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J.C. Campbell, N. Ikegami (Eds.)

Long-Term Care for Frail Older People

Reaching for the Ideal System

Springer

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Foreword

This volume contains the proceedings of the fourth symposium of the Keio University International Symposia for Life Sciences and Medicine under the sponsorship of the Keio University Medical Science Fund. As stated in the address by the President of Keio University at the opening of the symposium, the fund was established by the generous donation of Dr. Mitsunada Sakaguchi. The Keio University International Symposia for Life Sciences and Medicine constitute one of the core activities of the fund. The adjective is to contribute to the international community by developing human resources, promoting scientific knowledge, and encouraging mutual exchange. Every year, the Committee of the International Symposia for Life Sciences and Medicine selects the most interesting topics for the symposium from applications received in response to a call for papers to the Keio medical community. The publication of these proceedings is intended to publicize and distribute information arising from the lively discussions of the most exciting and current issues during the symposium. We are grateful to Dr. Mitsunada Sakaguchi, who made the symposium possible, the members of the program committee, and the office staff whose support guaranteed the success of the symposium. Finally, we thank Springer-Verlag, Tokyo, for their assistance in publishing this work.

Akimichi Kaneko, M.D., Ph.D.
Chairman
Committee of the International Symposia
for Life Sciences and Medicine

Keio University and the Keio University Medical Science Fund

Ladies and Gentlemen, Distinguished Guests:

I have great pleasure in extending to you a cordial welcome on behalf of Keio University and the Keio University Medical Science Fund. I am particularly grateful to those scientists who traveled such far distances from every part of the world in order to participate in this symposium, the first Keio University International Symposium for Life Sciences and Medicine. The special topic chosen for this occasion is "Oxygen Homeostasis and Its Dynamics," which, I believe, is essential to understand the principle of all forms of life.

There are several reasons for us at Keio University to host such an International Symposium for Life Sciences and Medicine, an occasion for international scientific exchange. To explain the reasons, I would like to give you a short history of Keio University and of the Keio University Medical Science Fund, though I will be brief.

Keio Gijuku, now Keio University, was founded in 1858 by Yukichi Fukuzawa, a pioneer of modern civilization in Japan. I assume some of you are already familiar with his personal appearance, because his portrait is on the 10 thousand-yen note of Japanese currency. In the more than 138 years since its establishment, we are proud that Keio, as Japan's oldest among 587 universities, has played a major role in developing human resources including academic, business, and political leaders. The present prime minister, Ryutaro Hashimoto, is one of our alumni. At Keio University we now have eight faculties and nine graduate schools, and among the faculties, the school of medicine is one of the most highly regarded medical schools in Japan.

Reproduced from the opening remarks given by Professor Yasuhiko Torii, the President of Keio University, at the First International Symposium for Life Sciences and Medicine

We have also been carrying out, for many years, a wide range of international exchanges with people from various countries. In this connection, I would like to tell you that Yukichi Fukuzawa, the founder, was a member of the very first mission of the Tokugawa Shogunate government to the United States in 1860. Before that year, Japan had closed its door to the world for almost 300 years until Admiral Perry (Matthew Calbraith Perry) knocked on our door in 1853.

During his visits to the United States and Europe as a member of the Japanese Official Mission, Mr. Fukuzawa realized that education was most important to the future of Japan, and therefore, after coming back to Japan, he established Keio Gijuku—now we call it Keio University—in Tokyo. Thus Keio has its origin in international exchanges and has long aimed for international exchanges of culture and science with many countries. Please understand that international exchanges such as this occasion have been one of the most important academic and social missions of Keio University from its birth.

In the fall of 1994, Dr. Mitsunada Sakaguchi, a 1940 alumnus of the medical school, donated 5 billion yen to the university expressing his wish that it be used to encourage research in life sciences and medicine at Keio University and to promote world-wide advances in biomedical sciences. Being a political economist especially interested in the nation's healthcare policy, I totally sympathized and agreed with his wishes, and thus launched the Keio University Medical Science Fund on April 1995 in order to fully reflect Dr. Sakaguchi's unwavering commitment to the cause of medical progress. The International Symposium for Life Sciences and Medicine has thus been organized as one of the several projects of the Keio University Medical Science Fund whose objective is, let me stress again, to contribute to the international community by developing human resources, promoting scientific knowledge, and encouraging mutual exchange.

Time flies. The year 1996 is passing by, and as we witness the dawn of the 21st century, we realize that our society faces many problems from this century which will be carried over into the next. In the field of life sciences and medicine alone, we are still unable to completely cure cancer or AIDS. In addition, many new and unknown problems await us in the new century. We will have to overcome numerous obstacles, including diseases and problems that arise with over-sophisticated civilization and the aging of our population.

I believe that exploring new horizons in life sciences is one of the most vital tasks that we face at the dawn of the 21st century. It is equally important to ensure that the knowledge obtained through these horizons is used in ways which bring genuine happiness to humankind. Conceived in the belief and philosophy I have described, Keio University has organized this first Keio University International Symposium for Life Sciences and Medicine. It is therefore more than a pleasure, and indeed an honor, for me to meet you distinguished medical researchers from world-renowned institutions, and to share and exchange views and opinions in the field of medicine and the life sciences. I also am grateful for the efforts of the organizing committee, chaired by Professor Yuzuru Ishimura, who devoted themselves to making the symposium a high-quality and enjoyable one.

Finally I do hope that this symposium will be both fruitful and productive for all of you. Let me close this address now by wishing you the best of health and further success in your research. Thank you very much for your attention.

December 9, 1996
Yasuhiko Torii
President of Keio University

Preface

This volume is the proceedings of the Keio University International Symposia for Life Sciences and Medicine, *Long-Term Care for Frail Older People: Reaching for the Ideal System*, which was held at the New North Building and the West Building 518 Hall, Mita Campus of Keio University, May 19–21, 1998.

This topic was chosen because the aging of society is an increasing concern in all advanced nations. At the forefront of concern is the problem of long-term care for frail older people, who need some degree of assistance to lead a decent life. In all nations this assistance comes from family, from community, from the market, and from government, but there is no consensus on how these responsibilities and costs should be divided up, and how care should actually be provided. Therefore, we felt that a conference focused on a particular topic, the ideal long-term care system for frail older people, would be of value. We had in mind the following key issues. What are the key factors to worry about? How can we deal with them? Where should we go from here, in terms of both research and practical planning?

The occasion for this conference is that Japan has just enacted a new public, mandatory program of Long-Term Care Insurance. It is likely to cost some $50 billion a year in the next decade or so. Interest in how this program and long-term care in general can and should work is widespread among Japanese government officials, health-care and social-service professionals, scholars, and the general public. We expected these discussions to have a substantial impact in Japan (the proceedings are being published in Japanese by Chuuou Houki). Moreover, because our approach is generic rather than system-specific, we felt confident that these ideas will contribute to a broader international discussion as well.

