homa Bay and Suba District don't have knowledge about caring/counselling for HIV/AIDS. PROJECT: A home care counseling workshop was organized by WOFAK members to gauge their understanding in taking care of people with AIDS who are usually taken from urban areas to rural homes to die there when they are already weak. The training was carried out in the Homa Bay town of Kenya. The trainees were women group leaders drawn from the surrounding districts. They were mainly nurses, teachers, church leaders and farmers. These women were already working in their communities in various groupings. After a five day training, we asked the participants to demonstrate what they had learned in those five days in their own ways and they chose to do this in role plays. RESULTS: One month
after the training we had already received encouraging response from the community leaders who took responsibility of the groups. They informed us that they were already working with the community closely. After three months when we went for our follow up, each group had trained at least 500 people or more. People with AIDS were this time included in the groups and the fear and stigma which was associated with AIDS was history. The only problem they had was the training materials and care giver items like gloves and disinfectant. LESSON LEARNED: In HIV/AIDS care, we need to work closely with the community for they are the ones who know their people in terms of culture and customs well. Care should not be left to doctors alone. Training materials should also be translated in local languages. (Abstract by: Author).

Keywords: Home Care - AIDS/HIV/Home Care - Training/AID1.MDL/A:/B:/C:/D:/Home/Home Care/Care/Volunteers
Notes: 92401137 Norwegian Red Cross, Oslo. PROBLEM: Families all over the world care for people with HIV disease in the home. Where access to health services is limited, palliative care in the home is often the only care available. Teaching families to provide basic nursing care in the home increases the quality of life in people with illnesses such as chronic malaria, tuberculosis and HIV disease. PROJECT: Two Rwandan nurses train Red Cross volunteers to teach families basic nursing skills. In the five-day course they teach skills in nursing care, hygiene, and HIV prevention. After the course, volunteers return to their villages to teach these skills to their families. RESULTS: Seven Red Cross volunteers attended the first training. All seven passed the skills evaluation at the end of the course. In the three months after the course they visited a total of 56 families to teach about home care. Evaluation indicates that families feel they benefited from the volunteers’ training. The nurses continue to train new volunteers and provide follow-up visits for old volunteers. LESSONS LEARNED: Volunteers can be trained to teach about nursing skills to families caring for people with HIV disease in the home. This presentation will provide the course content, information about the impact of the volunteers in their communities, and identified unmet needs of the families. (Abstract by: Author).

Keywords: Home Care - Training/Family/Caregiver/State/Hospitals/Patients/Home/Caregivers/Training/HomeCare/Health/Model/Stress/MED92-1,(JMCGOWAN)A:/B:/C:/D:/Models
Notes: 96380737 Department of Behavioral Science, Pennsylvania State University College of Medicine, Hershey, PA, USA. Early hospital discharges, greater reliance on outpatient care, and the growing prevalence of chronic diseases has increased the demands on family members who care for patients at home. Family caregivers need information and training to insure that patients’ needs are met and that home care is co-ordinated with that of health professionals. We
propose a prescriptive problem-solving model for how care should be managed at home and for the kinds of information and training family caregivers should receive. The Prepared Family Caregiver model, which is summarised in the acronym COPE (Creativity, Optimism, Planning, and Expert Information), teaches family caregivers how to develop and carry out orderly plans which address both medical and psychosocial problems and are co-ordinated with care plans of health professionals. The model is based on extensive research on problem-solving training and therapy. It empowers family members and patients for coping with illness and can help to moderate caregiver stress.


**Keywords:** Home Care - Training/Elderly/Home/Home Care/Aging/Perception/Training/Assessment/Terminology/AgeLine: Homecare/Instruction/Learning/75+/Development/Psychological Aging/Home Health Care/Teaching Techniques/Patient Education

**Notes:** Summarises the implications of changes due to ageing that most affect the teaching of elders, and reviews basic principles to guide teaching and learning in the home care setting. Cognitive changes affect intelligence, perception, information processing and cognition, and response time; the variability among activities for age groupings 65-74, 75-84, and 85+ are shown. Sensory vision and hearing difficulties increase with age (almost 46% of those over 85 cannot read even with glasses and 25% cannot hear the normal voice). Cognitive processing research shows that the elderly need some adaptations, such as repeating information for the secondary memory to function and to increase information storage in long-term memory, associating new learning with prior knowledge to improve retention in the secondary memory, and providing cognitive training that uses relevant material for enhancement of problem solving and concept formation. Developmental tasks for the age groups over 65 are shown. Appendices include a learner assessment guide and a mental status examination, terminology for writing behavioural objectives (in the cognitive, affective, and psychomotor domains), and a sample care plan using these domains in teaching about the use of sublingual nitroglycerin tablets. Resource suggestions are listed. (AW) (*AgeLine Database*, ©1984, American Association of Retired Persons, all rights reserved).

**Adult Day Care and Respite Care Issues**


**Keywords:** Home Care - Adult Day Care/Home Care - Respite Care/Adult/Female/Family/Caregivers/MISED4.MDL(MEDLINE 1993-7:PRIMARY RESEARCH)/A:/B:/C:/D:
Notes: 94257833 Gerontology Research Centre, Simon Fraser University. This paper discusses a 1989 study of new admissions to 22 adult day care centres in British Columbia and compares it to similar studies in the U.S. The B.C. study investigated clients’ characteristics, reasons for referral to the centres, and why some referrals did not attend. Of the new admissions, 63% were female and 30% lived alone. Compared to those in American studies, B.C. clients were older and more likely to live with a spouse. The primary medical conditions of B.C. clients were related to diseases of the circulatory system. As for daily activities, 58% could not bathe without supervision and 43% required assistance with dressing. Some 37% were unable to prepare their own meals; 31% needed help with housekeeping and 62% with shopping. The proportion of clients with mental diseases (38%) was similar to that in American adult day care centres. The three most common reasons for referring clients to adult day care centres were: To assist those who were socially isolated; to give family caregivers some respite; and to give clients emotional help. Perceptions varied as to why referred clients did not attend: For continuing care staff there were psychosocial factors; for adult day care staff it was related to characteristics of the service delivery system; and clients themselves cited functional, physical and operational factors (e.g., problems related to hearing and vision, transportation or physical barriers).


Keywords: Home Care - Adult Day Care/Home Care - Respite Care/Disabled/Elderly/Home/Male/Female/Males/Dementia/Females/Volunteers/Survey/Household Composition/Living Conditions/Welfare

Abstract: This study investigated the effects of a day service centre on the physical and mental condition of the disabled elderly living at home, and clarified the factors which related to physical and mental effects after using the day service centre. Sixty-nine male and 141 female subjects (mean age: 79.5 years) were studied by questionnaire. Among males, the characteristics of “having a spouse” and “dementia” occurred with significantly greater frequency than among female subjects, while the prevalence of “more advanced age” and “three-generation household” were significantly higher among females than males. The enjoyments at the centre for the elderly were baths and/or meals, and meeting and talking with staff members, volunteers and other elders using the day service centre. The survey found that the day service centre helped to improve the physical and mental conditions such as cleanliness and cheerfulness. The main factors related to physical and mental effects after using the day service centre were age distribution, household composition, degree of dementia and manner of bathing at the centre. From the results obtained, it was concluded that the day service centre provides the opportunity to improve actual living conditions and promote the welfare of the disabled elderly living at home.


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Keywords: Home Care - Adult Day Care/Home Care - Respite Care/Community/Geriatrics/Geriatric Care/South/Home Care/Home

Abstract: In most Western societies, and that includes the South African white society, the fastest-growing cohort in the population is the geriatric one. The implications of this population explosion are many. Of particular concern to the medical profession, however, is the provision of medical care facilities to cope with the expected demands. The first proposal is to provide a co-ordinated home-care programme in an attempt to keep the elderly functional at home. This concept comes with a variety of advantages.


Keywords: Home Care - Adult Day Care/Home Care - Respite Care/Development/Community/Community Care/Home/Ambulatory Care/Hospitals

Abstract: The aim of this project is to establish an ambulatory and semi-ambulatory community care centre for the elderly. We intend to keep the elderly in their own homes for as long as possible while at the same time minimising the cost of caring for them, maintaining their autonomy, and permitting them to live and die with dignity in their own homes. The present paper outlines the principles of organising this new institution and its working conditions.


Keywords: Home Care - Adult Day Care/Home Care - Respite Care/Dementia/RespiteCare/Caregivers/Health/Patients/Adult/Child/Care/Activities of Daily Living/Personal Care/High Risk/Nursing

Abstract: In the studies on the effects of temporary institutional respite (TIR) published to date, a slight reduction of subjective burden has been established. The hope that this form of respite care might have a positive effect on the activities of daily living or on the health of the care recipients has not yet been confirmed. A considerable deficit in the methodology applied might be a reason for this. There is no denying the fact that there is a clear need for respite services, particularly because every seventh person providing care for a dementia patient requiring personal care, belongs to a high-risk group that is characterised by serious reduction in his or her physical health and psychological well-being. TIR is primarily utilised by adult child caregivers (daughters and daughters-in-law) affected by high subjective burden who are providing care for dementia patients with extensive nursing needs.


Keywords: Home Care - Adult Day Care/Home Care - Respite Care/Respite Care/Dementia/Patients/Caregivers/Canada/Nursing Homes/Home/Caregiver/
MEINT/.MDL (MEDLINE 1966-92)/A:/B:/C:/D:/Manitoba/Nursing/Nursing
Home/Care
Notes: 90027402 University of Manitoba, Winnipeg, Canada. The impact of a
respite programme on the cognitive and physical functioning of dementia and non-
dementia patients, and on the burden perceived by their caregivers, was assessed in
a pre-test/post-test design. A total of 55 caregivers were interviewed twice, five
weeks apart. In the respite group, the caregiver's patient experienced a two-week
respite stay in a nursing home during the five-week interval, whereas in the
waiting-list comparison group, the patient experienced ongoing in-home care
during the interval. We hypothesised that patient diagnosis (dementia vs. non-
dementia) would interact with respite exposure, with non-dementia patients
showing more improvement from respite than dementia patients. Regardless of
diagnosis, however, positive effects from respite exposure were found for
caregiver reports of the patient's memory and behaviour.

Cox, C. (1997). Findings From a Statewide Program of Respite Care: A
Comparison of Service Users, Stoppers, and Nonusers. Gerontologist 37[4], 511-
517.
Keywords: Home Care - Adult Day Care/Home Care - Respite Care/Respite
Care/Care/Caregivers/Health/State/Relative/
Abstract: This study compared respite users with stoppers and nonusers in the
Health Resources and Services Administration-funded Alzheimer's disease
demonstration grant in the State of Maryland. Of those accepted into the
programme, only 54% participated for at least six months. The primary reasons for
stopping were the death or institutionalization of the relative, while those not using
respite services felt they didn't really need them. Determinants of programme use
included the poorer cognitive status of the relative and less anxiety and greater
burden among the caregivers. After six months, users reported fewer hours of
informal assistance, less burden, and that the relative had fewer behavioural
problems although cognitive status and activities of daily living (ADL's) had
deteriorated.

Related To Fatigue of In-Home Caregivers Who Utilize Temporary Nursing Home
Assistance]. [Japanese]. Nihon Kango Kagakkai Shi [Journal of Japan Academy of
Keywords: Home Care - Adult Day Care/Home Care - Respite Care/Caregivers/
Home/Nursing Homes/Respite /MESED3.MDL (MEDLINE 1993-7:PRIMARY
RESEARCH)/A:/B:/C:/D:
Notes: In order to understand the fatigue of in-home caregivers of the elderly
and the remedial effects of temporary nursing home assistance (i.e., "respite care
service"), pre- and post-service surveys were conducted on the Cumulative Fatigue
Symptoms Index (CFSI) of 34 in-home caregivers who use the respite care service
offered by a nursing home in Shizuoka, Japan. The results of these two surveys
are as follows: 1.) The physical fatigue of caregivers before using the respite
service is higher, and caregiver's free time is related to their feelings of fatigue. 2.)
According to CFSI figures, chronic fatigue, general fatigue, anxiety, depression (p
< 0.01), and irritability caused by excessive workload and reduced vitality (p < 0.05) were significantly reduced by the services given. 3.) Twenty-seven caregivers, or 79% of the sample, showed some improvement, while the remaining seven caregivers (21%) showed none. 4.) Factors which may have affected the degree of fatigue recovery were shown, including reasons and days for using the respite service.


**Keywords:** Home Care - Adult Day Care/Home Care - RespiteCare/Home/Home Care/Volunteers/Caregivers/Frail Elderly/England/Community/Roles/Program Description/Interview/AgeLine: Homecare/Outside United States/United Kingdom/Social Services/Older Adults/ Respite Care/Informal Support Systems/Program Evaluation

**Notes:** Describes a successful volunteer support program for caregivers of the frail elderly in York, England, including advice for establishing such a program elsewhere. The primary focus is to describe the experience of “In Safe Hands”, a scheme organized by Age Concern York to meet the relief and respite care needs of wives, husbands, daughters, and sons who support the frail elderly people in the community, as well as meet the care needs of the elderly themselves. The book is designed for a wide range of readers, including planners of service delivery, and it discusses, at a more strategic level, how services can be designed to meet the needs of informal caregivers particularly when such respite service initiatives use volunteers. The guide discusses the following topics: The primacy of relief care for supporters of elderly people and the challenges presented in meeting their needs; the range of approaches to home care relief (respite) and the role of volunteers in England; a programme description of “In Safe Hands” over a seven-year period from 1981 to 1987; a description of the establishment of the programme, including key policy and practice issues; a description of the organizer’s role; perspectives of the frail elderly and their caregivers; and approaches to monitoring and evaluating the programme’s success. An appendix includes the results of an evaluative study carried out between October 1987 and September 1988 that included retrospective interviews with key individuals in setting up the scheme, participant observation, and a survey of frail elderly and their caregivers involved in the program. (TS) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).

**Nurses in Home Care**


**Keywords:** Home Care - Nursing/Assessment/Nursing/Rehabilitation/ Noninstitutionalized Elderly/Long Term Care/Long Term Care Insurance/Patients/ Nurses/Health/Health Status/Disability/Embase/Asia 0407/Mammal 0738/
Human 0888/Major Clinical Study 0150/Aged 0019/Article 0060/Aging/Health Service/Elderly Care/Nursing Home/Japan/Human/Major Clinical Study/Aged/ Article/Visiting Nurses

Notes: AB-The author assessed the potential need for visiting nursing and rehabilitation services on a national level to estimate the volume of services expected for Japan’s proposed new long-term care insurance. Baseline data were obtained from the national survey on free-standing visiting nursing stations conducted in September 1994, in which the population of 18,500 patients was professionally assessed by visiting nurses. The baseline data were then applied to the national sampling survey on households conducted in June 1992, in which respondents self-reported their activities of daily living (ADL) and health status. There are estimated to be 836,000 non-institutionalized elderly with disability. Their need for visiting nursing and rehabilitation services is expressed as 48.26 million visits or 57.33 million working hours annually. Current service volume accounts for only 5% of the potential need, suggesting a sharp rise in demand once the new insurance is fully implemented.


Keywords: Hospitals/Home Care - Nursing/Community/Family/Caregivers/ Minnesota/Nursing/Hospitalization/Health/CommunityServices/Patients/ Functional Ability/Home/Home Care/Visiting Nurses/Nurse/MESED3.MDL

Notes: 94284426 University of Minnesota, School of Nursing, Minneapolis 55455. Early identification of elders who need care following hospitalisation might enhance their health and the health of family members who help them with managing their care. The purpose of this study was to: 1.) Identify pre-discharge predictors of resource use following hospitalisation; 2.) describe the formal community services used by elders and their family caregivers during the two weeks following hospitalisation; and 3.) determine whether there is a difference in hospital re-admissions between elders who receive community nursing services compared with those who do not receive any services. The sample consisted of 185 elder/caregiver dyads in which the elders were hospitalised for an acute episode of a chronic condition. Both patients and family caregivers were interviewed before discharge and two weeks post-discharge. The findings indicate that pre-discharge functional ability and age are statistically significant predictors of home care services used two weeks post-discharge. The findings also suggest that elders who receive visiting nurse services are less likely to be re-admitted to the hospital.