Our symposium, which was the fourth of this series, was unique in that it was not focused on biomedical science, but on the clinical aspects of long-term care and systems. We therefore invited a multidisciplinary group of experts from within Japan, and from Denmark, Germany, the Netherlands, Sweden, United Kingdom, and the United States, as well as a representative from the OECD (Organisation of Economic Co-operation and Development). In total, 27 participated, 14 from overseas and 13 from within Japan. The disciplines included medicine (geriatrics, rehabilitation medicine, nursing home medicine), nursing, social work, gerontology, political science, economics, and sociology. Because we recognized the importance of real-life situations, we invited not only academics but also people with practical experience and responsibility in provider organizations, government, and journalism.

The organization of the symposium was also unusual. All participants were asked to write short papers on a topic that we suggested, based on our knowledge of their expertise and expected contribution to the conference. We asked that they draw on real examples and general consideration from their own experience and the literature, rather than reports on research projects and so forth. To provide some orientation to the situation in Japan, we sent out information on its health and social service systems, including an article on the new long-term care insurance (see the Appendix). These papers were published and distributed before the meeting in a Special Issue of the *Keio Journal of Medicine* (Vol. 47, Suppl. 2). To maximize the time available for discussion, the papers were not formally delivered at the conference. The revised versions of these papers are included in this volume.

The meeting was divided into eight sessions. The first four sessions lasted the entire morning or afternoon and were organized according to the following themes.

1. Family and social care: The role of the family, relationship between formal and informal care, the role of professionals.
2. Clinical aspects: How physicians and nurses deal with long-term care, boundaries between acute and long-term care, the role of education, training and research.
3. Macroeconomic and macropolitical setting: The extent of public responsibility, manpower issues, financing and political support.
4. Program design: The role of housing and other sectors, how to decide eligibility, the role of care managers, how to develop services.

We as editors grouped the papers according to these themes, and for each session asked a member to make a short introduction and summary, which was followed by comments from a discussant. The rest of the time was spent on discussion among the participants.

The fifth session was a short one in which the participants were divided into four groups defined by these themes to discuss the main issues and come up with suggestions for the conclusion. The sixth was also short to initiate a discussion of how all the factors we had talked about can function to improve the life of a frail older person. The seventh discussed the preliminary summary of our conclusions (based on a draft by the Organizing Committee).

The eighth and final session was a public symposium in which we presented our conclusions briefly and heard short presentations from several of the conference participants. More than 400 academics, policymakers, practitioners, and students attended, and although the time was limited, the discussion was lively and interesting.

We organized our meeting this way because the problems surrounding frail older people are so difficult and so interrelated. We hoped for an open dialog among people of different disciplines from countries that have contrasting policies toward long-term care. As the discussion represents the real essence of our meeting, we as editors spent some considerable time summarizing it in this volume. We hope our efforts have succeeded in catching some of the animated discussion and the cross-fertilization of ideas, which we felt were very productive and exciting.

We wish to thank all participants for their contributions. To the Organizing Committee members, those who made the introduction and summary or were discussants, or sat on the panel in the public symposium, we extend our special thanks for their extra efforts. We are grateful to the American Geriatrics Society and the Japan Medical Association for their endorsement of the conference. We were greatly helped by the excellent simultaneous translation made by Communicators and the detailed transcriptions prepared by John Traphagan. We could not have managed without the untiring administrative support of Hiroshi Ohin, Junko Shimane, and Hajime Ebihara, the Conference Secretariat, and Keita Yamauchi and Ikuko Tominaga as assistants. Finally, we would like to express our gratitude toward the staff of Springer-Verlag, Tokyo, for their untiring support.

August 1998
John C. Campbell, Naoki Ikegami
THE EDITORS

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Session 1

Social and Family Aspects of Care

Introduction and Summary

CHRISTINE E. SWANE

The topic of this session includes six papers that take us to the United States, Japan, Sweden, and Denmark. The authors are Ruth Campbell from the States, Naoki Ikegami, Yukiko Okuma, and Akako Sodei from Japan, Margareta Ivehammar from Sweden, and myself, Christine E. Swane, from Denmark.

I have emphasized ten issues from the papers on family and social care that integrate perspectives concerning the main groups involved in long-term care (LTC): the frail elderly, family, professionals, and volunteers.

1. Once a model for LTC is established, in the practical work professionals who manage and organize care work must look into the specific situation of each frail older person and their family situation. There is not one general solution at the individual level.
2. It is a myth that family care per se represents an idyllic way of giving and receiving care, even in Japan.
3. Family is not a caregiving entity as such; there is always one person, most often a woman, who is responsible and doing most if not all of the work. Despite spouses who are caring for one another, family caregivers are mainly daughters and daughters-in-law. Overload of care work is health threatening to the caregiver herself.
4. The interests of frail older people and family caregivers are not always, if ever, the same, and the needs of both the old person and the family caregiver must be met to establish a good supportive system. To ensure that the rights of the mentally frail elderly especially are respected, some kind of guardianship is recommended.
5. There is a need for sufficient training of staff—doctors, nurses, nurse aids, and home helpers—who should be trained in both social and medical disciplines in which the theories in social work and occupational therapy represent this dual perspective.

6. LTC must focus on interdisciplinary cooperation of staff. The development of Scandinavian LTC shows that there are major cultural differences between doctors, care staff, and therapy staff, and between professionals and volunteers, but that these can be overcome if they are dealt with directly.
7. LTC must create pathways of information and communication between the elderly person, the family caregiver, and the social and health care system. It could be through a care manager or a professional contact person.
8. LTC must create pathways of information and communication between social and health care organizations, i.e., between home care, general practitioners (family doctors), institutions such as nursing homes and hospitals, and the voluntary organizations.
9. As is found in health care, it is also in family and social care better to prevent than to cure. A so-called snowball effect should be prevented, i.e., situations in which the lack of response to an older person's minor health and social problems causes the person eventually to become "bedridden," hospitalized, or in a nursing home, now not as a frail person but as a person totally unable to take care of himself or herself and without much remaining dignity.
10. The creation of a LTC system in which formal and informal care mutually support each other relies on a change in attitudes among the elderly, family, and staff. Each frail person must be seen as representing more than a symptom or one or several medical diagnoses; the person is still a social and historical human being.

The conference is organized for scholars to discuss and work on strategies for an ideal LTC system for frail older people. The process will demand much construction of categories such as the elderly, family caregivers, the professionals, and volunteers. These are categories based on concepts we may immediately find easy to understand, as they seem to be rather self-evident. We often speak in very general terms; this is the reason why I at the very beginning of this conference want to look closer at some of the concepts, by doing a bit of deconstructioning of some of the keywords in the family and social care theme.

Family caregivers, staff, volunteers, the elderly, nursing homes, LTC, care work—these are all categories that we most often talk about and write about as if they were quite univocal entities. We take many things for granted concerning the meanings we ascribe to these words or categories.

The papers in this session appear all to be arguing, in one way or another, to view such categories in more complex ways, as categories representing multiple worlds and realities. The papers want to take us closer to the lives of real people who inhabit the categories of the elderly, the family caregivers, and the staff. Or, one could say, the papers tell us to look into the issue of care relationships and the cooperation between organizations, with open eyes, to make us able to grasp the dynamics of the groups and people involved and of the organizations and institutions involved.

Concerning the category of family, one of the main reasons we are together at this conference is that families as entities are different and function in a variety of ways. The Japanese family care structure has been different from that of the Western countries, but as structures of modernity include changes of the work structure and the life course, particularly of women, matters of how to organize family and social care become somehow more similar all over the world. The countries represented at this conference all do experience jointly how the family now includes more generations—four, five. The frail older people in the family need care for more years than the frail oldest did just some decades ago. In modernized societies we are able to keep frail and diseased people alive longer, which is one of the reasons why the number of people with dementia is growing so rapidly. In some countries the birthrate is falling to such an extent that there is no longer a chance for society to rely on family care as the main care source.

The family is not a very precise concept or entity if we look at the family dynamics—the way people relate to each other and feel responsible for one another. The family entity certainly varies by the actual people in the family and how they get along, what their positions of power versus dependency are in relationship to one another. Takako Sodei (see chapter by Sodei) refers to recent surveys in Japan that show how the percentage of frail elderly who prefer to be cared for by their spouse or daughter is increasing, but the percentage of those who prefer to be cared for by their daughter-in-law is decreasing.

Care work in the family is practical care, but also provides psychological comfort, as Sodei also points out. How this psychological comfort is done can be questioned when care work in the family is (1) unskilled, meaning that the women lack knowledge of how to help in the best ways, and (2) an obligation as it is in the tradition of the "Oyomesan," the wife of the eldest son having the care responsibility. Yukiko Okuma writes about how the policy called "Nihongata Fukushi" (Japanese style welfare) anounced in 1979 built on family care, nursing home business, and the use of volunteers (see chapter by Okuma). She writes how "Oyomesans" while in their seventies can be responsible for the care of parents-in-law who are in their nineties now that old people live longer. This is almost bound to lead to different kinds of neglect and abuse at times.

Concerning the category of the elderly who stand at the center of our concerns, Ruth Campbell's paper is quoted: "Older persons are squeezed into a box that doesn't fit." (see chapter by Campbell). This box has some kind of label that stigmatizes old age as a period of life when a person's physical decay necessarily is followed by intellectual and emotional decay. We keep referring to the category of old age by this label, despite the general knowledge of the heterogeneity of the population.

Talking about expansion and improvement of voluntary organizations, there is a potential in the aging population itself where physically fit and mentally healthy elderly help the more needy elderly, as pointed out by Campbell. In Denmark, the Ministry of Social Affairs presently has a huge program named Elderly Help Elderly that initiates activities around the country. One of the really positive effects of such kind of activities lies in the self-preventive effect, prevention of becoming frail yourself. When you help others voluntarily, you help yourself by, for instance, finding meaning in life, socializing with other people, doing physical exercise, etc.

The issue of training of staff is discussed by Naoki Ikegami, Margareta Ivehammer, and myself. Staff is a category of very different professional cultures. Due to the historical development of science, we have constructed a hierarchy of medical and social knowledge, placing medical knowledge above the social. This is true at the organizational level, too, where we find a higher status and prestige related to work in hospitals as opposed to the lower status related to work in nursing homes and home care, as discussed by Ivehammer (see chapter by Ivehammar). And low-paid care work is everywhere present. One of the main consequences of the predominating medical thinking in care work and rehabilitation is found to be the focus on the problem, i.e., the disease or the symptom, rather than the individual person and the person's everyday life situation.

There is a need for staff who are "cross-trained" in social and health disciplines, as Naoki Ikegami wishes for future LTC staff in Japan, staff who share a common learning experience or at least a common knowledge base (see chapter by Ikegami).

In Denmark, a unified social and health education was established 6 years ago to upgrade the skills of people who provide services and care to the frail elderly, which means people "on the floor," the home helpers and nurse assistants—and to train newcomers into the field. Because the hierarchy in social and health care organizations puts physicians at the top positions, and as role models, as Ikegami puts it, an emphasis should be made in teaching disciplines needed for the development of LTC at medical schools.

Bringing teaching about care and rehabilitation strategies up front in medical schools is very important. This goes for nursing schools as well, where "pure" medical knowledge is often taught without paying enough attention to the personal history of the people whom the nurses are going to treat, cure, or care for. In the papers on care in Sweden and Denmark, the role of occupational therapists and social workers as important members of social and health care teams is emphasized. They, if any particular group, can supply the medically oriented practice work with a way of thinking that goes beyond the disease or specific symptoms. As Ivehammar writes about Sweden, medical and social care are working jointly on the same goals in the new care strategies, which goes for Denmark as well. She points out how the culture of medical and social thinking is very different; hence, concepts such as "self-determination, freedom of choice, and integrity" do not mean the same thing in a social organization and in a medical one. Campbell writes how, according to Akiko Hashimoto, the sence of security, as being central to expectations for support in old age, is conceptualized differently in Japan and America. In Japan there is a protective approach based on care provided by children, whereas Americans equate security with the ability to maintain autonomy and the possiblility to choose from multiple options. But as family structures, work structures, and life courses are changing these years, so are the experiences attached to these concepts likely to be changing.

The papers address the issue of attitudes or images of old age either directly or in between the lines. "Change of attitudes" has been, and still is, a key issue in the changes of the Scandinavian social and health care systems. To get people to cooperate who are not used to communicating, making plans, or actually working together, attention must be paid to their attitudes to old age and to each other as having different professional backgrounds. The need for changes of attitudes is explicit in the development of care strategies for people with dementia. Dementia care can be seen as an area of model testing to explore coordinated, flexible, caring environments where social care plays a larger role than the medical.

Commentary: Will We Have the Wisdom to Learn?

PETER J. WHITEHOUSE

Let me begin by thanking the organizers, Professors John Campbell and Naoki Ikegami, for this timely conference to celebrate and assist the birth of Japan's long-term care insurance (LTC) system. Let me also like to thank them for the wisdom for beginning the conference (and as you will see ending also) by focusing on the frail individual and their family. Let me also congratulate the authors of papers in this session and Christine Swane for her excellent summary.

To explain my title, I will claim that there is a revolution ongoing in the field of education not unlike that under way in health care. The fruits of this educational revolution will need to be applied at all levels of health care systems to solve the problems that Japan and other countries will face as they develop care for their citizens in the future. Like the revolution in health care, the revolution in education focuses on the consumer, i.e., the student or patient, rather than the provider, and asks for demonstrations of value to society. New educational approaches are being developed, including use of information systems to provide multimedia individually tailored educational modules. Through lifelong learning, individuals are committing not just to obtaining educational degrees but to acquiring new knowledge throughout life. This learning will not just be the accumulation of facts and not even just the integration of these facts into knowledge but rather a genuine quest for wisdom that includes the integration of knowledge with human values and its application in real life. I presume for the rest of this discussion that this new enthusiasm for different ways of learning will be critical to the thriving of LTC systems.