Keywords: Home Care - Nursing/Nurses/Home/Home Care/Home Health Care/ ealth/Hospitals/Patients/Hospital Physician/Physicians/Nursing/United States/ State/Family/Nurse/Health Insurance/Roles/Transportation/AgeLine: Homecare/ Hospital Services/Taiwan/Post Hospitalization Care/Taxis/Program Description/ Older Adults/Outside United States
Notes: Describes a home health care service for Taiwanese elderly known as the taxi nurses programme. Instituted by a private hospital in 1976, the programme serves patients discharged from the hospital. To be eligible, patients must have been hospitalised, be referred by a hospital physician, need nursing services, and live within a 30-minute commuting distance from the hospital. Hospital-based home care nurses provide skilled care similar to the services provided in the United States, with the family providing for all needs related to feeding and hygiene. Services are provided according to an individualised nursing care plan, and the nurse often visits the patient and family in the ward before discharge. Because health insurance is rare, services are either paid for by the patient or family or are charity care. In 11 years, the program has served 270 middle- and upper-class patients whose average age is 70 years. While the programme is similar to home care programmes in the United States in terms of services provided and the role of the nurse, it differs in terms of payment mechanisms and transportation. The use of taxis for transportation for the nurses is unique to the Taiwanese program. (CM) (AgeLine Database, ©1988, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Nursing/Nursing/Canada/Nurses/Economic/Health/Treatment/Family/Symptoms/Adjustment/Quality of Life/Ambulatory Care/Case Management/Home/Home Care/Organizations/CANCER93.(JMCGOVAN)/A:/B:/C:/D:

Notes: 97624511 Ordre des infirmieres et infirmiers du Quebec, 4200 Dorchester Blvd. West, Montreal, Quebec, Canada H3Z 1V4. The greatest challenge facing oncology nurses over the next two decades will be to maintain sufficient quality of care and services in a context of change occasioned by scientific and technological advances, economic constraint and the evolving health needs of the cancer-afflicted population. Nurses’ clinical contribution in the various stages of intervention will include specific activities in prevention, detection, care and treatment, as well as support services to users and their families, education and research. Symptom management, pain control, social adjustment and quality of life are among the paramount concerns for nurses working with this clientele. As regards management, given the shift toward ambulatory care, nurses will take the lead and collaborate with other care providers in ensuring proper case management of clientele (both those hospitalised and those receiving home care) with the goal of improving both the organization and the efficiency of care and services.


Keywords: Home Care-Nursing/Patients/Treatment/Nursing/Assessment/Family/Roles/Nurse/Nurses/Home/Home Care/MEINT2.MDL (MEDLINE 1993-7)/A:/B:/C:/D:/Management/Care/Technology/Health Care

Notes: 96088164 Peripheral artery occlusive disease affects approximately 12% of the population. The evolution of vascular surgery and technologic advances has provided relatively safe and effective treatment regimens for patients with
Peripheral artery occlusive disease. Vascular surgeries, including carotid endarterectomy, repair of abdominal aortic aneurysm, femoral artery surgeries, thromboembolectomy, and amputation are common surgical interventions performed routinely in many operating rooms. Technologic advances have provided for the success of surgery on occluded arteries. Perioperative nursing care of the patient involves a thorough understanding of the progressive nature of the disease, surgical intervention as palliative, available technology to assist with assessment, and patient and family coping mechanisms. The role of the nurse in caring for patients with peripheral artery occlusive disease spans the health-care continuum from acute care to chronic care. Perioperative, postanesthesia, and intensive care nurses focus on acute care associated with surgical intervention. Practitioners in the rehabilitative and home care arenas must find innovative methods to educate patients and families to become independent and active participants in their care. [References: 33] [Review].


**Keywords:** Home Care - Technology/Home Care - Nursing/Community/Nurses/Home/Health/Canada/Treatment/Patients/Family/Nursing/Economic/Disabilities/Home Care/Home Care Agencies/Support/MEINT2.MDL (MEDLINE 1993-7)/A:/B:/C:/D:/Assistive Devices

**Notes:** 96284558 Sunnybrook Health Science Centre, Toronto, Ontario, Canada. In the late 1970’s, continuous ambulatory peritoneal dialysis was first introduced as a mode of treatment for patients with end-stage renal disease. Since that time many patients, themselves or with the help of family members, have routinely performed the therapy at home. There are now 2935 home peritoneal dialysis patients in Canada (36% of the total dialysis population). Today, however, the average patient on dialysis is likely to be older and have other complicating illnesses; moreover, patients may live alone, or have family members who are working. Over the past three years, through the use of innovative assistive devices and strong educational links with community nursing agencies, we have been able to manage peritoneal dialysis patients with complex needs in the home. We performed a retrospective analysis of 18 patients, with severe comorbid conditions, who were managed in the home with the help of community nurses. We will show that this is an economic, efficient, and effective method of caring for home dialysis patients with severe disabilities. Home care agencies need our support so that they can continue to help us manage the complex peritoneal dialysis patient in the 1990’s.


**Keywords:** Home Care - Nursing/Patients/Article/Home/Home Care/Nurse/MEINT2.MDL (MEDLINE 1993-7)/A:/B:/C:/D:/Nurses/Care

**Notes:** 96380665 Managing chronic pain in patients with advanced disease and a substance-related disorder is difficult. This article helps the home care nurse
identify these specific patients, understand their unique pain-management problems, and effectively manage these complex situations. [References: 25] [Review].

**Keywords:** Home Care - Nursing/Geriatrics/Nurses/Nursing/Nurse  
**Abstract:** The author gives a survey of the various forms of nursing available to elderly people in the district Ceske Budejovice, Czechoslovakia. He reports on the various activities of the geriatric nurse there and describes the operation of a nursing system for elderly people suffering from diabetes.

**Keywords:** Home Care - Nursing/Home/Home Care/Rural/Patients/Nurses/ CINAHL.(JMCGOWAN)/A/:B:/C:/D:  
**Notes:** 1997034993 Despite the fact that terminally ill patients are approaching the end-stage of their lives, the need for information and continuing involvement in their own care remains paramount and does not necessarily diminish as their dependency increases. This paper supports the view that nurses working in the area of rural palliative care are in an optimum position to establish the kind of relationship with patients and informal carers that augments a sense of involvement, self determination, equity and trust. This is of particular significance to rural palliative care where service provision may be under-resourced and where domiciliary nurses are often the key provider for continuing care and support. (24 ref).

**Keywords:** Home Care - Nursing/Home/Home Care/Medicare/Nurse/Nursing/ Patients/Transportation/Follow Up/Physicians/Physician Visits/Health/Family /Institutionalization/AgeLine: Homecare/Nurses/Instruction/Living Conditions/ Home Health Care/Visiting Nurses/Patient Care  
**Notes:** A home care nurse explains why it is not possible to limit her activities to the Medicare definition of skilled nursing care when the patient's basic needs are not being met by others. Several case examples are presented to illustrate the variety of non-skilled tasks that must be performed before skilled nursing care can be effective. Although in theory these tasks should be handled by someone else, in many instances referral would not be timely. For example, the purpose of the nurse's visit may be to monitor the patient's status and provide instruction on medication; however, the effectiveness of these measures would be questionable if the patient is soiled or without food if the heat has gone out. Other activities that the home care nurse may perform that do not meet the definition of skilled care include arranging transportation for follow-up physician visits, contacting the health department about unsanitary living conditions, rearranging furniture for easier access, spending extra time with lonely patients, and helping a family
recognize the need for institutionalization. (CM) (AgeLine Database, ©1987, American Association of Retired Persons, all rights reserved).

Keywords: Home Care - Nursing/Visiting Nurses/Nurse/Home/Home Care/ Home Care Agencies/Family/HS2REF.TXT/A:/B:/C:/D:/Nurses
Notes: 92282759 Visiting Nurse Association, Springfield, MA. Home care agencies and family members are confronted on a daily basis with ethical issues that have a strong impact on methods of operation and care. Where can they turn for guidance when these ethical dilemmas occur? An ethics advisory committee has proven an effective and powerful answer in a VNA setting. (Abstract by: Author).

Keywords: Home Care - Nursing/Geriatrics/Nurse/Home/Home Care/Nursing/ Development/Roles/Health/Health Care System/Physicians/Community/AgeLine: Homecare/Nurses/Case Management/Nurse Practitioners/Gerontological Nursing/Home Health Care/Interdisciplinary Team Care
Notes: Describes the challenges, stressors, and rewards of the geriatric nurse practitioner in home care. Reviews the history of home nursing care and describes its status today. Traces the development and specialisation of the geriatric nurse practitioner and provides a description of the role of the nurse in the home care setting, with emphasis on case management, linkages to the health care system, and provision of needed services. Describes wellness, preventive care, and care of elders with chronic illnesses. Discusses the role of the geriatric nurse practitioner in the collaborative process with physicians and as part of a multidisciplinary care team. Analyses the future implications of home care for the practitioner. Presents three case studies that illustrate a health maintenance programme for an elderly homebound woman, management of a chronic illness by a nurse practitioner in the community, and management of an acute illness. (CB) (AgeLine Database, ©1990, American Association of Retired Persons, all rights reserved).

Keywords: Home Care - Nursing/Health/Home/Home Care/Home Health Care/ Caregivers/Family/Nurses/Caregiver/Assessment/Patients/Treatment/AgeLine: Homecare/Health Promotion/Falls/United States/Older Adults/Home Care Workers/Visiting Nurses/Gerontological Nursing/Preventive Health Services/ Supportive Services/Intervention Strategies
Notes: Describes health promotion and disease prevention strategies for elderly home care recipients and their caregivers. Three levels of prevention are described and illustrated: Primary care to prevent disease, secondary care to curtail disease progression and restore health, and tertiary care to intervene in the process of active disease and promote optimal functioning. All levels of
prevention apply to the elder, the care provider, and family members. At the primary level, home care nurses should assess the primary caregiver and family members for potential health problems and review factors such as immunisation status, diet, and home safety. At the secondary level, periodic assessment of the caregiver’s health can assist in early diagnosis and prevention of secondary infections, complications from chronic disease, and organ decomposition and help maintain the caregiver’s ability to provide care. Most home care patients fall within the realm of tertiary levels of prevention activities—activities with the goal of achieving the highest level of functioning possible. Examples include respiratory therapy, maintenance of prescribed medications and treatments for cardiovascular diseases, use of antibiotics to combat infections, physical therapy to restore mobility, and wound care to promote healing. Nurses should include all three levels of services for the home care patient, the caregiver, and family members. (PH) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Nursing/Home/Home Care/FamilyPatients/Assessment/Nurse/Prescription/AgeLine: Homecare/Nurses/Prescription Drugs/Drug Use/Treatment Compliance/Intervention Strategies/Home Health Care/Nursing/Older Adults/United States/Home Care Workers

Notes: Discusses various types and causes of medication non-compliance in home care and presents some solutions that can be implemented in the home. Factors that affect drug compliance include, among others, financial difficulties, lack of understanding the medication regimen, poor cognitive function/poor literacy, presence of undesirable side effects, emotional problems, absence of support from family and friends, environmental difficulties, fear of administration method, vision/dexterity problems with packaging, and patients’ beliefs (or lack of) about their susceptibility to illness. Compliance assessment in home care should start with non-threatening discussions about the patient and others who help the patient manage the medications. Various solutions exist for non-compliance, such as tailoring the medication regimen to the patient’s lifestyle, using a “picture schedule”, using instruction/reminder sheets, using over-the-counter medication organizers, using calendar blister packs, and using a cap on the medication that indicates the next scheduled dosing interval. The home care nurse should carefully look at all the medications being taken, both prescription and over the counter, to assess the complexity of the regimen and assess factors that may be inhibiting compliance. (WD) (AgeLine Database, ©1992, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Nursing/Caregivers/Community/Caregiver/Nurses/Outcomes/Home/Home Care/Nursing/Nursing Homes/Assessment/Relative/
Functional Ability/MESED6.MDL (MEDLINE 1966-92: PRIMARY RESEARCH) A:/B:/C:/D:

Notes: 89279485 This investigation is a descriptive survey of 53 functionally impaired elderly who were receiving care from an informal caregiver as well as from professional nurses. The eventual outcome of care for the 53 subjects in terms of whether they continued to receive home care or entered a nursing home is also presented. Implications regarding the need for nursing assessments and interventions relative to functional abilities of elderly at home are presented.


Keywords: Home Care - Nursing/Home/Home Care/Nursing/Patients/Aged/
Health/Community/Nurse/Female/Family/AgeLine: Homecare/Nurses/Females/
Whites/Older Adults/United States/Home Health Care/Visiting Nurses/Service
Utilization/Duration of Institutionalization/Home Care Agencies/65+

Notes: Explored the influence of nursing dependency over and above sociodemographic factors and medical conditions on the use of home care nursing resources by elderly patients. A sample of 236 patients aged 65 and older (average age 77) who were admitted for nursing services to an official, certified home health agency participated in the study. Participants had a primary medical or surgical diagnosis and received at least one visit from a community health nurse (CHN) who consented in writing to participate in the study. The sample of elderly patients was predominately female (64%), white (84%), and not currently married (65%) but living with others (61%). Dependent measures included the total number of completed visits made to a patient during a single home care admission or re-admission episode. Independent measures included three categories: Sociodemographic factors, medical conditions, and nursing dependency. The latter included nursing problems, nursing care requirements, functional status, and family coping. Correlation analysis was used to explore the relationship among the dependent variables and between each independent and dependent variable. A significant relationship was found between the dependent variables, as more nursing visits were associated with more days of nursing care. A significant correlation was seen between each nursing dependency variable and number of visits and length of nursing stay. (TS) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Nursing/Home/Home Care/Nursing/Human/Health/
Follow Up/Infant/Nurse/Patients/Nurses/MESED1.MDL (MEDLINE 1993-7:
PRIMARY RESEARCH) A:/B:/C:/D:/Care/Demographics/Relationships/ Support
Notes: 97417974 Hope is an important concept to nursing. It is a powerful human response seen in every age group, across all demographic lines, and within all health care settings. Hope is a component of virtually every nurse-patient relationship developed in every field of nursing. Nowhere is the significance of hope more visible than in the home care setting. Whether it is a hospice visit or a postpartum follow-up visit with a new mother and infant, the home care nurse
instinctively searches for evidence of hope in the patient and his or her support system. Hope has long been recognized by nurses as not only valuable but also essential to health. [References: 35][Review].


**Keywords:** Home Care - Nursing/Outcomes/Nursing/Public Policy/Economic/Social Change/Family/Caregivers/Health/Social Status/Patients/Language Development/Article/Caregiver/Roles/Nurses/COSTM1.MDL/A:B:/C:/D:

**Notes:** 97332008 College of Nursing, University of Iowa, USA. More than ever before, caregiving has become a salient public policy issue. A number of recent and anticipated demographic, economic and social changes have occurred that make it imperative for researchers to critically examine the impact of caregiving on family caregivers' health, behaviour, emotions, and social status. Researchers at the University of Iowa College of Nursing are working to classify standardised nursing-sensitive patient outcomes for use in language development, practice, research, and education to evaluate the effectiveness of nursing interventions and clinical nursing services. This article focuses on family caregiving and the analysis of caregiver role performance in both direct and indirect care, linking outcomes and indicators, to enable nurses to promote the health of caregivers.


**Keywords:** Home Care - Nursing/Nurse/Caregiver/Stress/Health/Benefits/Home/HomeCare/Patients/Nurses/Caregivers/HS2REF.TXT/A:/B:/C:/D:

**Notes:** 93121450 Mercy Health Center, Oklahoma City, OK. The benefits of home care can carry a hefty price for the overburdened elderly caregiver, typically the patient's spouse, in terms of stress, deteriorating health, even burnout. The home care nurse can watch for warning signs and intervene to prevent situations that could endanger the caregiver and patient from escalating. (Abstract by: Author).


**Keywords:** Home Care - Nursing/Dementia/Nursing/Family/Health/MED92-1.(JMCGOWAN)/A:/B:/C:/D:/Service Demand/Gerontological Research/Research/Policy/Review

**Notes:** This paper explores the early experience of dementia when the veil of uncertainty that surrounds the diagnosis of this condition is lifted. Consideration will also be given to the impact of dementia on carers and the service demands that are created. In the UK alone there are estimated to be 636,000 people living with dementia, with this figure rising to just under 900,000 by the year 2021. In the USA the projected number of people with Alzheimer's disease is expected to be 9,000,000 by the year 2040. Despite a wealth of social and gerontological research on the impact of dementia upon family carers, service responses and policy initiatives are fragmented because dementia is excluded from some
important recent initiatives, such as the Mental Health Task Force. Current services and interventions focus predominantly on the later stages of dementia, when a meaningful perspective of the person with dementia is difficult to obtain. Nursing has a relatively long history of caring for people with dementia and their family carers. The paper will also consider the contribution of nursing and nursing research to the field and explore additional avenues for service intervention and education. [References: 207] [Review].


**Keywords:** Home Care - Physicians/Family/Caregivers/Home/Home Care/Chronically Ill/Caregiver/Roles/Care/MED66-1(JMCGOWAN)/A:/B:/C:/D:

**Notes:** 91285888 Family caregivers provide the majority of home care for chronically ill family members. Many times, family caregivers become overburdened when the responsibility for caring for a chronically dependent family member is added to other family and occupational responsibilities. Such overburdening is implicated in caregiver burnout. Caregiver respite is one way to decrease role overburdening. Humour is one type of respite that has been underused in primary prevention of caregiver burnout.

**Physicians in Home Care**


**Keywords:** Home Care - Physicians/Home/Home Care/Patients/Physicians/Hospitals/Family/Roles/Support/Treatment/Functional Ability/Environment/R0 rehabilitation/Disabled/Elderly/AgeLine: Homecare/Physician Patient Relations/Home Health Care/Caregivers/Assessment/Functional Assessment

**Notes:** Describes the responsibilities of the physician in overseeing home care of older patients. One of the responsibilities of the physician is to encourage hospital staff to share care responsibility with the family prior to discharge, allowing them to rehearse the roles they will play at home. Once at home, the physician can support the family in attempting to perform its major tasks of providing emotional support for the patient, making observations, providing physical assistance, performing household chores, participating in the treatment regimen, and calling for assistance. These functions are the backbone of successful family involvement in home care, even when “high-tech” procedures are being used. Periodically, the physician needs to assess overall functional ability in the home. Specific home visits for this purpose should incorporate a home care “review of systems”, exploring the adequacy of the home environment, the patient’s capabilities, the family’s ability, and the accuracy of medication administration. A sidebar by Marilyn A. Daly and Jay Portnow describes when to consider home rehabilitation for the disabled elderly patient. (WD) *AgeLine Database*, ©1991 American Association of Retired Persons, all rights reserved.)

**Keywords:** Ambulatory Care/AgeLine: Homecare/Physicians/Home Care/ Patients/Roles/Geriatrics/Benefits/Home Health Care/Level of Care/Environment/ Development/Training/Physician Visits/Housebound

**Notes:** Discusses the role of the physician as part of the geriatric home care team and outlines the benefits of home visits for elderly patients. Physicians have been conspicuously absent from home health care teams, although they have the potential to play an instrumental role in the co-ordination and leadership of home health care activities for homebound elderly patients. A great number of home care services are being made available to elderly patients. In order to authorise the appropriate level of care, the physician must know the patient as a person in the context of his or her environment and family. Ideally, the physician's role in home care involves development and review of the medical care plan through ongoing communication with the other members of the home care team. Lists ten indications for a home visit by the physician and describes types of valuable information that can be gleaned from a home visit that cannot be obtained during an office visit. Residents and medical students should be exposed to house calls during their training so that they will be equipped to meet this challenge in their future practices. (LS) *AgeLine Database, ©1988, American Association of Retired Persons, all rights reserved*.


**Keywords:** Ambulatory Care/Home Care/Patients/AgeLine: Homecare/Stress/ Organizations/Hospitals/Medicare/Medicaid/Legislation/Regulation/Home Care Agencies/Reimbursement/Home Health Care/Physician Services/Physician Education

**Notes:** Stresses the need for physician knowledge about home care services and for physician involvement in the planning and delivery of such services. Describes the recent expansion in home care. Suggests that the medical profession has remained isolated from home care because of the diversity of service programs and organizations that make up home care, the high-technology explosion that made hospital care more appropriate than home care, the increase in malpractice litigation, and Medicare and Medicaid legislation that did not adequately reimburse physicians for home visits. In the current fiscal and political climate, however, it becomes necessary for physicians to acquaint themselves with home care as a system of services to supplement the care they provide to patients in their offices and institutions. The medical profession needs to examine more carefully the qualifications and competence of those designing and implementing home care plans. Physicians also must become patient advocates to assure access to needed services as the home care industry comes under increasing regulation. Home care agencies probably will need to employ their own physicians, but new approaches to reimbursement are needed to encourage doctors to become active and involved participants in home care. (CM) *AgeLine Database, ©1986, American Association of Retired Persons, all rights reserved*.

**Keywords:** Home Care - Physicians/Long Term Care/Support/Frail Elderly/Elderly/MEINT2.MDL (MEDLINE 1993-7)/A:/B:/C:/D:/Long-Term Care/Care/Policy

**Notes:** 96016542 Johns Hopkins University School of Medicine, Baltimore, Maryland, USA. Non-institutional long-term care is a broad, poorly defined, rapidly developing field. The need for it, the technologic ability to provide it, and the amount of money spent on it are all growing. Reconciling the public’s reluctance to support social programmes with the inevitable overlap of social and medical needs in the care of the frail elderly presents a serious challenge in formulating policy. Medical directors of programmes in non-institutional long-term care will have to face governmental constraints and will be responsible for developing and implementing new policy in the future. [References: 15] [Review]


**Keywords:** Home Care - Physicians/Disability/Elderly/Geriatrics/Assessment/Patients/Disabilities/Mortality/Functional Assessment/Home/HomeCare Institutionalization/Follow Up/Disabled/Activities of Daily Living/Economic/Health/Health Status/Relative/MED66-1.(JMCGOWAN)/A:/B:/C:/D:

**Notes:** 91165842 Department of Medicine, Yale University School of Medicine, New Haven, Connecticut. PURPOSE: Although multi-disciplinary geriatric assessment of elderly patients has been shown to be effective in identifying new diagnoses and previously unknown disabilities and in decreasing hospitalisation and mortality, time and financial constraints prevent most internists and office practitioners from using this approach with their older patients. Several instruments to screen older persons for functional disability have been proposed, but there are limited data regarding their utility or effectiveness in clinical medicine. This study developed a short, patient-completed screening assessment instrument (the Functional Assessment Screen), compared it to a standard, multi-disciplinary geriatric evaluation, and determined the screening instrument’s ability to predict future use of home care services in a group of elderly patients. PATIENTS AND METHODS: The screening instrument was piloted retrospectively using data from patients seen in the previous two years at a hospital-based geriatrics clinic in Wisconsin. Using these results, a revised instrument was developed and mailed to 80 consecutive new patients who presented to the clinic for multi-disciplinary geriatric assessment and primary care. These patients were interviewed 18 months later to determine use of home services, institutionalization, and death after the initial visit. RESULTS: Fifty-eight of 80 eligible patients (72%) completed both the clinic evaluation and 18-month follow-up. The patients were an elderly (mean age of 76), frail (average of three medical diagnoses), functionally disabled group (dependent in an average of 3.7 instrumental activities of daily living and 2.7 activities of daily living). Nine of the 58 enrolled patients (15%) were institutionalized, five (9%) died, and 31 (53%)
required new home services after 18 months. The screening variables were sensitive but less specific than clinic providers’ judgement in identifying abnormalities in social, economic, or physical health status. The relative risk of eventual home service use was elevated in patients reporting poor health status (relative risk of 3.5, 95% confidence interval [CI] 9.9 to 1.2), and dependency in housework (relative risk of 3.0, 95% CI 5.1 to 1.7), shopping (relative risk of 2.6, 95% CI 4.7 to 1.5), meals (relative risk of 2.4, 95% CI 3.4 to 1.7), dressing (relative risk of 2.2, 95% CI 3.0 to 1.6), or bathing (relative risk of 2.2, 95% CI 3.2 to 1.5). Home services were used in 16% of patients with no positive responses to a subset of four of the screening questions; usage rose to 22% with one positive response, and to 89% (relative risk of 4.5, 95% CI 9.2 to 2.1) with two or more positive responses. CONCLUSIONS: This screening instrument identified a group of elderly patients at much higher risk for increased home service use than other patients in a geriatrics clinic. If validated in other populations, such an instrument may identify frail, elderly patients in office practice at high risk for use of home services. These patients could be targeted for more complete multi-disciplinary geriatric assessment to identify and treat disease and disability responsible for increased service use and declining health.


Keywords: Home Care - Physicians/Home/Hospitalization/Community/geriatrics/GeriatricCare/Assessment/Patients/Hospitals/Physicians/Nursing/Nurses/Family/Work/Health/Health Maintenance Organizations/Organizations/Ambulatory Care/Satisfaction/Economic

Abstract: The Home Hospitalization Programme was initiated in Jerusalem in 1991 to provide intensive medical care at home in order to prevent or shorten hospitalisations. The programme was based upon regular home visits by physicians, and nursing assessment to determine the need for regular nursing care. Primary-care physicians and nurses were re-munerated by a global monthly fee, and were on 24-hr call in addition to their periodic visits. Patients were recruited by senior geriatric physicians from acute hospital wards, as well as from the community, at the family doctor’s request. Ancillary services available to the home hospitalisation team included laboratory and electrocardiographic testing, specialty consultations, physical occupational or speech therapy, social work and home help up to 3 hr daily. Monthly visits by a senior physician provided oversight and further consultation. Home hospitalisation grew out of the continuing care division of the Clatic Sick Fund, a health maintenance organization providing umbrella medical insurance and ambulatory care. The programme grew synergistically with the other facilities of continuing care to encompass a network of comprehensive services to acute, sub-acute and chronic patients both at home and in institutional settings. In four years this network succeeded in establishing the focus of sub-acute intensive care in the community, achieving high levels of patient and family satisfaction, as well as striking economic advantages. In its first two years of operation home hospitalisation saved US Dollars 4 million due to reduced hospital utilisation, and preliminary data for
the subsequent two years indicated that this trend continued. Home hospitalisation became the hub of a far-reaching system of supportive, intensive and humane care in the community.

Technology, especially "High" Technology in Home Care


Keywords: Home Care - Technology/Home/Home Care/Costs/Benefits/Family/Caregivers/Patients/Stress/Support/AgeLine: Homecare/Home Health Care/Technology/Caregiving Burden/Home Care Agencies

Notes: Discusses issues home care agencies should consider when deciding whether to establish a high-tech program. Determination of the costs and benefits of high-tech home care is hampered by a lack of reliable data about the users of various high-tech options, the dollar costs to insurers and families, the effects on caregivers of providing high-tech care, and the appropriateness of the home as a setting for delivery of high-tech care. The most common types of high-tech home care are dialysis for patients with end-stage renal disease, antibiotic and chemotherapy with infusion pumps, ventilation, hydration, and enteral and total parenteral nutrition. A major factor in high-tech home care that requires further investigation is the additional stress on family caregivers of the introduction of high-tech care. Caregivers’ feelings of control and competency can be undermined when high-tech home care is introduced, and their lack of experience requires special attention if emergency situations should arise. The medicalization of the home associated with high-tech also can have negative effects on the quality of home life. Caregivers also may be reluctant to admit that they no longer can deal with the burden of high-tech home care, and they may become ill themselves. Because of the trend toward increased high-tech home care, action is needed on several fronts, including research and more immediate measures to provide support to caregivers. (CM) (AgeLine Database, ©1989, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Technology/Technology/Home/Home Care/Economic/Funding/Reimbursement/Costs/Cost/Containment/Savings/Regulation/Quality of Care/Medicare/Family/Health/Environment/Physicians/Patients/Treatment/Model/AgeLine: Homecare/Certificate of Need/Liabilities/Models/Home Health Care/Federal Regulations/Tube Feeding/Legal System/Medical Ethics/Life Sustaining Treatment

Notes: Presents the views of an interdisciplinary group of experts on the clinical, moral, psychological, legal, economic, organizational, and regulatory ramifications of high technology home care (HTHC). Provides a historical overview of high technology care in the home and identifies the major types of technology that now play a role—infusion therapy, monitors, and ventilators. Examines the issues of
funding, reimbursement, fraud and abuse, and cost containment, arguing that the emphasis on cost savings leads policymakers and practitioners to do "the right thing for the wrong reason". Presents the rationale for government regulation of HTHC and considers regulatory goals and modes of enforcement, quality of care, Medicare conditions of participation, certificate-of-need requirements, voluntary accreditation, professional certification, and standards for procedures and personnel. Discusses the ethical issues arising from changes in demography and family values, changes in the health care economic environment, and the emergence of new technologies. Looks at the legal liability of the various providers of HTHC--home health agencies, physicians, and direct care providers--and identifies common problem areas, such as inadequate staffing, inappropriate placement of patients, negligent transfer or discharge, improperly used or malfunctioning medical equipment, and patient's refusal of treatment. Addresses the psychological effects of HTHC on patients, family members, and providers, and presents a model for the practice of home intravenous therapy. Discusses U.S. Food and Drug Administration policies and practices for home use of high technology medical devices. Includes chapter references. (AY) (AgeLine Database, ©1992, American Association of Retired Persons, all rights reserved).

Champlin, L. (1989). Home Care Goes "High-Tech". Geriatrics 44[July], 83-86. Keywords: Home Care - Technology/Home/Home Care/Patients/Benefits/Physicians/Hospitals/Cancer/Patient Care/Treatment/Treatment Compliance/Caregiver/Home Care Agencies/Medicare/AgeLine:Homecare/Technology/Caregivers/Home Health Care/Post Hospitalization Care/Physician Patient Relations/Assistive Devices

Notes: Describes patient benefits, physician concerns, and insurance coverage issues related to the dramatic expansion of home care technology. The technology now includes computerised telemonitoring devices, total enteral nutrition, IU therapy pumps, and other equipment that once was reserved for hospital use. Patients who benefit from home care include those being treated for cancer, those recuperating from surgery, those suffering from chronic conditions such as diabetes or heart disease, those who require close monitoring, those who require IV antibiotic therapy, and those who depend on enteral or total parenteral nutrition. Despite the popularity of home care, many physicians are concerned about losing control of patient care, the adequacy of information they receive on patient conditions, and patient treatment compliance. To address these concerns, the physician should meet with the hospital discharge planner, patient or caregiver, and home care agency to discuss implementation of the home care plan. Currently, there are several insurance coverage gaps for home care, some of which will be closed when expanded home care and catastrophic benefits under Medicare begin taking effect in 1990. (WD) (AgeLine Database, ©1989, American Association of Retired Persons, all rights reserved).