I will structure the remainder of my comments by examining relevant educational and training issues at different levels of the health care system. We begin with the individual frail elderly and their family, continuing through individual providers and teams of providers, and finally discussing social policy.

A critical component of the successful LTC system is to instill a sense that each individual person has responsibility for his or her own health. Preventative measures, such as attention to diet and exercise, will increasingly be emphasized. Throughout life individuals and families will be expected to acquire the latest knowledge to keep themselves and their loved ones mentally and physically fit. Already the use of the World Wide Web as well as other methods of education are creating a more educated populace of potential users of LTC. Families and communities will also need to learn together to adapt to local variations in the LTC. Individual providers who wish to be LTC care experts will also need to have access to the latest information to support care. Long-term changes in attitude will be fostered by the addition of material about geriatrics and health care systems early in the education of future professionals.

Increasingly, care will be provided by teams of individuals (for MD, RN, SW, and others). Thus, learning to effectively communicate not only with patients and families but with other professionals will be an essential part of the education of geriatric professional caregivers. Moreover, attention to group dynamics and the sharing of power among disciplines and with patients and families will be important to the development of effective interdisciplinary care. The commitment of families to provide informal care will need to be enhanced and the interface between formal and informal care monitored vigilantly to ensure that professionals do not undermine the appropriate inclinations that families have to provide care for one another.

Perhaps the greatest need is more education (and wisdom) is at the level of public policy. Too often the issues of LTC are not well understood by those who influence and make decisions about public policy. Yet, it is at this level that every individual citizen needs to be sure to think through the priorities for society in the future. One of the abilities that human beings possess more than other life forms is to envision the future. These abilities will be greatly challenged over the decades to come by the aging of ourselves and fellow citizens.

In this last section we will briefly consider some of the broad trends that are altering our world and how a response to these changes need to be integrated into the development of LTC systems. First, although the development of LTC insurance in Japan represents important social recognition of the epidemiological trends leading to the graying of the world's population, still more needs to be done. The implications of the increasing number of elderly people combined with lowered birthrates in many parts of the world will lead to fundamental shifts in the organization of society. We already see the stress on younger individuals to provide care for older individuals is dramatically increasing.

A major part of the change in the social organization involves women. Women live longer and are more at risk for the consequences of fragility in old age. Women are entering the workforce in greater numbers in many countries, thus becoming unable to provide the same forms of informal care that they have traditionally in the past. Although one might argue that the rate of accumulation of formal power in the hands of women is still too slow, it does seem clear that women are gaining more positions of prominence in many of the world's major countries. We must have the wisdom to understand the consequence of this shift in power. Women communicate and problem solve differently than men. Women tend to focus more on the social relationship and community issues. It seems quite possible that the attention to LTC where women have traditionally had many of the major roles already will be well served by the ascendancy of women into greater positions of formal responsibility in society. Another general trend that will need to be thought about is the increasing destruction of our environment. This may contribute to major health care problems, environmental limitations, and economic consequences, which will affect our ability to provide LTC.

The biological sciences underlying medicine and other health care disciplines are also changing dramatically. The power to understand our very essence as biological creatures, namely our DNA makeup, is accelerating rapidly. Our understanding of neurodegenerative diseases such as Alzheimer's disease from which the frail elderly suffer all too much is also increasing. Yet, we are beginning to recognize the limitations of our ability to use the knowledge wisely. We continue to overexaggerate the potential for science to solve problems, which may in fact be of their own creation. Identifying a gene in disease has not led quickly to effective therapies. Thus, we need to respect the contributions of biological science but also question about how much we must depend upon this approach to solve our problems with chronic degenerative diseases of the elderly.

In the evaluation of medications and other health care interventions, we are also, perhaps, placing too much faith in the ability of scientific method to answer important questions. Although the trend toward evidence-based medicine and outcomes research should be encouraged, the complex questions that face policymakers developing LTC systems cannot always be answered by randomized control trials or even other forms of outcomes research. The number of variables is enormous, and the possible interpretations of outcomes increase with the complexity of the study.

We are also increasingly recognizing that there are many value issues underlying health care system development. Thus, the ascendancy of biomedical ethics in the last 25 years, particularly in the West and now increasingly in Japan, is an illustration that values and not just facts are important to development of health care systems. The development of medical technology can create tremendous ethical dilemmas. Increasingly, the distribution of resources in "have" and "have-not" countries will be an issue. There clearly seems a sense that these ethical problems can be informed by but not handled effectively with purely scientific approaches. In an age that has been referred to as postmodern, individuals are struggling to define what is meant by quality of life and what gives purpose to life. As we develop our health care systems we must attend to these noncognitive or emotional sides of people's lives. Religious and spiritual values will also need to be reflected in LTC, particularly those components that are concerned with individuals at the end of their life. Assessment of the impact of health care interventions on quality of life will be key.

In summary, the effective use of training and educational approaches throughout the LTC system starting with the patient/client/consumer and ending with each one of us who are involved in establishing social policy will be critical. Educational programs can provide us with basic information relevant to providing daily care for the frail elderly, as well as the foundation of wisdom that we will need to ensure not only the development of effective LTC systems but the survival of the human race as well.

From the Perspective of the Older Person

RUTH CAMPBELL

Key words: Geriatrics—Community care—Assisted living—Social work—Elderly

My comments are based on my experiences working as a social worker with the elderly for more than 30 years, first in a senior center in New York City (NY, USA) and, for the past 20 years, in a university-based outpatient geriatric clinic. I think we do a pretty good job when people are healthy. Older Americans are traveling, going to classes, exercising in greater numbers than ever before. And all evidence seems to point to the fact that most of them are healthier, more educated, and in better financial condition than their parents were. The enormous growth in assisted living has produced housing that is better suited to their needs, especially if one can pay the price. It is at the point when health—physical, social, emotional—begins to fray that the problems become apparent.

The fallacy of the American long-term care system is that it offers many choices. Home care? In our county we have 24 different agencies offering about the same kinds of services, competing for the same staff. We have nursing homes, retirement homes, small group homes, one- or two-day care centers, and an array of other supportive services. The truth is that it seldom offers the choices people want. It is in most cases a system responsive to the provider rather than one responsive to the client. And as Kane et al. [1] pointed out in a study on nursing home residents and nursing assistants, both the providers and the clients are often caught in a self-defeating cycle in which they see autonomy and control as desirable goals but find no way to achieve them in their specific settings.