Cummings, J. E. (1987). Innovations In Homecare. Generations 12[Fall], 61-64. Keywords: Home Care - Technology/Home/Home Care/Technology/Public Policy/Development/Death/Quality of Life/Treatment/Health/Costs/Cost

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Containment/Hospitals/Outpatients/Continuum of Care/Ageline: Homecare/Life Sustaining Treatment/Living Wills/Home Health Care/Attitudes Toward Death/Legal Rights

Notes: Describes recent home care innovations in three general areas: Technology, psychosocial factors, and organizational or public policy issues. Home dialysis was the first area in which advanced technology was used in the home. Other significant technological developments include home parenteral nutrition, home enteral nutrition, long-term antibiotic therapy, chemotherapy, respiratory therapy, and emergency response systems. Developments in the psychosocial arena involve the concepts of death with dignity, quality of life, the right to forego life-sustaining treatment, living wills, orders not to resuscitate, and the right to health care. The shift in public policy emphasis toward cost containment objectives also has had a major impact on home care, particularly with the increased emphasis on early hospital discharges, outpatient care, vertical integration of hospital systems, and the provision of a continuum of care. (LS) (Ageline Database, ©1988, American Association of Retired Persons, all rights reserved).


Keywords: Home Care - Technology/Home/Home Care/Health/Health Care System/Nurses/Patients/Technology/Family/Family Relationships/Nurse/
MEINT2.MDL (MEDLINE 1966-92)/A:/B:/C:/D:

Notes: 89234290 High-technology home care is a reality in today’s health care system. Nurses, as health professionals, will be involved in high-technology home care for many patients, regardless of age or diagnosis. The nurse’s involvement may be in the pre-discharge setting or in the home actually providing care. High-technology home care cannot and should not merely be care of the technology (the “machines and tubes”) at home; rather, it should emphasize the care of the patients and families who are receiving technically complex therapies. To provide care for the patient and entire family, all nurses involved with the patient need to be aware of where the patient and family are developmentally, the structure of family relationships, the expectations with regard to home therapy, and the ability of the patient and family to physically or emotionally manage the therapy. Incorporating this information into a care plan for patient and family teaching can enable the nurse to provide care to the patient and family that surpasses that of merely seeing that the high-technology procedure is done safely and correctly.


Keywords: Home Care - Technology/Home Care - Nursing/Community/Nurses/Home/Health/Canada/Treatment/Patients/Family/Nursing/Economic/Disabilities/Home Care/Home Care Agencies/Support/MEINT2.MDL (MEDLINE 1993-7)/A:/B:/C:/D:/Assistive Devices

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Notes: 96284558 Sunnybrook Health Science Centre, Toronto, Ontario, Canada.
In the late 1970's, continuous ambulatory peritoneal dialysis was first introduced
as a mode of treatment for patients with end-stage renal disease. Since that time
many patients, themselves or with the help of family members, have routinely
performed the therapy at home. There are now 2935 home peritoneal dialysis
patients in Canada (36% of the total dialysis population). Today, however, the
average patient on dialysis is likely to be older and have other complicating
illnesses; moreover, patients may live alone, or have family members who are
working. Over the past three years, through the use of innovative assistive devices
and strong educational links with community nursing agencies, we have been able
to manage peritoneal dialysis patients with complex needs in the home. We
performed a retrospective analysis of 18 patients, with severe comorbid conditions,
who were managed in the home with the help of community nurses. We will show
that this is an economic, efficient, and effective method of caring for home dialysis
patients with severe disabilities. Home care agencies need our support so that they
can continue to help us manage the complex peritoneal dialysis patient in the
1990's.

Implantable Narcotic Delivery Systems. Journal of Pain and Symptom
Management 6[6], 368-373.

Keywords: Home Care -Technology/Costs/Survey/Patients/Hospitals/Savings/
Treatment/MED66-1.(JMCGOWAN)/A:/B:/C:/D:

Notes: This survey compares costs of two commonly utilised implantable
narcotic delivery systems. The systems are classified into type-I (exteriorised
system using the DuPen epidural catheter) and type-II (implanted system using the
Synchromed pump). Costs were analysed by reviewing actual patient hospital
financial service records and Homecare vendor quotations. From the perspective of
cost analysis alone, we conclude that savings accrue when patients requiring
treatment beyond three months' duration are managed with a type-II implanted
system compared with a type-I system with an external pump.

Domiciliary Care of Tumour Patients. Cancer Treatment Reviews 22[Suppl A],
137-140.

Keywords: Home Care - Technology/Patients/Hospitals/Germany/Environment/
Adjustment/Treatment/Home/Home Care/Death/Support/Nursing/MEINT2.MDL
(MEDLINE 1993-7)/A:/B:/C:/D:

Notes: 96214075 Medical Division, St. Elisabeth Hospital, Ravensburg,
Germany. Patient-controlled analgesia (PCA) was administered in the domiciliary
environment in 143 pre-terminally and terminally ill tumour patients suffering
either from excruciating chronic pain or severe chronic/acute complex pain that
could not be relieved adequately by oral analgesia. Morphine solutions were
infused subcutaneously in concentrations between 1% and 3%. The intravenous
route was preferred in patients with indwelling catheters or those susceptible to
inflammatory skin reactions at the infusion site. After initial dose adjustment,
lasting 2-3 days, the morphine amounts infused by PCA reached a median of 93
mg day(-1) (range 12-464 mg day(-1)). The median was 28% lower than the median dose administered orally. A total of 84% of patients utilised the option of bolus self-administration. The median percentage administered via the bolus mode amounted to 5.3% of the total requirements. During the course of treatment, morphine requirements increased by a median of 2.3 mg day(-1) (range -29 +52 mg day(-1)). Most patients were treated continuously in the home care setting until death, the median duration being 27 days (range 1-437 days). The terminal morphine demands reached a median of 188 mg day(-1) (range 15-1008 mg day(-1)). PCA turned out to be safe and effective, attaining excellent results in 95 (66%) patients and satisfactory pain relief in 43 (30%). PCA proved to be insufficient in five (4%) cases. Side-effects were mild: constipation, fatigue, nausea and local inflammatory skin reactions occurred in 9%. Thus, with support from an experienced mobile nursing team, PCA can be safely administered in the terminal domiciliary care of tumour patients. PCA is superior to oral analgesia, especially in the treatment of severe oscillating pain. PCA provides adequate pain control in about 96% of patients who are poorly responsive to oral opioids.


Keywords: Home Care - AIDS/HIV/Home Care - Nursing/AIDSLINE.

Notes: 93335895 Sunnybrook Health Science Centre, University of Toronto, North York, Ontario, Canada. OBJECTIVE: To describe outpatient management of CMV disease in HIV infected patients. PROJECT DESCRIPTION: When a diagnosis of CMV is made, the implications are discussed with patient. After the patient agrees to treatment, and Home care (provincially funded visiting nurses) is arranged, medication (ganciclovir or foscarinet) with intravenous supplies are delivered to the patient's home. The first dose is infused at the clinic to observe for any potential reactions and introductory teaching is done. Peripheral IV's or Landmark catheters are used until Port-a-cath or Hickman insertion. Blood work is done twice weekly, in the home, for the induction period then once weekly for maintenance therapy. Subsequent infusions are provided in the patient's home with the support of visiting nurses. Weekly Port-a-cath access can either be done in the home, by visiting nurses, or in the clinic. With total outpatient treatment our experience has shown a relatively low infection rate with indwelling catheters. (Abs. PoB 3889, 1992) RESULTS: Patients with CMV disease (retinitis, colitis, esophagitis) can be successfully treated at home, with intermittent visits to an outpatient clinic, and the support of visiting nurses. CONCLUSIONS: Patients with CMV disease, dependent on intravenous medications, can be managed at home, maintaining a normal lifestyle and improved quality of life. (Abstract by: Author).


Keywords: Home Care - Technology/Home/Health/Patients/Home Care/ Caregivers/Work/COSTA.MDL/A:/B:/C:/D:
Notes: 95196297 Hurtado Student Health Center, Rutgers University. With the increasing numbers of AIDS patients in home care settings, professional caregivers will be required to provide home infusion and to help informal caregivers in enteral and total parenteral nutrition. The first thing all caregivers—both professional and informal—need to understand is how the infusion devices work and what pointers will help keep the patients healthy. (Abstract by: Author).


Keywords: Home Care - Technology/Patients/Environment/Home/Support/Home Care/Nursing/Costs/MED92-1.(JMCOWAN)/A:/B:/C:/D:

Notes: 97027280 Neurologisch-psychiatrischen Abteilung, Krankenhauses der Barmherzigen Bruder, Graz-Eggenberg. Due to the instability of their respiratory functions, patients suffering from ALS are potentially patients for permanent intensive care. The desire to provide care in the familiar environment at home on the one hand, and qualified professional support on the other hand, gives rise to the concept of ambulatory intensive care. This concept might be successfully implemented if one proceeds according to the motto: It is not the patient who is committed to technical facilities, but rather that the technical facilities ought to be committed to the patient. Home care, gastrostomy, tracheostomy, mobile suction drainage and the feasibility of home ventilation provide the groundwork for competent palliative medical care even in the bulbar form of ALS. Home care of such patients would be enhanced in terms of both security and quality if it were possible to have regular ambulatory check of the vital functions at intensive care units. In emergency cases, once their respiratory functions are stabilised patients could be discharged into home nursing after a short-term stay at the intensive care unit. Ambulatory intensive therapy would both serve to ease the burden of intensive care units in terms of costs and personnel, and to improve the life quality of patients 9704. Entry Week: 97042.


Keywords: Home Care - Technology/Family/Caregivers/Patients/Home/Nursing/Caregiving/Relative/Interview/Model/Relatives/Adult/Interviews/Technology/Depression/Roles/Stress/MESED4.MDL (MEDLINE 1993-7:PRIMARY RESEARCH)/A:/B:/C:/D:/Home Care/Models

Notes: 93391265 School of Nursing, Kansas City, KS 66103. This prospective study assessed the caregiving responsibilities and reactions of family members who provide home care to a relative who is dependent on total parenteral nutrition (TPN). A short, semi-structured interview based on the Roy adaptation model was used to gather data about the caregiving experiences of 20 relatives of adult TPN-dependent patients. Data were content analysed, and frequently occurring themes identified. Results indicated that altered family responsibilities as well as negative and positive psychologic reactions to caregiving do occur. The interviews suggested that caregivers master TPN technology but make little use of assistance.
from extended family or professionals. Although depression and fatigue were reported as common, these family members felt capable and successful in their caregiving roles. Further longitudinal research with larger samples should allow for comparison of caregivers on demographic differences, stress, and other variables pertinent to managing complex home care.


Keywords: Home Care With Informal Caregivers Of Dementia Sufferers/Home Care - Technology/Support/Home/Caregiver/France/Nursing/Ohio/Home Care/Elderly/Nurses/Caregivers/MED66-1.(JMCGOWAN)/A:/B:/C:/D:

Notes: 91282421 Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, Ohio. Computers have become ubiquitous in contemporary society, as has the demand for home care for the elderly. Caregiving is recognized as a normal experience across the life span, and nurses must develop innovative responses to support caregivers. Computer networks offer caregivers access to a wide range of services such as communication, information, and decision support. Presented here is an interim report of a randomised field experiment demonstrating the feasibility of computer networks as a mechanism for delivering nursing services to caregivers of persons with Alzheimer’s disease. Caregivers can and do use the computer network in home care.


Keywords: Home Care - Technology/Home/Health/Support/Management/Japan/Home Health Care/Technology/Development/Home Care/Work/Model/Physicians/Public Health/Nurses/Patients/State/MEINT2.MDL (MEDLINE 1993-7)

Notes: 96174342 Department of Medical Systems Management, Kagawa Medical School, Japan. The need for home health care has been increasing in Japan and the expectation is to apply advanced technology to home health care in order to promote it. We already studied the development of a home care support information system using a personal computer and a telephone set with multifunction. In the present study a new system using a new telephone terminal was developed in order to increase flexibility. To work out the concrete social system in the near future, a model of a PHD (Personal Health Data) management system was constructed and tested. Experimental studies were conducted by physicians and public health nurses. The model system would be useful for daily monitoring of home patients in the chronic stage of a disease and for dealing with their emergency states.


Keywords: Home Care - Technology/Community/Technology/Article/Support/
Elderly/Home/Institutional Care/Environment

**Abstract:** The article deals with a case report on the technology transfer of the Lifeline community social alarm system to Slovenia. The main reason the project was initiated is the ageing of the Slovenian population (11% of the population is 65 or over). With this system we intend to support the public's wish to allow the elderly to remain in their own homes for as long as possible instead of placing them in institutional care. Between 1992 and 1995 the following results were achieved: The acceptability of the system in the social environment was increased; a pilot control centre in Ljubljana was established and has been operational for two-and-a-half years; a national dissemination plan was prepared; the integration of the programme into other information systems has been started. One of the main conclusions is that for the successful transfer of a technology which also affects social values in society, a social innovation must support the process.


**Keywords:** Home Care - Technology/Rehabilitation/Netherlands/Environment/Support/Independent Living/Organizations/Social Welfare/Welfare/Elderly/Development/Home/Satisfaction/HS2REF.TXT/A:/B:/C:/D:

**Notes:** 93285758 Institute for Rehabilitation Research, The Netherlands. The percentage of senior citizens in the Netherlands will rise in coming years. The expected percentage for the year 2010 of persons over age 65 in the total population is 15%. More persons over age 65 than ever before will continue to live in their own environment. Emergency response systems (ERS) can support independent living. The most common type of organization distributing ERS is a small, partly subsidised local alarm organization run by a social welfare office for the elderly. Government subsidy has been reduced in recent years which has motivated small organizations to join together into larger regional organizations in order to get a more solid financial base. On the other hand new semi-commercial and commercial organizations have come into being. These developments are part of the growing importance of home care, leading to more medical applications of ERS. User satisfaction with ERS is high. Portable triggers can enhance the effectiveness of the system. However, many users do not wear the portable trigger when feeling well. Future technical developments will result in multi-functionality of ERS-devices. In the long term the hardware of today will be integrated in a multimedia home terminal replacing the telephone. The portable trigger will remain the only specific hardware at home for ERS. (Abstract by: Author).

**Component of the Health Care System:**

The final grouping in this bibliography includes a wide-ranging collection of sources within which home care is viewed as a component of some other part of the health care system. In the first section, home care is treated as a component of ambulatory care, followed by a section where it is seen as a component of community care. In both of these cases, home care is seldom well integrated within the larger portion of the system, whether ambulatory or community care.
The third section presents examples of home care as a component of hospital care. In this category, home care is usually tightly integrated into the hospital system, in fact in some cases, it is difficult to identify where hospital care ends and home care begins. The final section treats home care as a component of the overall health system as a part of health care planning.

**Ambulatory Care**


**Keywords:** Home Care - Adult Day Care/Home Care - Respite Care/Development/Community/Community Care/Home/Ambulatory Care/Hospitals

**Abstract:** The aim of this project is to establish an ambulatory and semi-ambulatory community care centre for the elderly. We intend to keep the elderly in their own homes for as long as possible while at the same time minimising the cost of caring for them, maintaining their autonomy, and permitting them to live and die with dignity in their own homes. The present paper outlines the principles of organising this new institution and its working conditions.


**Keywords:** Ambulatory Care/Physicians/Patients/Embase/Health Care Access/Perception/Drug Use/Brazil/Elderly Care/Interview/Prescription/Social Status/Health Care Utilization/Health Care Financing/Pharmacy/Multivariate Analysis/Model/Variance/Human/Male/Female/Aged/Article

**Notes:** CS-C.L. Kimberlin, Dept. Pharmacy Health Care Admin., University of Florida, Box 100496, Gainesville, FL 32610. CS- United States AB. This study examined physician and non-physician prescribed medication use of a growing segment of Brazilian society—the elderly. Personal interviews were conducted with 436 subjects in a stratified random sampling of elderly respondents to the previously completed 1990 Brazilian Old Age Survey (BOAS). The BOAS sample had been stratified according to the socio-economic status (SES) of three communities within Rio de Janeiro. This study focused on medication use of these subjects as a function of the predisposing, enabling, and need variables which have been found in previous research to predict other types of health services utilisation (HSU). The enabling variables of access to care were measured as patient perceived availability, affordability, and acceptability of both medical and pharmacy services. ANOVA results found differences among the different communities in perceived availability and affordability of medical and pharmacy services and acceptability of pharmacy services. Subjects from Santa Cruz, the lowest SES area, consistently reported lesser availability of services, more difficulties with affordability but greater perceived acceptability of pharmacy services than those from the highest SES area. Multivariate regressions modelling both prescribed and non-prescribed medication use for the three areas found that...
the access-oriented HSU framework was much more effective in explaining the variance in medication use for the lowest SES area (45% and 48% for prescribed and non-prescribed use, respectively) than for the highest SES area where only 16% and 18% of prescribed and non-prescribed medication use was explained.


**Keywords:** Ambulatory Care/Patients/Roles/Geriatrics/Hospitals/Embase/Epidemiology 0400/Diagnosis 0140/Therapy 0160/South and Central/Cardiovascular Disease, Epidemiology, Ep/Geriatric Care/Acute Heart Infarction, Diagnosis, Di/Acute Heart Infarction, Drugtherapy, Dt/Acute Heart Infarction, Epidemiology, Ep/Acute Heart Infarction, Surgery, Su/Acute Heart Infarction, Therapy, Th/Hypertension, Drug Therapy, Dt/Heartarrhythmia, Drug Therapy, Dt/Heart Arrhythmia, Therapy, Th/Argentina/UnitedStates/Mortality/Clinical Feature/Heart Muscleischemia/Artificial Heart Pacemaker/Coronary Care Unit/Confusion, Drugtheraphy, Dt/Coronary Artery Dilatation/Coronary Artery Bypassgraft/Angiocardiology/Human/Clinical Trial/ConferencePaper

**Notes:** CS-Hospital Italiano de Buenos Aires, Capital Federal, Buenos Aires CS-Argentina.


**Keywords:** AmbulatoryCare/Patients/Physicians/Hospitals/Training/Environment/Embase/Asia0407/Middle East 4071/Methodology 0130/Therapy 0160/Mammal 0738/Human 0888/Male 004 1/Female 0042/Major Clinical Study 0150/Normal Humans 0800/Adult 0018/Article 0060/Elderly Care/Home/Primary Health Care/Health Care Delivery/Saudi Arabia/Questionnaire/Hospital Physician/Health Care Personnel/Work/Stroke,Rehabilitation, Rh/Physician Attitude/Occupational Therapist/Osteoarthritis, Rehabilitation, Rh/Osteoarthritis, Therapy/Physiotherapist/Health Care Need/Human/Male/Female/Major Clinical Study/Normal Human/Adult/Article

**Notes:** CS-Dr. S.A. Al Shammary, Department Family Community Medicine, King Saud University, PO Box 2925, Riyadh 11461. CS-Saudi Arabia AB- The present study was conducted to examine the perception of participating physicians in hospital and primary health care (PHC) on the nature of illness that requires home visits, type and job description of health personnel that should make home visits and other prerequisites needed for successful home visits. A pre-designed questionnaire consisting of demographic and professional characteristics of doctors was sent confidentially to randomly selected PHC and hospital doctors during the period January to June 1994. The respondents were asked to give their opinion on the categories of health problems that necessitate home visits, job descriptions of various professionals needed and the prerequisites for the successful running of home visits. Three hundred and ninety-six PHC and 238 hospital doctors participated in the study. PHC doctors were younger, having more females and less qualified than hospital doctors. Both PHC doctors and hospital doctors gave priority to bed-ridden patients and lowest priority to mobile chronically ill patients.
PHC doctors were more keen on home visits than hospital doctors. More PHC doctors than their hospital counterparts would like nurses and health visitors to be involved in nursing procedures performed at home except when it comes to notifying doctors about patients' problems. In case of stroke more hospital doctors would like physiotherapists to be involved than PHC doctors and vice versa in the case of osteoarthritis. Most PHC doctors preferred occupational therapists involvement in training patients and the modification of their environment to lead independent lives. More hospital doctors than their PHC counterparts preferred afternoon sessions for home visits. The respondents' views in the present study can be made use of in establishing a home visit programme to the Saudi elderly in need of such services. In addition, the number, qualifications and responsibilities of the various professionals involved in the visit should be re-evaluated after adequate implementation.

Community Care


Keywords: Community Care/Nursing Homes/Funding/AgeLine: (Community Care NOT Home Care)/Long Term Care/United States/Older Adults/Home Care Agencies/Home Health Care/Community Services/Financing/Program Description/State

Notes: Describes the increasing legitimacy of community-based long-term care for the elderly. States that the popularity of community-based care, or home-based care, stems from the simple fact that people often prefer to stay in their own homes, their relatives' homes, or even in small group settings and receive periodic assistance than to live in a nursing home. Suggests that community-based care is also more economical than institutionalized care and therefore should be taken more seriously at the state and federal funding levels. Describes successful community-based care programmes funded at the state level in Wisconsin, Indiana, and North Dakota. (TS) (AgeLine Database, ©1995, American Association of Retired Persons, all rights reserved).


Keywords: Community Care/Training/Roles/AgeLine: (Community Care NOT Home Care)/Social Services/Assessment/Minority Groups/Funding/England/Housing Needs/Community Services/Supportive Services/Program Evaluation Asians/Outcomes/Caregivers/Noninstitutionalized Elderly/Institutionalized Elderly/Nursing Homes/Case Management/Older Adults/Outside United States/Managed Care

Notes: Investigates the relationship between the provision of community housing for the elderly and community care in Britain. The Community Care Act (CCA) implemented in 1993 has changed the nature of social service provision in Britain.
A team of researchers in Oxfordshire and researchers from the University of Humberside collaborated in a 15-month investigation of housing and community care in Oxfordshire. Empirical issues are explored, including database dilemmas and identification of housing needs, showing the problems with information collection for assessments of housing needs and the difficulties of enumerating ethnic minority elders. Problems faced by housing providers with community care provisions are examined, including issues of demand and supply, hidden housing needs, housing for ageing Bangladeshi people in Oxford, and access to housing and care options for older people. An information strategy is developed to help identify both community care and housing needs. Recommendations include the following: Better definition of "vulnerability" in relation to the housing of homeless or near-homeless people; joint training on the housing basis of community care assessment and management; encouraging sheltered housing as a community resource for minority groups; funding of extended housing management role in community care; and improved co-ordination of community care plans and housing investment programs. (TS) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


**Keywords**: Home Care With Elderly Clients/Community Care/Home/ Community/Long Term Care/Aged/United States/State/Home Health Care/Health/Nursing/Nursing Homes/Financing/Medicare/Medicaid/Health Services/Social Services/Income/Frail Elderly/Independence/Quality of Life/Caregivers/AgeLine: (Community Care NOT Home Care)/OlderAdults/65+/
Honoinstitutionalized Elderly/Home Care/Community Services/Public Policy

**Notes**: Discusses the evolution of and trends in home-based and community-based long-term care (LTC) for those aged 65 and older in the United States. The American LTC system is large and complex, consisting of informal care, formal home-based and community-based care (including home health care), and institutional (mainly nursing home) care. Home-based and community-based care includes a variety of services and financing streams, including Medicare home health care, Medicaid home health services, Medicaid home-based and community-based services, programmes and services under the Older Americans Act, state-sponsored social services, Supplemental Security Income payments, and a range of supportive housing arrangements. Data on the LTC system in the United States are available from national surveys, administrative records, inventories, state and local data systems, and demonstration programmes. Over the past decade, there has been significant growth in LTC databases, accompanied by major shifts within the LTC system; however, the system remains decentralised. The frail elderly want dignity and independence in the latter years, plus access to needed services and an acceptable quality of life. In policy terms, their caregivers and the taxpaying public continue to struggle to find the appropriate mix of public and private support to meet the needs of the LTC population. (AR) (AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved).

Keywords: Community Care/Health/Family/Caregivers/Health Program/ Organizations/Community

Abstract: The Diversity of Aging experiences is discussed by reviewing results of the Pan American Health Organization (PAHO) survey on the needs of elderly in selected Latin American and Caribbean countries. Included in the initial study were habitants of Trinidad and Tobago (N=875), Costa Rica (N=1,156), and Chile (N=1, 562). Questions about formal and informal care, quality of life, dependency, and effect of community size on elder care were investigated. It was found that elder care by families is variable throughout this region, although several similarities remain. Of these, spouses and daughters most often become primary caregivers of the increasingly-dependent elder. Deterioration of the senses, decreased basic abilities required for everyday functioning after age 80, and small size of the community seem to affect the quality of care received in old-age. Family size correlates with chances of receiving required assistance. Important social changes, such as population increase, migration, social and political upheaval, and cultural differences account for some of the diversity found in this region. Both health programs and policies will need to be variable in responding to this diversity.-GH


Keywords: Community Care/Adult/Aged/Female/AgeLine: (Community Care NOT Home Care)/China/Urban/Community Involvement/Community Services/Volunteers/Volunteer Services/Service Involvement/Service Utilization/ Older Adults/Outside United States

Notes: Examined the involvement of elderly persons as providers and consumers of neighbourhood community care services in Guangzhou, China. China has an elaborate urban grassroots mobilisation network of Residents’ Committees and Street Offices--local government offices. Elderly citizens are active volunteers in providing neighbourhood services, mutual help, and public educational activities. Neighbourhood participation and service provision in 24 local government offices in Guangzhou was studied, and a citizen survey of knowledge of and participation in neighbourhood activities was taken. The 374 adult respondents (16% were aged 50 and above) were drawn from a general household survey sampling frame. The data on neighbourhood participation showed that the majority of the committees’ officials were elderly and female, the amount of financial subsidy to hardship families was very small and was not keeping up with inflation, and the family was still the main source of protection for the old and poor. The citizen survey showed that most respondents were not aware of the services in their neighborhood; however, the utilization of services for the elderly was quite high when taking into account the fact that those aged 50 and above made up only 16 percent of the survey. It is suggested that the government will have to design specific approaches to attract volunteers from different age groups to participate in neighborhood
activities. (SW) (AgeLine Database, copyright 1993 American Association of Retired Persons, all rights reserved)


**Keywords:** Home Care Canada/Long-Term Care/Care/Health/Social Services/Support/Home/Home Care/Nursing/Nursing Home/Hospitals/Physicians/Pension/Housing/Educational Programs/Roles/Technology/Rural/Community/United States/Age/Continuum of Care/Aging in Place/Case Management/Service Needs/Needs Assessment/Health Services/Patient Care/Independence/Aging

**Notes:** Discusses the co-ordination of formal and informal long-term care services for seniors and examines four different case examples. The full continuum of health and social services includes not only informal care, support services, home care, nursing home care, extended and rehabilitative institutional care, day hospitals, acute care, and care from physicians and other health professionals, but also the broad spectrum of social services including pensions, affordable housing, senior centres, senior educational programs, and all the age-integrated social programs. Co-ordination of these options is the key to making the continuum responsive to individual need. With the "system" providing the co-ordinating role, there is one locus of responsibility for examining all available options to develop the right mix of services to keep each individual functioning at the most independent level possible. Even with the support of the formal long-term care system and all of the new technologies available, it will still be the strength of the informal, interpersonal networks in rural communities that will provide a long-term care continuum uniquely adapted to meeting the needs of individuals, albeit differently in each community. (AR) (AgeLine Database, ©1993, American Association of Retired Persons, all rights reserved).


**Keywords:** Community Care/Model/Community Involvement/Development/Models/Embase/Africa 0403/Africa South Of The Sahara 4032/Article 0060/Health Program/Self Care/Health Practitioner/South Africa/Family/Elderlyxxcare/Article/Community/Health/Central/South/Africa/Nurse

**Notes:** CS-Quad-Cities Program, University Illinois College Nursing, 2525 24th Street, CS- USA AB-Community involvement in health (CIH), a central concept in health.

**Abstract:** Community involvement in health (CIH), a central concept in health development, is a participatory approach to health care that is organized from the perspective of the recipient. Putting CIH into practice represents a learning experience for the community, the health professionals involved and those responsible for the national climate in which this change takes place. The CIH process was operationalised over a two-year period in a black township in South Africa. A community survey identified the health needs and capacities related to the elderly, their families and their support system. Community groups and individuals, in partnership with the researcher, prioritised the needs that had been
identified and then implemented four programmes related to those needs. A process model was developed that provided the structure for initiating and maintaining these programmes. The model helped people who were new to the community organising to focus on general principles. It was flexible so that programmes could be interpreted and implemented in the context of local culture and resources. The model was functional in guiding community nurses, lay community members and employees in health-related programs through the process of starting new programmes. This approach empowered participants to move beyond only hoping for change or being puzzled by its elusiveness.


Keywords: Community Care/Caregiver/Health/Health Care System/Caregivers Human/Benefits/Work/COSTM2.MDL/A:/B:/C:/D:

Notes: A group of “informal” caregivers, local people to whom residents turn for information and advice, was identified in the east Harlem community and enlisted in a two-month study. Results suggest that formal human services agencies and their intended clientele would benefit by increased efforts on the part of these institutions to locate and work with community caregivers.


Keywords: Community Care/Community Services/Health/Work/Hospitals/Home/MEINT2.MDL (MEDLINE 1993-7)/A:/B:/C:/D:/ Community/The Elderly/Elderly/Disabled/Care/Nursing/Physiotherapy/Occupational Therapy

Notes: 96439766 Department of Medicine for the Elderly, Leeds General Infirmary. Many frail or disabled elderly people are now being maintained in the community, partially at least as a consequence of the Community Care Act 1993. This paper details the work of the major health professionals who are involved in caring for older people in the community and describes how to access nursing, palliative care, continence, mental health, Hospital at Home, physiotherapy, occupational therapy, equipment, and optical, dental, and dietetic services. In many areas, services are evolving to meet needs and some examples of innovative practice are included. [References: 6][Review].


Keywords: Community Care/Benefits/MEINT5.MDL (MEDLINE 1966-92)/A:/B:/C:/D:

Notes: Care in the community is much lauded as a concept, but has yet to be fully implemented. A community care nursing service set up in Cambridgeshire provides one example of how community care can be effectively employed to benefit clients and carers.