Policy Issues

1. Although the heterogeneity of the over-65 age group is a cliche of the gerontological literature, services are not designed to meet individual needs. The older person must be squeezed into a box which does not fit. For example, Mrs. Green is discharged from the hospital after 5 days during which she has been mostly bedbound. Her condition is improved; according to the hospital staff, she does not need skilled nursing care at home. But she has no family, her bed is upstairs, she is very weak and anxious. To get basic help for her at home to get her back on her feet, I have to convince the physician to send in a skilled nurse, which she does not need, so she can get the basic help she does need. Care management? She does not fit the guidelines for our local program, which, even if she did, has met its capacity of 40 persons and has a waiting list. Of course, the purpose of guidelines is to keep most people ineligible, thus containing costs.

2. Another cliche in the field is the "continuum of care." An array of services make up the long-term care system with nursing home care at one end and community services at the other. In reality, services are fragmented and there are no smooth links to convey the individual from one segment to another. For example, in home care, Mr. Smith enjoys the multiple services of a nurse, physical therapist, and aide after hospitalization. He improves; services stop. Mrs. Smith becomes exhausted from the care still needed but the home care agency is finished and does not bother to tell her what else might be available to her. Very often, people do not even realize when they are in the hospital that a short stay in a nursing home for rehabilitation is available to them. Even within a Continuing Care Center, people are moved from one level to another without understanding or receiving sufficient support to manage the transition. The services are mysterious and hard to access for most people. And family members, newly introduced to these mysteries, often have no idea where to turn.

3. As is clear from the previous points, the long-term care system is mostly a medical one. How did the social services become subsumed by the medical? Why are nursing homes like minihospitals rather than homes? Why is all the attention and much of the research devoted to "up-front" services like diagnosis and assessment while the "long-termness" of care is more or less ignored? Energy and time is spent on systems such as the MDS so that we know what the problems are, but we still seem

far from addressing the major problems of long-term care, which are fear of change, loneliness, isolation, and ongoing need for care from someone.

4. The people who provide most of the care are the family and other unskilled workers. Highly paid professionals move in and out, and the bulk of the care is given by people who are often unsure of what they should be doing, distressed by their lack of knowledge, and frustrated by their subservience to superiors whom they often feel do not understand the nature of the problem. This important sector, the grassroots, "on-the-line" people, need higher pay, better training, and emotional support. A 90-year-old woman with Parkinson's disease living in a group home, which costs $1800 a month and will never be covered by Medicaid or Medicare, is cared for, along with the four other elderly woman in the home, by a 60-year-old woman with an aching back who is relieved at intervals of the day by a rotating crew of inexperienced helpers.

Some Solutions

1. I think there are some excellent models that seem to provide what people want. One of the most successful, I think, has been hospice care, which is largely performed in people's homes, but there is an increasing recognition that for some people an inpatient setting is also needed. Hospice is rooted in the community. Family members are key participants with professional staff. Volunteers are routinely used to supplement staff. Careful attention is paid to the patient's perception of pain, rather than abstract rules about when to use pain killers. But hospice care lasts on an average of less than a month. As one older woman put it, "Why does everyone care so much about people who are dying and pay less attention to people who are living?" Many hospice agencies are part of licensed home care agencies, and yet the model used for hospice care does not flow into home care practice.

Another model is seen in all the environmental and staff innovations for patients with Alzheimer's. Although the benefits of these units are not clear, the idea of providing kitchens that residents can use freely, spaces for wandering, and more attention to individual differences, is something all nursing home residents would like. William Thomas' ideas [2] about empowering staff, bringing the community, plants, and animals into the home, and offering flexibility and freedom are not designed for one diagnosis but for anyone living in an institutional setting. These models should be supported and replicated widely.

2. Communities need to be strengthened so that transportation, day care, and minimum services for community care are uniformly available everywhere, and local newspapers and media should use their expertise to publicize and market these services.
3. There should be a shift from medical personnel delivering many of the services to a well-trained and better paid corps of home helper-type people with promotional opportunities available. Professionals should be integrated into the system as trainers, consultants, and mentors, providing their expertise as needed. But entry into the system should not be based on medical or ADL (activities of daily living) needs only.
4. Older people themselves should serve as helpers to their more needy peers. The elderly population has a large potential that has barely been tapped. A senior helping corps could operate on a volunteer or stipend basis to provide essential ongoing services to their peers.
5. The elderly in need of help and their family members have to feel that their input is important and that their often-varying needs and fears are addressed.

Akiko Hashimoto [3] talks about the sense of security as being central to expectations for support in old age. She sees this sense of security conceptualized differently in Japan and America. Japanese prefer a "protective" approach focused on care provided by children because it promotes a sense of certainty. Americans equate security with the ability to maintain autonomy and choose from multiple options, what she calls the "contingency" approach. "For the Japanese, the open-endedness of the American practice does not create a sense of security, because it promotes uncertainty; by the same token, the predictability of the Japanese practice does not foster a sense of security for the Americans, because it offers no choices (p. 152)."

I think these differences are real but they may be diverging to some place in between. Japanese are becoming more interested in choice and living apart from their children, and Americans are becoming more aware as life gets extended that the meaning of autonomy and independence deepens as it gets revised. Even within frailty, older adults fight to maintain what is important to them and to avoid anything which threatens that. To return to the beginning, for me an ideal long-term care system promotes individual change and growth while keeping the externals such as housing, support, and health care as stable and secure as possible.

References

1. Kane R, Caplan AL, Urv-Wong EK, Freeman IC, Aroskar MA, Finch M (1997) Everyday matters in the lives of nursing home residents: wish for and perception of choice and control. J Am Geriatr Soc 45:1086–1093
2. Thomas WH (1994) The Eden alternative: natures, hope and nursing homes. The Eden Alternative Foundation, Sherburne, NY
3. Hashimoto A (1996) The gift of generations. Cambridge University Press, Cambridge.

Further Reading

Mack R, Salmoni A, Viverais-Dressler G, Porter E, Garg R (1997) Perceived risks to independent living: the views of older community-dwelling adults. Gerontologist 37:729–736

Improving the Quality and Expanding the Quantity of Long-Term Care Staff

NAOKI IKEGAMI

Key words: Certification—Cross-training—Career paths—Care manager—Credits

Apart from the cost aspects, the greatest challenge that we face for establishing an ideal LTC (long-term care) system is that of human resources. First, regarding the quality: few professionals have adequate knowledge of LTC, nor have they had experience in working in teams. One of the reasons why medical and social services staff remain so divided lies in the fact that the professions are educated and trained in isolation to one other. Thus, each has little knowledge of the other.

Because LTC will be composing a significant part of social security programs, I think that all those electing to enter the health and social service sectors should be required to have basic knowledge of LTC, with courses jointly designed and taught for this purpose. For those who already have qualifications, cross-training should be made compulsory as part of continuing education programs. Thus, by eventually sharing a common learning experience, or at least having a common knowledge base, the present barriers can be lowered and communication improved.