**Keywords:** Policy Europe/Community Care/Health/Aging/Europe/Roles/ Family/Review/Older Adults/Adults/Support/Rural/United Kingdom/ Netherlands/Canada/United States/State/England/Model/Training/AgeLine: (Community Care NOT Home Care)/Models/Outside United States/Conference Proceedings/Health Services/Social Services/Community Services/Long Term Care/Informal Support Systems/Public Policy

**Notes:** Presents 11 papers that address common issues associated with transitions in health and social care provision from an international conference (Aging in Europe: Innovation and Good Practice in Community Care) that took place in Wales in October 1993. Discusses the future of eldercare in Europe, examines the status and role of families and women, and suggests ways in which greater involvement for users of services can be developed. Reviews trends in community care goals and in service provision concerning long-term care and discusses trade-offs between these trends in a variety of countries. Examines variation in the capacity of older adults for participation in formal community care decisions affecting their own situation. Identifies five different types of informal support networks among older adults. Reviews the distribution of different types of support networks in rural areas of Wales (United Kingdom) and the Netherlands. Examines the social integration of older adults in the rural areas of a range of European countries. Explores policy and service changes in the Netherlands since the 1980's. Analyses the concepts of subsidiarity and empowerment and illustrates the discussion with examples from Canada, the United States, and England. Provides background information on the Baden-Wurtemberg model regions project, a German community care project that has increased self-reliance in older adults. Describes two projects that demonstrate how constructive training partnerships between West and East can be developed. Includes chapter references. (AR) *AgeLine Database, ©1996, American Association of Retired Persons, all rights reserved.*

**Hospital Delivery of Home Care**


**Keywords:** Ambulatory Care/Hospitals/Questionnaire/Patients/Aged/Home/ MESED2.MDL (MEDLINE 1993-7:PRIMARY RESEARCH)/A:/B:/C:/D:

**Notes:** 96033329 Department of Public Health, Leicestershire Health.

**BACKGROUND:** The shift in care from secondary to primary services is likely to place greater demands on community hospitals. Before changes in the provision of community hospitals can occur, baseline data are needed, outlining their current use. **AIM:** A study was undertaken to obtain baseline data describing the use of general practitioner beds in Leicestershire community hospitals. **METHOD:** A
three-month prospective, observational study was carried out between February and May 1992 using data from a questionnaire completed by nurses and general practitioners and from patient hospital records. Study patients comprised all patients admitted to general practitioner beds in all eight Leicestershire community hospitals. RESULTS: A 100% questionnaire response rate was obtained giving data on 685 hospital admissions. Around 70% of admissions were of patients aged 75 years and over. Of admissions, 35% were for acute care, 31% for respite care, 22% for rehabilitation, 7% for terminal/palliative care and 5% for other reasons. Fifteen per cent of patients had been transferred from a consultant bed. Of those not transferred, 91% were admitted by their usual general practitioner or practice partner and for 96% of these patients this was the general practitioner’s first choice for care. There was significant variation in both the age mix and care category mix of patients between individual hospitals. Medical deterioration in an underlying condition and family pressure on the general practitioner or carers’ inability to cope each contributed to around half of all admissions. Of all admissions, 38% lived alone, and 18% of carers were disabled. Incontinence was reported for 35% of patients, and 26% of all patients were of a high nursing dependency. There was low utilisation of community services before admission and 33% received none. There was variation between individual hospitals in use of local and district general hospital investigations, specialist referral and types of therapy. Of 685 admissions 11% died during their stay. Of those discharged, 76% went to their own or a relative’s home, 10% to a residential or nursing home and 9% were transferred to an acute bed. Nine percent of discharges were postponed and 10% were brought forward. On discharge to non-residential care, 26% of patients received no community services. CONCLUSION: Shifting resources from secondary to primary care is a priority for purchasers. Both the introduction of the National Health Service and Community Care Act 1990, and acute units having increasing incentives for earlier discharge, are likely to place greater demands on community hospital beds. Not all general practitioners have the option of community hospital beds. Before access to general practitioner beds can be broadened, existing beds should be used appropriately and shown to be cost-effective. Purchasers therefore require criteria for the appropriateness of admissions to general practitioner beds, and the results of a general practitioner bed cost-benefit analysis.


**Keywords:** Hospitals/Elderly/Ireland/Surveys/Dementia/Patients/Aged/State/MED92-1.(JMCGOWAN)/A:/B:/C:/D:

**Notes:** 97196399 Department of Medicine for the Elderly, Limerick Regional Hospital, Ireland. Surveys of older populations reveal rates of senile dementia varying from 5.2% to 25%. The specialist branch of psychiatry dealing with the elderly advocates that services for these patients and their carers should predominantly be based outside hospital. The following study was conducted in Limerick, Ireland before the arrival of a consultant in old age psychiatry and associated services. Its aim was to assess the extent to which the patients with
dementing disorders were using hospital facilities other than those in psychiatric wards. The study assessed 371 patients aged 65 years and over in various medical and surgical units. The Mini Mental State Examination was performed on all patients. Patients with scores of 23/31 or less were considered to have significant cognitive impairment and those with 16 or less to have severe impairment. As mental performance can be impaired by acute illness, methods were used to avoid such patients being wrongly labelled as suffering from dementia. In the acute hospital 112 patients with an average age of 74.7 years were examined and 22.3% of these had significant cognitive impairment. These patients were predominantly sited on medical wards. On acute medical wards 31% of older patients had significant impairment compared to only 7.3% on the surgical wards. In the orthopaedic unit 15.8% of the elderly had evidence of cognitive impairment. In hospitals specialising in continuing care of the elderly the proportion was 70.6% and of these 46% were severely impaired. We conclude that in the absence of specialised dementia services for the elderly, medical beds both in the acute and long-stay sector will be used for these patients more than their medical needs might otherwise require 9705. Entry Week: 97054.


Keywords: Hospitals/Home/Home Care/Community/Hospitalization/Ambulatory Care/Health/Urban/Health Care Need/Patients/Death/Family/Physicians/MEINT8.MDL (MEDLINE 1966-92)/A:/B:/C:/D:

Notes: This report presents the annual activity of a home care unit which operates as an extension of a regional hospital into the community. This “intermediate-care” (between hospitalisation and ambulatory care) was developed because of the demographic and health characteristics of the urban population served and in response to their specific health care needs (immediate availability and accessibility of care). During this period, 471 patients were under care, 85% of whom were 65 years old and over. Forty percent were referred with a diagnosis of a malignant disease, about 20% with a diagnosis of a cerebral event and 15% with cardiac and vascular problems. The average period of stay in the programme was three months, with less than 10% remaining under supervision for more than a year. In about 50% of the patients involved the care goals were attained and in an additional 25% (terminal cases) the patients were cared for at home until death. The service was found to be an important factor in the intermix phase between acute hospitalisation and the continuance of care provided by the family physician. The multidisciplinary team care approach was found to be effective in providing services to that group of patients characterised by old age, multiple medical problems and being homebound. The concerned service is continuously developing in compliance with the changing and growing needs of particular groups of patients such as advanced malignant disease, complex cardiovascular problems and multiple (simultaneous) diseases.

**Keywords:** Hospitals/Home/Home Care/Development/Health/New York/Patients/Assessment/Benefits/AgeLine: Homecare/Psychiatric Services/Management/Program Description/Home Health Care/Hospital Services

**Notes:** Describes the development and characteristics of a psychiatric home care programme implemented by the Montefiore Home Health Agency, a hospital-based home health agency in New York City. All of the agency’s patients have a primary medical diagnosis; about three-quarters are over 65. Many are in need of psychiatric services. The psychiatric home care programme was developed in cooperation with the Division of Consultation and Liaison Psychiatry at Montefiore Hospital. It has three components: Direct patient assessment in the home by a psychiatrist and by consultation with home health agency staff; education of health care professionals; and a clinical research fellowship. In a three-month period, 25 of 40 patient referrals were to discuss management issues alone, six were for the evaluation of a specific diagnostic question, and nine involved both diagnostic and management issues. In the future, the program hopes to expand services to patients whose principal diagnosis is psychiatric. Describes benefits and advantages of the programme, and discusses specific cases. (LS) *AgeLine Database*, ©1987, American Association of Retired Persons, all rights reserved.


**Keywords:** Hospitals/Home/Home Care/Veterans Administration/Patients/Family/Support/Quality of Life/Nursing/Nursing Home/Benefits/AgeLine: Homecare/Veterans/Cancer/Nursing Homes/Outpatients/Veterans Administration Hospitals/Decision Making/Life Sustaining Treatment/Terminal Care

**Notes:** Describes the experiences of the Veterans Administration Hospital-Based Home Care program in discussing do-not-resuscitate (DNR) decisions with severely debilitated patients. Over a six-month period, code status discussions were held in the homes of 37 patients. Family, friends, or legal guardians were involved in the discussion in 23 cases. DNR status was felt to be appropriate for 20 of the 37 patients. Seven patients expressed a desire to be resuscitated but not sustained on artificial life support if recovery was unlikely. Rationales for DNR status included terminal cancer (10 patients), poor quality of life (7 patients), and unacceptable quality of life with decompensation (3 patients). During the six-month study period, 17 of the patients were hospitalised, 7 died in the hospital, 4 died at home, and 1 died in a nursing home. Benefits of initiating code status discussions in this outpatient group are outlined. (LS) *AgeLine Database*, ©1989, American Association of Retired Persons, all rights reserved.


**Keywords:** Hospitals/Costs/Cost Effectiveness/Home/Home Care/Veterans/Health/Health Services/Development/Patients/Caregivers/Caregiver/Satisfaction/

Notes: 921447439 Department of Veterans Affairs, Health Services Research and Development (HSRandD) Field Program, Edward Hines, Jr. VA Hospital, Hines, IL. All admissions to a 1,100-bed Department of Veterans Affairs (VA) hospital were screened to identify 171 terminally ill patients with informal caregivers who were then randomly assigned to VA hospital-based team home care (HBHC, N = 85) or customary care (N = 86). Patient functioning, and patient and caregiver morale and satisfaction with care were measured at baseline, one month, and six months. Health services utilisation was monitored over the six-month study period and converted to cost. Findings included no differences in patient survival, activities of daily living (ADL), cognitive functioning, or morale, but a significant increase in patient (p = .02) and caregiver (p = .005) satisfaction with care at one month. A substitution effect of HBHC was seen. Those in the experimental group used 5.9 fewer VA hospital days (p = .03), resulting in a US Dollars 1,639 or 47% per capita saving in VA hospital costs (p = .02). As a result, total per capita health care costs, including HBHC, were US Dollars 769 or 18% (n.s.) lower in the HBHC sample, indicating that expansion of VA HBHC to serve terminally ill veterans would increase satisfaction with care at no additional cost.


Keywords: Hospitals/Home/Home Care/Massachusetts/Patients/Central/Visiting Nurses/Nurse/Institutionalization/Organizations/Funding/Health/Community/
MEIN11.MDL (MEDLINE 1966-92)A:/B:/C:/D:

Notes: The problem of post-hospital care remains a continued challenge, as many patients who no longer require expensive acute care facilities continue to occupy these beds, awaiting appropriate placement. The Massachusetts General Hospital Coordinated Home Care programme, under the central administration of the Boston Visiting Nurse Association, has demonstrated that home care can be a viable, economically feasible alternative to institutionalization for carefully selected patients, when the appropriate medical and social needs can be met. Three major groups of patients have been effectively cared for: 1.) Patients with multi-system chronic illness; 2.) patients with terminal malignancies; and 3.) patients with catastrophic neurologic disease. The organization of the Coordinated Home Care programme, the criteria for patient selection, and the issue of funding are reviewed. The impact of this programme is examined in terms of its potential for better utilisation of the Massachusetts General Hospital facilities, as well as the more appropriate co-ordination and use of existing health care resources in the community.

Health Care Planning

Keywords: Health Care Planning/Aging/Article/Death/Health/Perception/
Health Promotion/Community/Community Involvement/Elderly/Primary Health
Care/Rehabilitation

Abstract: WHO has re-named its programme for healthy ageing to Ageing and
Health. This new name reflects the changing perceptions of the concept of ageing.
Topics discussed in this article include: Ageing as a life-cycle rather than a last
step preceding death, and long-term health promotion emphasised throughout life,
not simply as a means of intervention. Cultural and gender influences on the
ageing process, community involvement in the well-being of the elderly and
intergenerational cohesiveness are also explored. This programme will have an
effect on several other areas of interest dealing with ageing, such as Primary
Health Care, Reproductive Health, Rehabilitation, among others.-GH.

Bowe, F. G. (1990). Disabled and Elderly People in the First, Second and Third

Keywords: Policy Overview/Health Care Planning/Disabled/Elderly/
Disabilities/United Nations/Projection/Development/Disability/Rehabilitation/
Employment/Support

Abstract: While disabilities occur in all societies, their causes and effects differ
in the First (developed), Second (communist) and Third (developing) “worlds”.
Of the 500 million persons with disabilities, about 80% live in the Third World, and
United Nations projections suggest that the proportion soon will be 90%. Two
values, integration and normalization, may guide development of national policies
in all three worlds. In addition, two design principles, accessibility and
adaptability, may prove useful. It may also be that information-age technology
will assist in disability prevention and rehabilitation, as well as in employment of
individuals with disabilities. First World economies facilitate application of
technology to meet special needs, Second World economies impede that, and
Third World economies often cannot support it. The challenge for policy makers is
to find ways of bringing together integration, normalization, accessibility and
adaptability so as to help nations to fashion cost-effective solutions to their
disability-related problems.

Keywords: Health Care Planning/Population Aging/Aging/Elderly/
Health/Embassy/Organization And Management 0142/South and Central America
0404/Central/Geriatric Care/South and Central America/Population Research/
Central America/Mortality/Cause of Death/Cerebrovascular Disease,
Epidemiology/Socioeconomics/Sex Difference/Public Health/Service/Social
Security/Human/Male/Female/Review

Notes: CS- Health of the Elderly, WHO, CH-1211, Geneva 27 CS- Switzerland

Berthold, H., Landahl, S., and Svanborg, A. (1994). Home Care and
Intermittent Care--A Realistic Alternative to Nursing-Home Care? *Comprehensive
Gerontology* 1, 24-30.
Keywords: Health Care Planning/Home/Home Care/Nursing Home/Geriatrics
Long Term Care/Sweden/Elderly/Patients/Nursing/Health/Nursing Homes/
MEINT7.MDL (MEDLINE 1966-92)/A:/B:/C:/D:
Notes: 89028545 Department of Geriatric and Long-Term Care Medicine,
University of Goteborg, Sweden. An inventory was made among 210 elderly
nursing-home patients to investigate the feasibility of exchanging their permanent
stay in the nursing home for another form of care and whether they wanted to. The
main alternative was intermittent nursing-home care. The patients were assessed as
to physical and mental health and social conditions. The majority (62.7%) were
considered too ill for other than nursing-home care. In some patients (24.8%) there
were social factors, the main one being that they no longer had a home of their
own. However, 26 patients (12.4%) were recommended for intermittent care, but
only three were interested. From these results it was concluded that if intermittent
home care is to represent a realistic alternative it should be offered to the patients
before they move into a nursing home.

Keywords: Health Care Planning/Service Delivery/Health/Canada/Elderly/
Disabled/Long Term Care/Home/Home Care/Community/MEINT2.MDL
(MEDLINE 1993-7)/A:/B:/C:/D:
Notes: 96044902 Ministry of Health and Ministry Responsible for Seniors,
Victoria, British Columbia, Canada. The Ministry of Health and Ministry
Responsible for Seniors in British Columbia, Canada, has developed a
comprehensive and integrated service delivery system for the care of the elderly
and the disabled. This system has a single point of entry, and contains all of the
major components of Long-Term Care and Home Care services under one
administrative umbrella, the Continuing Care Division. This paper presents an
overview of the Division’s service delivery system and its planning framework.
The latter provides a vehicle for decision makers to pro-actively re-allocate
resources from residential services to community and home-based services within
Continuing Care.

UK, Oxford University Press.
Keywords: Home Care Canada/Care/The Elderly/Elderly/Health/Home/Home Care

Havens, B. (1995a). Long-Term Care of Frail Elderly People. 35-54. Lanham,
MD, University Press of America.
Keywords: Home Care Canada/Long-Term Care/Care/Frail Elderly/
Elderly/Long Term Care/Demographics/Projection/Review/Development/
National Health Insurance/Health/Health Insurance/Benefits/Canada/
Policy/Public Policy/Roles/Private Sector/Continuum of Care/Outside United
States/Historical Perspectives/Service Delivery/Universal Health Care/Health
Services/Population Aging/Service Accessibility/Financing/Health Care
Reform/Long Term Care Insurance/Health Care/Health Care System/United States/State

Notes: Evaluates the long-term care (LTC) of frail older Canadians during the past three decades and the direction of reform for the 1990's and beyond. Describes the demographic changes in the population over the last 30 years and provides a projection of the number of older Canadians into the future. Reviews the development and evolution of Canada's national health insurance system. Describes the main services and cash benefits that are available to frail older persons in Canada at both the national and provincial level. Considers the various co-ordination mechanisms that have been developed to formulate and manage LTC policies and programmes in Canada. Discusses the financial aspects of LTC in Canada, both from a public policy perspective (federal and provincial roles and responsibilities) and private sector perspective (individual out-of-pocket expenses, co-payments, or user fees, and third-party insurance). Reviews various reform pressures and processes of the provinces/territories to illustrate how Canada is providing a full continuum of care for frail older persons. References are included. (WD) (AgeLine Database, ©1995. American Association of Retired Persons, all rights reserved).