Lowering Barriers for Obtaining Professional Qualifications

This reform should be part of a more comprehensive effort to redesign the way professionals obtain their qualifications. At present, to be allowed to sit for certification examinations, one must first graduate from schools that are specific for each profession. Once new professions are established, their associations become primarily concerned with improving the status, earnings, and working conditions of their members. As prestige and income tend to be correlated with the length of the training period, there has been a constant push to extend it so that it approaches that of physicians. Such highly trained and specialized staff may improve quality, but perhaps not to the degree to justify the much higher costs. For after all, especially in LTC, the bulk of hands-on care continues to be provided by staff without much specialized training. Another negative aspect is that each profession imprints its unique culture, value, and language on their members so that they tend to have greater affinity among themselves than with other professionals of the care team.

I believe that training should depart from this model and become more flexible. Only by offering opportunities for career development and decent wages for the lowest paid worker can the general quality of LTC staff be improved. Individuals, especially those who have had experiential learning or have qualifications in related fields, should be allowed to sit for professional qualification examinations without being required to go through the prescribed number of years of training in professional schools. Credits should be given for practical experience, on-the-job training, or courses already taken in other schools. By shortening or sometimes waiving the time spent in formal education, career paths could be opened even for those entering at the lowest level. Quality can be assured by requiring a high mark for passing the qualification examinations, mandating short training courses after passing the examination, and periodic recertification. LTC would particularly benefit from this new approach, in that the caliber of people entering into to this field is not always high, the essential skills are more centered on human interaction gained from experience, and there is a tremendous need to expand qualified staff. In this way, the second issue of expanding quantity can be solved without compromising on quality and, indeed, improving it by boosting the morale of the average worker and simply by more appropriate training.

Apart from those who provide hands-on care, the occupation that would greatly benefit from this new approach is that of care managers. The care manager is the key person who coordinates the care provided by the various agencies. She must act as the advocate of the client, yet be responsible for remaining within budgetary constraints. This role is centrally important, and yet there is an acute shortage of people who are capable of adequately performing it. No single profession should be in a position to monopolize this position, precisely because the combination of medical and social skills that is required is not being taught. Thus, the flexible approach to obtaining a license that has been proposed in Japan would be particularly appropriate for care managers.

Need for Government Intervention

The education and certification of LTC staff is one area where the government must actively intervene because the prospect of reform emerging internally from among the professions is unlikely. In addition to changing the legislation concerning professional certification requirements, appropriate financial incentives should be introduced to universities and training schools for joint training purposes. In particular, because physicians often serve as role models for the other professions, the curriculum in medical schools should be revised to place greater emphasis on LTC.

Further Reading

Ikegami N (1992) Policy choices in health care (Iryou no seisaku-sentaku) (in Japanese). Keisou Shobou, Tokyo

Ikegami N (1998) Deregulation in health care—professional qualifications (Iryou ni okeru kisei-kanwa) (in Japanese). Shakai Hoken Junpou 1970:9–14

Social Aspects of Care and How They Relate with the Medical

MARGARETA IVEHAMMAR

Key words: Cooperation—Knowledge—Commitment—Attitudes—Evaluation

Reform for Cooperation

In Sweden, the municipalities, through the ADEL reform (in 1992) assumed the combined responsibility of providing the elderly with long-term care and service. Under the reform, 31 500 long-term care beds were transferred from the county councils to the municipalities. The Social Service Act establishes a right to help if the need for it cannot be met in any other way. If an individual is dissatisfied with a decision, he or she can appeal against it in a court of law.

Help in the home, transport services, and organized daytime activities are examples of service which, the Act states, shall be available in every municipality. For old people who cannot manage at home, the municipalities must provide special housing, e.g., old people's homes, service flats, group dwellings, and nursing homes. Since 1992, group dwelling has become more common. This is intended for small groups of people who have their own private apartment plus communal areas. The type combines individual and communal living, care, and smallness of scale.

I worked in Linkoping city at the time for the ADEL reform until recently. Linkoping is the fifth largest city in Sweden with 131 000 inhabitants. Of these, about 15 600 are 65–79 years of age. About 5300 persons are 80 years or older. At least 16% of the population 80 years and older need special care and/or sheltered housing. This group is steadily increasing, and will be 10% greater in 1999, with the maximum in 2007.

There are at present about 65 units of service housing and sheltered housing. These are distributed all over the city and in the villages surrounding the city. These units are 930 service flats (2 rooms, with kitchen and bathroom, 850 rooms/small flats in all) in nursing homes, old people's homes, and group dwellings for persons with dementia. After 1992, the long-term care beds were replaced with the small group homes.

Respect for Different Knowledge

When the city of Linkoping received the responsibility for all long-term care, we also got the responsibility for 600 new care workers from the county council. The municipality social service organization already had 1600 staff working in social care for the elderly. The task was to mix staff with long experience from medical care and staff having experience with social care. The various staff groups were home helpers, supervisors, nurses, nurse assistants, physiotherapists, and occupational therapists.

We met a lot of suspicion and even sorrow during the introduction from our new staff members. There has always been a difference in status working in an "hospital-like institution" and working with social care. Some of our new staff members felt that they really lost something important to them. But we also met a lot of enthusiasm from those who thought that it was the right idea to offer elderly a more homelike place to live in, even when they need a lot of aid and care. The organization had to work hard with their attitudes. Today we have a very good mixture of knowledge in our staff groups.

ADEL reform gave the municipality responsibility for the basic medical care provided by nurses in all sheltered housing. Medical care given by doctors is still the responsibility for the county council. Suddenly, the doctors and the nurses giving care to the elderly were organized in different organizations. Sometimes this is a problem. It can be difficult to get in touch with the doctor. Just after the start of the ADEL reform we found it very hard to be on "speaking terms" with the doctors. Doctors were collectively very negative toward the reform. My experience is that we really had to work with that. Today I can say that our relations between the social organization and the medical are much better.

From some places in Sweden, however, there have been reports from long-term care units where appropriate medical care has not been provide. Of that we feel very ashamed. After these events, a discussion in Sweden has arisen of making the care for elderly more medicalized in its structure again. I do not think that is the appropriate thing to do. We must work harder in our cooperation. Maybe there should be doctors more connected to the organization that is responsible for the basic care. Medical care and social care have worked together on goals, but still we fail, and I think that the culture is so different and goals as "self-determination, freedom of choice or integrity" do not mean the same thing in a social care organization as in a medical organization.

Goals for the Future

Here are some examples of goals we have written for special types of housing:

To offer people who are in need of much care secure housing with a good everyday life and culturalleisure-time activity for a good quality of life.

To offer everyday care, round-the-clock care, and qualified medical service/treatment when needed. The care shall be offered as an individually adapted care. Individual demands should be respected and not subordinated to staff routines. The staff should be able to understand the importance of a welcoming attitude toward relatives and friends.

To guide and help relatives when they want to take part in complicated caregiving, but also to respect others if these contacts should not lead to any cooperation.

To have an "everyday" discussion about the theoretical ideas and goals with your staff is very important, but you must also make sure that the goals have a practical meaning to everyone and that they can be measured as quality. To be successful in giving good care, it is important to create a method in planning the care, to document the care given, and to evaluate the care at regular intervals. We have worked with the model when you have a special "contact-person" among the staff. This person is responsible for the planning and the evaluation. The supervisor must be a good tutor and make sure to get feedback from the staff about how care is given. Staff must know when it is time to get help from the "next level"; from OTs, Pts, or from a trained nurse.

Quality of Care

In Sweden, there are systems for inspection to maintain quality of care for the frail elderly. The local authority is responsible for evaluating and making sure that each individual has an adequate standard of living.

Every Swedish municipality must have special nurses (Medical Responsible Nurse), who are responsible that you as a client receive the medical care you need.

The National Board of Health and Welfare has given general advice about abuse toward elderly. If you as staff found that abuse toward the elderly, who are depending on help and care, has happened, you must report that via a special routine that each municipality must organize. The manager of a unit makes sure that all staff knows about this.

In Sweden we have opportunities to create good care for the elderly. We have powerful legislation, good housing, and staff with good knowledge and commitment. Still, you have to keep the discussion going in the organization, evaluate the activities at regular intervals, and offer staff new knowledge and support in their professional work.

Further Reading

Commission on Response to the Elderly. Responding to the elderly. Fritzes, Stockholm
Okumura Y. Den svenska äldreomsorgen (Japanese edition). Fritzes, Stockholm
Svenska Institute. The care of the elderly in Sweden. Fact sheets on Sweden. Svenska Institutet, Stockholm

Women's Roles as Caregivers: Family, Worker, Volunteer

YUKIKO OKUMA

Key words: Japanese style welfare—Netakiri Rojin—Denmark

It was in the year 1985 that I came to realize the importance of long-term care (LTC) and began cross-cultural research in this field. Until then, being a journalist specializing in science and medical care myself, I was misled by the term "Netakiri Rojin."

"Netakiri Rojin" is an administrative term for elderly people who spend their last years in their beds from morning to night in their nightgowns. It is a term used on a daily basis. In 1985, statistics such as "in the year 2000, the number of Netakiri Rojin will be 1 million" were accepted in Japan. Engineers were busy developing "beds especially for Netakiri Rojin" so that the elderly could bathe and excrete while lying in their beds. Municipalities providing "Netakiri Rojin benefits" were considered kind.

In 1985, I began visiting countries where an aging society had begun before it had in Japan. It was then that I realized that the term "Netakiri Rojin" was unique to Japan. Table 1 shows the differences between Japan and Denmark concerning human resources and administrative philosophy underlying this issue.

When I was probing the cause, a policy called "Nihongata Fukushi (Japanese-style welfare)" which the Economic Council announced in 1979 came to mind. This policy was composed of three main support columns: the first is support of the family, the second is the use of the nursing home business, and the third is the use of volunteers. It was thought that Japan had now caught up with Western countries. If Japan provided satisfactory services following the examples of countries such as the Scandinavian countries and the United Kingdom, the Japanese economy would collapse. Therefore, Japan must seek its own unique method. From then on, this view became the basis of the welfare policy for the elderly.

Table 1. Denmark and Japan: a comparison of long-term care for the elderly[a]

	Campaign begins in 1985: the reported differences		Summer 1989–end of 1997	
	In Denmark	However, in Japan	Japan: the nation and municipalities begin to change!	
	No administrative term such as "Netakiri Rojin" (Life with activity has rehabilitation effect)	"Netakiri Rojin" used daily as administrative term (Keeping them lying down leads to inactivity syndrome)	1989	Care Committee inaugurated by Ministry of Welfare
Care	500 000 home helpers (number adjusted per population for comparison with Japan)	25 000 home helpers		First woman chief in charge. Suggest and begin the following: LTC that does not confine the elderly to bed
	Provided 24 hours/day according to need	Provided a few times a week during daytime		Municipality-centered
	Is a right regardless of income	Low-income families eligible; considered shameful		Possibility of financing through social insurance
	Home helper has authority and high salary	Home helpers have low salary	1990	Ruling party suggests tax increase and loses women's vote—and the election
	Has right to vacation and consideration and is respected	Men do not want to become home helpers		To regain women's vote, "Gold plan," "Zero Netakiri Rojin Strategy," and "100 000-Helpers Plan" introduced
	Home helpers (municipal employees) provide humane services	Home helpers (civil servants) carry out administrative duties		

Technical aid	Technical aid center lends self-help equipment and technical aid when necessary	The level and quality of assistance equipment very low	1994 Council at Ministry of Welfare proposes long-term care insurance (LTCI) 1995 24-hour visit project 1997 LTCI Act approved
	Individuals with disabilities participate in assessment	“Beds made for the bedridden” and wheelchairs used	1993 Ministry of Welfare and MITI enforce Welfare Aid Act
	Call-bell that can be used when lonely	Call-bell that can be used only in emergency	
Housing	Barrier-free facilites required by the Building Standards Act	The law regulates only structural defects and fire hazards; results in houses with steps	1989 Group home system for individuals with intellectual disabilities 1990 Housing alteration support project begins in Edogawa Ward (Tokyo)
	Construction Act includes “Friendly housing for the elderly”	Dreary private nursing homes with rooms that are shared	1993 Ministry of Construction announces Guide for Construction for Longevity Society
	Single-bedroom institutions in urban areas	Placed in hospitals for the elderly—4.3 m^2/bed	1996 Model project for group home for dementia begins
	Atmosphere similar to that of home		

Table 1. *Continued*

	Campaign begins in 1985: the reported differences		Summer 1989–end of 1997	
	In Denmark	However, in Japan	Japan: country and municipalities begin to change!	
Food and going out	Daily food delivery service Transportation service to go shopping and to concerts The elderly and individuals with disabilities dress up and go out (effect of barrier-free act) Testing of non-step bus Day center for each school district	Monthly luncheon by housewife volunteers Home care = "Oyomesan"; confined in closed room Elderly and individuals with disabilities cannot go out (shops and buildings have steps) Transportation facilities full of barriers Nowhere to go, so stay at home	1989 1992 1994	10 000 day-care centers planned for the elderly Ministry of Welfare starts support of transportation service Ministry of Construction enforces "Heart-build" Act
Cooperation with medical care	Investigative municipal visiting nurse	Nurse acts only by doctor's order	1992	Visiting nurse station system for the elderly
	Dehospitalization plan begins when hospitalized	Apply at government office after dehospitalization	1988	Health facilities for the elderly start (8 m^2/bed)
	Home doctors visits patients at home	Doctors seldom visit patients at home	1990	Hospitals emphasizing care for elderly start (4.3 m^2/bed)
	Leave hospital when cured. Hospital for the elderly does not exist	Fed by tubes, strapped to bed, and drugged in hospitals	1992	Institutions for recuperation start (6.4 m^2/bed) One nurse suggests care which does not involve strapping to bed