Keywords: Health Care Planning/Community/Health/Canada/Health Services/Chronically Ill/Caregivers/Outcomes/Health Insurance/Caregiver/Health Service/Service Utilization/Community Care/HS1REF.TXT/A:/B:/C:/D:/Care/Health Care

Notes: 96101122 Faculty of Health Sciences, McMaster University, Ontario, Canada. Does the nature of community health services used by chronically ill clients and their caregivers have an impact on utilisation of services, expenditure and well-being outcomes? A series of five studies, (four historic cohort and one randomised trial) examined clients suffering from a variety of chronic conditions in a number of community settings in different regions of Southern Ontario. Study sample composition and size varied. Each study was designed to quantify the well-being outcomes, and expenditure associated with different community approaches as covered under a nation-wide system of health insurance plans. As a collective, these studies represent increasing methodological rigor. Multiple-perspective client well-being outcome measures were used. Caregiver burden was also analysed. A common approach to quantification and evaluation of expenditure for service consumption was applied across all five studies. The nature of community health services (proactive versus reactive approaches to care) was found to have direct and measurable impact on total expenditure for health service utilisation and client well-being outcomes. A recurring pattern of lower expenditure for community health service utilisation and equal or better client outcomes was associated with well-integrated proactive services when compared with individual fragmented, reactive approaches to care. The main lesson emerging from examining the five studies on approaches to community care is that it is as, or more, effective and less expensive to offer complete proactive health care services.
to chronically ill people in the early stages of their illness than to provide services on demand in a piecemeal manner. (28 Refs) (Abstract by: Author)(Review).


**Keywords:** Health Care Planning/Health/Elderly/Aging/Costs/Human/Aged/Priority/Funding

**Abstract:** Modern societies are becoming increasingly concerned with the ageing of their populations. The accompanying rise in chronic disorders and resultant frailty and dependency produce burgeoning health care costs. The situation also poses a new challenge to the medical profession. The human organism even in the absence of disease is faced with a finite life span. Is it therefore possible to compress or postpone the period of morbidity from chronic illness, and thus decrease the need for medical care in later life? If this were so, there would be good reason to place clinical emphasis on health maintenance and give it high priority for funding. The promises of health maintenance and disease prevention for younger age groups have not always been fulfilled, however, and the topic has become a complex and controversial issue of health care. Before developing national programs for the aged therefore, it is necessary to examine critically available information on the efficacy of health maintenance for this age group.


**Keywords:** Health Care Planning/Home Care/Home/Costs/Nursing/Patients/Institutionalization/Benefits/Outcomes/AgeLine/Homecare/Death/Hospitalization/Home Health Care/Cost Containment/CostEffectiveness/Resource Allocation/Health Service/Costs/Older Adults/United States

**Notes:** Argues that it may be time to lay aside studies showing that home care is not cost-effective and get started on ways to make it become cost-effective. While home care has certainly cost more than it has saved, the good news is that it has not cost all that much more (about 15%), and it could be made cheaper. A number of efficiency-inducing strategies offer some promise, while others suggest themselves as ways to make home care more efficacious. More money could be saved by preventing nursing home stays if services were targeted to patients at higher risk of institutionalization. Another promising approach is to concentrate more heavily on improving the “quality of death” of home care patients--emphasising the goals of death at home and planning for it, to avoid unnecessary hospitalisations. Protocols to reduce intensity of home care use as duration extends beyond three-six months might produce benefits equal to more intensive use patterns. Better programme cost management may offer additional promise. If home care patients were evaluated initially to determine the risks they actually face, resources might be used more judiciously and outcomes might be more likely to be produced and detected. While none of these strategies guarantees that home care will save money or become more efficacious, they represent reasonable goals for enhancing both the efficiency and the efficacy of home care. (WD) (*AgeLine Database*, ©1994, American Association of Retired Persons, all rights reserved).

Keywords: Health Care Planning/Elderly/Egypt/Models/Male/Female/Noninstitutionalized Elderly/Work/Family/Roles/Health/Males/Females/Activities of Daily Living/Economic/Disability/Rural/Model/Disabilities/Personal Care

Abstract: The purpose of this paper is to examine gender-specific models to determine whether different combinations of correlates are associated with male and female disablement, using a sample of non-institutionalized elderly persons in Egypt. Because women and men have different work, family, and household roles, as well as different health risks, it is reasonable to assume that there may be differing correlates for disablement for elderly males and females. The dichotomous dependent variable indicates problems, or the inability, in performing at least one of six activities of daily living (ADL). Of interest is the association of health, economic, and family variables, controlling for age. Logistic regression models are estimated for the total, male, and female samples. The results indicate that for males, having to stop working due to illness and having an unattended medical need are associated with higher odds for disablement as compared with females. Additionally, illiteracy increases the odds for male disablement, yet it has no effect on female disablement. Having experienced an injury in the past year is associated with disability for females, as is spending a lifetime in a rural setting and currently living in a fair to poor residence. Also for the females, increased number of living children significantly increases the odds for functional disability. Separate male and female models were estimated for each of the six ADL items. The trends indicated that the model covariates were more useful in modelling female disabilities in personal care activities, rather than problems with eating and mobility. The health variables were significantly associated with most of the specific ADL problems for the males.


Keywords: Health Care Planning/Aged/China/Hospitals/United Kingdom/State/Social Welfare/Welfare/Economic/Family/Elderly/Urban/Development/Home/International/Embase/Asia 0407/Economic Aspects 0139/Article 0060/Priority Journal 0007/Aging/Elderly Care/Residential Care/FamilySize/Migration/Income/Article/Priority Journal/Care

Notes: CS-H. Bartlett, Oxford Brookes University, Academic Centre, John Radcliffe Hospital, Oxford OX3 9DU CS- United Kingdom AB- China’s population is rapidly ageing at a time when former socialist collective provision and provision by the state in all sectors, especially in social welfare, is being radically reduced because of economic reform and financial stringency. The traditional Chinese approach to family care for elderly members is being encouraged but may be difficult because of smaller family sizes and the disruption of migration. This paper discusses some urban responses to pressures for change in care of elderly people, drawing on the example of Guangzhou (Canton) in southern China, which typifies many of the problems of caring for elderly people in times of social and economic change. It notes the development of homes and
facilities for elderly people and the emergence of some prestige homes, often occupied by the better off, which have received both local and international investment. By contrast, the bulk of elderly people will not be adequately provided for by a declining public/collective sector. The dilemmas faced by the Chinese authorities attempting to stimulate local provision for all elderly people are identified.


**Keywords:** Home Care Informal Caregivers/Health Care Planning/Home Care - Developing Nations/Home Care Urban/Chronically Ill/Elderly/China/Caregivers/Activities of Daily Living/Health/Patients/Family/Work/Nursing/Nursing Homes/Relative/Roles/State/Health Care System

**Abstract:** This study examines the home care situation of 75 urban chronically ill men and women and their caregivers in three cities in the People’s Republic of China. It documents the type of home care provided, the severity of illness, and the dependency in activities of daily living in order to appreciate the complexity of these care situations. The findings reveal that women serve as the caregivers in the majority of the cases and often they are elderly spouses with health problems of their own. The physical, social, psychological, and financial problems experienced by these patients create an enormous burden for the caregivers whether spouses or younger family members coming home from work to a second shift. If alternatives to home care, such as nursing homes, were available, 54% of these caregivers would be willing to institutionalize their elderly relative. All caregivers express the need for more assistance in providing home care. This study raises questions regarding the role of the family, the state, and specifically the health care system in caring for the elderly chronically ill in light of their increasing numbers in the population.


**Keywords:** Health Care Planning/Patients/Survey/Chronically Ill/Blacks/Whites/Community/Care

**Abstract:** A survey was conducted to evaluate the care being received by non-institutionalized chronically ill persons in the Black, Coloured and White communities residing in the Municipality of Cape Town. Of the chronically ill persons identified, 170 (71%) of the Blacks, 188 (62%) of the Coloureds and 43 (86%) of the Whites were receiving care at the time of the survey, and the type, location and duration of this care are outlined. Only 26% of the chronically ill persons were considered to be receiving optimal care, and new recommendations for care were made for 201 (84%) of the Blacks, 203 (67%) of the Coloureds and 36 (72%) of the Whites. Of the patients for whom new recommendations were made, 37% were not currently receiving any care. The financial and occupational
repercussions of chronic illness are considered, and methods of improving the comprehensive care of chronically ill persons are discussed.


**Keywords:** Health Care Planning/Roles/Welfare/Aged/Article/Community/Elderly/Organizations/The Elderly

**Abstract:** This article summarises the various facilities available to the aged living in the community and some of the problems associated with providing accommodation for the elderly, and for the mentally frail person in particular. The importance of closer co-operation between the medical profession and voluntary welfare organizations is emphasised.


**Keywords:** Health Care Planning/Policy Middle East/Roles/Community/Community Services/Long Term Care/Elderly/Israel/Chronically Ill/State/Aged/Central/Development

**Abstract:** Israel faces a major challenge to its capacity to deal adequately with the needs of the chronically ill. This paper describes the present state of long-term care services for the chronically ill and documents the extensive disparities in the rate of institutional and community services by region. In view of the expected dramatic increase in the number of aged greater than or equal to 75 years old (from 106,800 to 181,500 between 1980 and 1990), the authors project a 50% increase in the need for institutional and community services just to maintain existing service patterns. The paper discusses the central issues related to the development of both types of services in response to the increase in needs.


**Keywords:** Health Care Planning/Home/Geriatrics/Japan/Review/Central/Hospitals/Aged/Male/Nursing/Nursing Homes/Length of Stay/Dementia/Living Arrangements

**Abstract:** OBJECTIVES: To determine the factors that influence users’ destinations on discharge from Geriatric Intermediate Care Facilities (GICF’s), which were established in Japan in 1987 to help hospitalised older people return home. DESIGN: Retrospective chart review. SETTING: A 94-bed GICF attached to Saku Central Hospital in Japan. SUBJECTS: Charts of all users (N=437) aged 65 years and older, discharged from the GICF between July 1987 and February 1991, were reviewed. MEASUREMENTS: The independent variables, obtained from users’ admission records, were age, sex, place of residence before admission, length of stay, intellectual impairment (assessed by Karasawa’s diagnostic criteria for senile dementia), ability to perform activities of daily living (ADL’s), and living arrangement of users in the GICF. The dependent variable was destination
after discharge from the GICF. MAIN RESULTS: Multiple logistic regression analyses revealed that, compared with users who were able to successfully return home, users with little ability to perform ADL’s, male users, and those admitted from other institutions were more likely to be hospitalised. Such analyses also revealed that users who came from institutions, had low ability to perform ADL’s, and lived alone were more likely to be institutionalized in nursing homes. CONCLUSIONS: Evaluating a user’s physical, mental, and socio-economic conditions at an early stage of admission to GICF may allow us to predict whether the user can be successfully discharged to his or her home or will have to remain in the GICF for an extended period.


Keywords: Health Care Planning/Support/Health/Service Utilization/Work/Israel/Survey/Elderly/Family/Health Service/Health Services/Embase/Asia 0407/Middle East 4071/Mammal 0738/Human 0888/Human Experiment 0104/Aged 0019/Adult 0018/Article 0060/Health Care Utilization/SocialSupport/Geriatric Care/Family Life/Religion/Human/Human Experiment/Aaged/Adult/Article

Notes: CS-H. Litwin, Paul Baerwald School of Social Work, Hebrew University of Jerusalem, Jerusalem CS- Israel AB-. A secondary analysis of data from a national survey of elderly people in Israel applied a quick clustering procedure to a set of relational and interactional variables to derive a typology of support networks. The procedure produced six network types significantly differentiated by the gender, age, education, years of residence in the country, and health status of the focal elders in the network. They are characterised respectively as: 1.) Diversified, 2.) friend and family, 3.) narrow family focused, 4.) attenuated. 5.) religious family focused, and 6.) traditional extended family support networks. Respondents in the different network types were found to have differing degrees of health service utilisation, as measured on a combined index of nine health services. The healthiest respondents with the most diversified support networks made the greatest use, and those with family-focused networks made the least use of health services.


Keywords: Health Care Planning/Patients/Home/Family/Canada/Hospitals/Priority/Home Care/Home Care Agencies/Roles/Treatment/Rural/Urban/Caregivers/Work/Physicians/COSTM1.MDL/A:B://C://D:

Notes: 95041001 Centre for Studies in Family Medicine, University of Western Ontario. London, Canada. Discharging older patients from hospital to care at home presents considerable challenges for those concerned about the current mandate of quality management. A great many professionals with different priorities and organizational commitments are involved. The policies and procedures of at least two agencies, a hospital and a home care agency, play a role in shaping the whole process. The purpose of this study was to explore and
describe factors other than medical condition and treatment which shaped the quality of the discharge experiences of older patients. Qualitative research methodology was used to document the discharge process from the perspective of 12 rural and 9 urban patients, and a purposeful sample of 22 family caregivers and 117 professionals involved in their care. As well, 24 agency administrators with an overview of related policies and procedures provided data. Findings provide an in-depth description of the different implementation approaches and related quality issues in rural and urban settings. Quality management was undermined by role confusion, compromised and overly zealous pursuit of efficiency, fragmented work, variable physician practice style, and communication and co-ordination problems. Several readily implemented solutions to these problems are recommended. The implications of the more difficult leadership challenges related to achieving reasonable efficiency and maintaining a humane orientation in the complex care system are addressed.


**Keywords:** Health Care Planning/Health/Elderly/Male/Income/Health Status/Males/Analysis/Relationships/Status/Health Care/Care/Health Care Utilization

**Abstract:** Secondary analysis of data to measure relationship between perceived health status and reported health care utilization among 145 Nigerian males 50 years and older. Results show an inverse relationship between perceived health status and health care utilisation: Individuals who perceive their health negatively paid more visits to the doctors than those who view their health positively. Age, income or stoicisim appear to have no influence on this relationship between subjective health feelings and health care utilisation.


**Keywords:** Health Care Planning/Home/Home Care/Netherlands/Health/Health Services/Primary Health Care/Hospitals/Nursing/Nursing Home/Elderly/United States/State/Symptoms/Statistical Data/Patients/Family/Informal Care/Health Care System/Nursing Homes/AgeLine: Homecare/Long Term Care/Terminal Care/Home Health Care/Health Insurance/Public Policy/Health Service Costs/Service Delivery/Over Older Adults/Outside United States

**Notes:** Provides an overview of the trend toward terminal home care in the Netherlands. Offers background information on the Dutch health services, especially primary health care, hospital care, and nursing home care. Notes that care for the elderly is well developed, with 1.56% of the gross national product spent on long-term care (compared with 0.90% in the United States). Defines terminal home care as care at home for the symptoms of an incurable fatal disease, and provides statistical data on the different types of home care. Discusses the six guidelines governing terminal home care that are recommended by the Health Council: a positive choice of the patient among home care, hospital care, and nursing home care; agreement from the family; sufficient informal care available; co-ordination between primary health care and hospital care; knowledge about
palliative care within the primary health care team; and a guarantee of emergency admission or consultation on request of patients or their families. Presents findings of three recent studies of terminal home care. Suggests that the lack of cooperation between medical specialists and family doctors and the need for more comprehensive services in the primary health care system are the main reasons for the continued reliance on hospitals or nursing homes for the care of the terminally ill population. (SW) (AgeLine Database, ©1994, American Association of Retired Persons, all rights reserved).


Keywords: Health Care Planning/Elderly/Community/Elderly Care/Health Support/Research/Health Care/Care

Abstract: The purpose of this research was to assess the well-being of elderly people in three different community types in Zimbabwe. Well-being was defined as general health, health resource access, nutrition, habits, and physical function. Major health problems, hygiene, nutrition and access to health care did vary between communities, but there was a low level of physical dependency throughout. The findings suggest that once a critical decline in fitness occurs, elderly people may rapidly die as a result of diminished medical and physical support. These findings are relevant to future plans for elderly care services in Zimbabwe.


Keywords: Hospitals/Costs/Health/Patients/Developing Country/Family/Males/Females/Model/Home/Home Care/AID1.MDL/A/:B:/C:/D:/Health Care/Care

Notes: 96925255 AIDS Counselling Trust, (ACT) Harare, Zimbabwe. Fax: 792340. ISSUE: The burden of health care of a terminally ill AIDS patient is enormous to both family and the nation. As the AIDS cases continue to rise sharply the capacity of developing countries to deliver even basic services to the population is threatened. OBJECTIVE: To examine the direct costs incurred by an AIDS patient in the last twelve months for consultation to doctors, hospital admissions, drugs, laboratory tests and X-rays. METHOD: Computer records of 19 patients belonging to a medical insurance were retrospectively studied for hospitalisation, consultations and drug costs, pathology and X-ray tests over the last 12 months of their lives. All patients had been attending ACT counselling sessions over the last 2-3 years of their illness. RESULTS: There were 14 males, and 5 females. Age range 25-52 (mean 34.4). Average expenditure per patient was Z Dollars 8,017,00 and total paid out for the 19 patients was Z Dollars 153,360,00. IMPLICATIONS: The current health budget by the national government only provides for Z Dollars 30 expenditure per head. Approximately 10,000 AIDS cases are reported per year and 1 million people thought to carry the HIV virus. The implication of the actual cost per patient and the health budget provision is discussed. RECOMMENDATIONS: Tertiary hospital care for AIDS
in developing countries is beyond most national budgets. A cheaper model based on home care is recommended. (Abstract by: Author).

**Benjamin, A. E. (1988). Long-Term Care And AIDS: Perspectives From Experience With The Elderly. Milbank Quarterly 66[3], 415-443.**

**Keywords:** Health Care Planning/Long Term Care/Elderly/California/Patients/Costs/Cost Containment/Hospitals/Nursing/Nursing Home/Home/ Roles/Institutional Care/Outcomes/Benefits/Community/Community Care/Hospitalization/Central/MEINT7.MDL (MEDLINE 1966-92)/A:/B:/C:/D:/Nursing Homes/Policy/The Elderly/Care/Management/Long-Term Care

**Notes:** 89096717 University of California, San Francisco. The driving concern of policy thinking in regard to both the elderly and AIDS patients has been cost containment. It has been presumed that the best way to cut costs, as well as to serve the medical and emotional needs of AIDS patients, is to limit hospital and nursing home stays and expand the role of community-based services. The experience of the elderly has demonstrated, however, that these services have had little impact on the use of institutional care, only limited outcome benefits, and have not reduced the overall costs; rather, they have increased the utilisation of all services and total expenditures. In the case of AIDS patients, a preoccupation with community care alternatives to hospitalisation fails to acknowledge the central role of medical care in the management of the disease. [References: 93] [Review].


**Keywords:** Home Care Canada/Nursing/Nursing Home/Home/Manitoba/Admissions/Health Care Utilization - Nursing Homes/Health Care Utilization/Nursing Homes/Policy/Canada/United States/Long-Term Care/Longitudinal Study/Health/Health Status/Status/Home Care/Care/State

**Abstract:** This paper reports data on the admissions, discharges, and changes in health status of eight admission cohorts to nursing homes in a jurisdiction with universally-insured nursing home and home care services. The findings are compared to those of U.S. studies and disclose differences which may reflect differences in payment mechanisms and in admission policies and procedures. The results of the study raise policy issues relevant to both Canada and the United States.

**Shapiro, E. and Tate, R. B. (1985). Predictors of Long Term Care Facility Use Among the Elderly. Canadian Journal of Aging 4[1], 11-19.**

**Keywords:** Home Care Canada/Elderly/Research/Manitoba/Longitudinal/Longitudinal Study/Aging/Logistic Regression/Regression Analysis/Analysis/Health/Health Status/Status/Nursing Homes/Nursing Home Admissions/Admissions/High Risk/Risk/Demographics/Relationships/Annot.Bib./Prediction/Determinants/Long-Term Care/Service Utilization/Sociodemographic Variables/Socioeconomics/Nursing/Nursing Home/Home/Demographic Characteristics

**Notes:** This research uses data from the Manitoba Longitudinal Study on Aging and multiple logistic regression analysis to assess the impact of 28 socio-economic
and health status variables on nursing home admission. The results indicate that all the short-term predictors continue to be significantly associated with facility bed use in the long run, suggesting that the high risk elderly can be identified relatively early. The key socio- demographic characteristics are better predictors of admission than health and physical function characteristics, and time itself appears to change the relationship of the study variables to admission.


**Keywords:** Health Care Planning/Community/Community Care/ Nursing/Nursing Home/Home/Disabled/Elderly/Aged/Massachusetts/ Caregivers/Follow Up/Interviews/Male/Caregiver/Adult/Relative/Risk Factors/Informal Care/Model/Female/Disability/AgeLine: (Community Care NOT Home care)/Models/United States/Older Adults/Nursing Homes/ Institutionalization/Noninstitutionalized Elderly/Informal Support Systems Longitudinal Study/70+

**Notes:** Examined the effects of informal and formal community care on the six-year risk of nursing home use among a sample of disabled elderly. A sample of 634 disabled persons aged 70 and older living in Massachusetts and their informal caregivers were interviewed at baseline and at three follow-up interviews over a six-year period. Data on the dependent variable--admission to a nursing home--were available for 586 participants between baseline and follow-up 1 (4 to 5 years after baseline); for 269 participants between follow-up 1 and follow-up 2 (1.5 years after follow-up 1); and for 189 participants between follow-up 2 and follow-up 3 (1.2 years after follow-up 2). Of the 586 participants at baseline, 45.6% were aged 70-79, 54.4% were aged 80 and over, and 23.3% were male. A total of 24.5% had their spouse as primary caregiver, 48.4% their adult children, 17.3% another relative, and 9.9% a non-relative. Independent variables--informal and formal community care--consisted of number of caregivers, relationship of the primary caregiver, co-residence, and the gender of the caregiver. Risk factor variables consisted of receipt of formal care alone, receipt of both formal and informal care, actual hours of informal and formal care, as well as the perceived burden of caregiving on the primary caregiver. Analyses, using a multivariate logit regression model of probability, showed increased risk of nursing home admissions associated with receiving formal care services and with caregiver burnout. Those receiving greater amounts of informal care showed a modest reduction of risk of using a nursing home. Elders with male caregivers were at over twice the risk of using a nursing home than those with female caregivers, while those who lived with their primary caregiver were at reduced risk. Increasing amount of formal services was associated with reduced risk of nursing home use for cognitively impaired older persons. However, formal community care did not buffer the effects of severity of disability on nursing home use. (TS) *AgeLine Database*, ©1995, American Association of Retired Persons, all rights reserved.)

**Keywords:** Health Care Planning/Mortality/Frail Elderly/Elderly/Home/Housing/Activities of Daily Living/Death/Aged/Disabled/Japan/Disability/Treatment/Family/Interview/Housebound/Adjustment/Home Care

**Abstract:** STUDY OBJECTIVE: The study was undertaken to identify any relationship between the mortality of frail elderly people living at home and their housing conditions. DESIGN AND SETTING: A cohort of frail elderly people living in Yao City, Osaka Prefecture, Japan was followed for six years. Data on demographic variables, activities of daily living, the disease that was the main cause of the disability, medical treatment, the feasibility of continuing family care, and some housing conditions were collected in December 1983 by interview during home visits. Deaths were checked for each year for five years. SUBJECTS: Altogether 423 people aged 65 years or more living at home in Yao City who were disabled and housebound for at least three months were studied. MEASUREMENTS AND MAIN RESULTS: Life table analysis and multivariate logistic regression analysis were done. The cumulative survival rates of old people with good housing conditions were higher than those with poor housing conditions in each group stratified by age, sex, or the activities of daily living level. The odds ratio for poor housing conditions compared with good housing conditions for five year mortality remained highly significant after adjustment for potential confounding factors including age, sex, and the activities of daily living level by logistic regression analysis. CONCLUSIONS: The mortality of frail elderly people living at home is affected by housing conditions. Programmes to improve housing conditions of the disabled are important for home care of the elderly.


**Keywords:** Health Care Planning/Sheltered Housing/Housing/Geriatrics/Health/Elderly/Developing Country/Health Care/Care/The Elderly/Risk

**Abstract:** The problem of health care of the elderly in developing countries such as Hong Kong is discussed. The setting up of a sheltered housing programme for those most at risk forms an important contribution to geriatric health care.


**Keywords:** Health Care Planning/Saudi Arabia/Nurses/Patients/Hospitals/Home Care/Male/Nursing/Health Services/Long Term Care/Survey/Health/Physicians/Social Workers/Workers/Relatives/Perception/Management/Home Males/Elderly/Institutional Care/Long-Term Care/Care

**Abstract:** The objective of this study was to ascertain the clinical and epidemiological pattern of long-term care inpatients in Saudi Arabia. A cross-sectional survey of all long-term care inpatient facilities in the Ministry of Health was conducted during the period January-June 1994. Trained research teams consisting of physicians, social workers, nurses and medical record officers completed a pre-designed data form. They interviewed the treating teams, patients
and their relatives. The data form consisted of socio-demographic data of patients, the duration of their stay in hospital and their clinical, social and psychological characteristics. In addition, the perceptions and preferences of doctors, patients, and their relatives about patient management in hospital vs home care were sought. Out of all patients, 61.3% were males, while 52.7% were elderly patients (> or = 60 years of age). Forty-three percent did not need any nursing care or required only routine nursing care. The treating doctors believed that 44.9% of patients could be cared for at home. However, 45.2% of the patients preferred to stay in hospital, while 67.5% of their relatives preferred institutional care. It is concluded that there is a need to plan for more cost-effective facilities for these patients. The proposed health services have to be culturally acceptable in order to encourage patients and their relatives to utilise them.


Keywords: Health Care Planning/Health/Elderly/Developing Country/ Case Study/Socioeconomics/Mortality/Aged/Hospitals/Development/ Disability/Social Policy/Training/Primary Health Care/Health Care System

Abstract: The elderly populations of many developing countries are increasing rapidly. These demographic changes are a direct result of the success of socio-economic development that has led to declines in mortality rates at all ages and reductions in fertility. However, an aged population might be expected to suffer with the problems of dependency and disability leading to an increased burden of disease. Adequate disability and life expectancy data are essential for planning health and social policy but are currently insufficient. Making best use of the limited resources available for health care will require an emphasis on training of professional staff and carers, but with integration of health care for elderly people with established health services, particularly the existing primary health care systems. Strategies aimed at developing separate services for elderly people should be avoided because of the high likelihood of producing services of low quality with an inappropriate hospital emphasis.


Keywords: Community Care/Community/Health/Japan/Health Care System/ Aged/Welfare/Roles/Support

Abstract: The population of Japan in the 21st century is expected to be distributed heavily on the side of higher ages. In view of the aged society, improved hygienic, medical, and welfare services must be provided in every community. In order to provide these services efficiently it is necessary to implement a Community Health Care System (CHCS). The role and responsibilities of the medical information system, which is intended to support comprehensively the CHCS with respect to providing the necessary information, will become increasingly important. This paper is intended to discuss the structure, features, and required activities of the community medical information
system which will have particular importance in the community health care services in the coming years. Problems in establishing and operating future medical information systems in the CHCS also are discussed. Lastly, problems and obstacles confronted when establishing and operating medical information systems in community health care which is organized around the medical association, which plays an important role and takes on heavy responsibility, are discussed, and a proposal is made.
Home Care Issues at the Approach of the 21st Century
From a World Health Organization Perspective

ANNOTATED BIBLIOGRAPHY
REFERENCE LIST


Birkel, R. C. 1987. Toward a social ecology of the home-care household. Psychology and Aging 2[September], 294-301.


239


Kaye, L. W. 1986. Worker views of the intensity of affective expression during the delivery of home care services for the elderly. Home Health Care Services Quarterly 7[Summer], 41-54.


250


Mann, K. J. 1985. Recommendations for the formulation of the Nursing Care Insurance Law. *Israel Journal of Medical Sciences* 21[3], 244-248.


McCann, K. and Wadsworth, E. 1992. The role of informal carers in supporting gay men who have HIV related illness: what do they do and what are their needs? *AIDS Care* 4[1], 25-34.


Shapiro, E. 1986. Patterns and predictors of home care use by the elderly when need is the sole basis for admission. *Home Health Care Services Quarterly* 7[Spring], 29-44.


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Web of Science.................................Interdisciplinary
LIST OF KEYWORDS USED IN SEARCH
Non-Standard Keywords or Indexing Terms Used

Indexing Terms -- Definitions
Ambulatory Care -- Ambulatory Care
Community Care -- Community Care
Dementia -- Home Care with the Dementing Diseases
Disaster -- Home Care during and following Disasters
Financing -- Financing or Funding Home Care
Health Care Planning -- Health Care Planning
Home Care - Adult Day Care -- Adult Day Care Issues
Home Care - Aids/Hiv -- Home Care with HIV/AIDS
Home Care - Caregivers -- Formal Caregivers
Home Care - Nursing -- Nurses in Home Care
Home Care - Physicians -- Physicians in Home Care
Home Care Terminal -- Providing Care to the Terminally Ill
Home Care - Respite Care -- Respite Care
Home Care - Technology -- Technology, especially "High"
  Technology in Home Care
Home Care - Training -- Training Issues in Home Care
Home Care By Illness -- Home Care with Specific Diseases Other than Dementia and HIV/AIDS
Home Care Canada/Home Care European -- Home Care in the "Developed" Nations
Home Care Informal Caregivers -- Informal Caregivers
Home Care International -- International Home Care
Home Care using Paid Informal Caregivers -- Issues of Paying Informal Caregivers
Home Care with Elderly Clients -- Home Care with Elderly Clients
Home Care with Informal Caregivers of Dementia Sufferers -- Informal Caregivers to Persons Suffering with Dementia
Home Care-All ages -- Home Care with Clients of All Ages
HomeCare-Developing Nations -- Home Care in the "Developing" Nations
Hospitals -- Hospital Delivery of Home Care
Policy Africa -- Policy Issues in African Countries
Policy Canada --Canadian Policy Issues
Policy Caregivers --Caregiver Policy
Policy China -- Policy Issues in China
Policy Comparisons -- Policy Comparisons
Policy Europe -- Policy Issues in European Countries
Policy Middle East -- Policy Issues in Middle Eastern Countries
Policy Overview -- Policy Overview
Policy Scandinavia -- Scandinavian Policy Issues
Policy United Kingdom --Policy Issues in the United Kingdom
Policy United States -- Policy Issues in the United States
HOME CARE ISSUES AT THE APPROACH OF THE 21ST CENTURY FROM A WORLD HEALTH ORGANIZATION PERSPECTIVE