Philosophy of administration	"Support for independence," decrease social expenditure Support for self-determination, home care, and financial support for life, with respect	Full satisfaction of welfare needs leads to economic collapse Support of home care and Japanese-style welfare depend on women's unpaid work Promotion of "self-help and effort"	Ideas such as "Welfare is investment—creation of jobs" appear 1992 Manual for health welfare for the elderly plan "Do not depend too much on care by families"
	Annual plan and enterprising spirit	Haphazard planning	1989 10-year strategy for promotion of medical welfare for the elderly
	Responsibility and authority Decrease in waste and increase in creativity Municipal employees visit homes and hospitals Promote "setting precedents"	Permission of central government necessary People are summoned to municipal office "Unprecedented, therefore NO!" is the favorite answer of bureaucracy	1990 Revision of Elderly Welfare Act allows municipalities to have control Edogawa Wards (Tokyo) starts delivery service Some heads of municipalities start saying "Unprecedented, therefore DO IT"
Consequences	Decrease in medical expenditure	Increase in medical expenditure due to social hospitalization	Medical expenditure of 9 trillion yen (increase of 0.6 trillion/year)
	Pride in personal appearance Four loving generations live near each other	False teeth are removed; blank expressions Killing of elderly wife by elderly husband; suicide by the elderly Oyomesan's life used up due to LTC burden; family love is shattered	Private nursing homes and Japanese-style group homes, patients smiling and dressing up 1982 Women's Association to Make Longevity Society a Better Place 1996 10 000 Citizens Association of Care Socialization Promotion 1997 Some heads of municipalities start welfare-oriented administration

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[a] Based on an editorial in the *Asahi* newspaper.

This "Nihongata Fukushi" can be explained from a woman's point of view.

The first main column of support presupposed unpaid work by women called "Oyomesan." "Oyomesan" denotes not only the wife of the eldest son but also indicates social position. An "oyomesan" cannot refuse to take care of her husband's aged parents. As decades go by, the period of care is becoming longer and longer, sometimes exceeding 10 years. It is not unusual to see a 70-year-old "Oyomesan" taking care of a 90-year-old parent-in-law. These "Oyomesans" are amateurs in LTC and are therefore creating "Netakiri Rojin" themselves, although this is done unintentionally and without malice. Family troubles, joint suicide, and murder related to LTC are reported frequently in the media today. "Japanese LTC by loving families," which is highly praised by other countries, is in fact creating a Japanese-style tragedy.

The second main column of support presupposed a workforce of low-paid women working at private nursing homes. At these nursing homes, inexperienced care techniques and violations of human rights are occurring daily. Some examples are elderly patients being fed three times within the employees' 8 working hours, and at night, the elderly being literally strapped to their beds.

The third main column of support also presupposed unpaid work by women. The essence of volunteering is "from one's own will," but in Japan it is misunderstood as "free labor."

Japanese women have always been in an inferior position in both administration and politics and could not freely express their thoughts. This is one reason why unpaid work by women and low-paid LTC labor became the basis of the Japanese welfare policy for the elderly.

After comparing the LTC systems of about 20 countries around the world, I have come to the following conclusions.

1. The country having a system that combines high-quality LTC and relatively low costs and is thus the nearest to the ideal is Denmark.
2. The secret to Denmark's success lies, first, in the notion that "care is not a role to be undertaken by women in the family, but is a responsibility of the whole society," a belief has taken root since the 1960s.
3. The second secret lies in decentralization. The pitfall that public-sector care systems are apt to fall into is obsessive concern with "objective standards." To avoid this problem, Denmark has a policy of

emphasizing the judgment and ingenuity of the visiting nurse, the home helper, and the client himself or herself. The fact that the authority and responsibility for providing care lies with the municipalities, and not at the national level, has also contributed to its flexible structure.

4. The third secret lies in the fact that health, social, and housing policies are integrated so that care can be provided in a comprehensive way. Those needing care have their care plans drawn up, housing renovation and technical aid provided, home helpers organized, and transportation to and from day-care services arranged, while they are still hospitalized. Also, 24-hour round-the-clock home help services have been made available from the early 1980s.
5. Fourth is the system of home doctors and visiting nurses, which has made it possible to be assured of receiving LTC at home without anxiety. As a result, the situation in which those needing care are occupying hospital beds is seen much less frequently than in other countries. This has contributed to Denmark's relatively low and stable health-care costs.

It is frequently said that the Scandinavian countries may have good systems but because their costs are so high, their economies are in shambles. However, this assertion is groundless. If Denmark's total cost of social security is calculated by adding its health care, social service, and pension costs, the amount is no different from Japan's, where LTC has been left to families and hospitals. Moreover, Denmark's economy is very healthy.

References

1. Mossialos E (1997) Citizens' view on health care systems in the 15 member states of the European Union. Health Economics. Vol. 6:109–116
2. Okuma Y (1990) Countries with "bedridden elderly" and without: a challenge towards true affluence. Budosha (Japanese edition)
3. Okuma K, Okuma Y (1992) In search of society with quality longevity society: a new wave from the municipalities. Budosha (Japanese edition)
4. Krog E (1994) (Compiled under the supervision of Yukiko Okuma) Sir Krog's cheerful tales about his hardships: story of how the Danish way of independent living started. Budosha, (Japanese edition)
5. EN MUSKELVINDLER historien om Evald Krog, Denmark, 1993
6. Okuma Y (1996) Welfare reform and health care reform: 70 editorials advocating change and reform in Japan. Budosha (Japanese and Korean edition)
7. Blendon RJ, Leitman R, Morrison I, Donelan K (1990) Satisfaction with health systems in ten nations. Health Affairs 1990:185–192

Further Reading

The Nordic Welfare State under pressure: the Danish Experience (1993) Policy and Politics 21(2)

Financing of local government with special reference to vertical and horizontal revenue sharing. Paper presented at the Friedrich Ebert Conference on Decentralization of Government, Kampala, August 1993

Role of the Family in Long-Term Care

TAKAKO SODEI

Key words: Eldercare—Caregiver—Gender role—Home care—Institutional care

The purpose of my paper is to clarify the current state of the Japanese family in home care and in institutional care, and to discuss the problems and to make some suggestions to policy makers. Mostly, I focus on long—term care of the elderly, but the points I discuss are applicable for other age categories.

First, I would like to discuss the meaning of the family to the frail elderly, or who is the family to the frail elderly. Second, I would like to point out difficulties and problems of the family who are caring for the elderly at home. Third, I would like to discuss problems of the family whose parents or parents-in-law are in institutions. Fourth, I would like to discuss what should be done to alleviate the burdens of the family without deteriorating the quality of life of the elderly.

Who Is the Family?

We often talk about the family without specifying who they are. However, the family does not always mean the same people. In Japan, the household is often used as a synonym of the family. According to the definition of the household that has been used in our census since 1920, the household is a group of people who share a house and a livelihood. It includes nonrelatives or domestic servants who are living together, and does not include family members who live apart for reasons of study or a job. Recently, the number of families who do not live together has been increasing because of increase in mobility.

Additionally, people's attitude toward the family has been changing. In prewar Japan when the patriarchal stem family system existed, there were not big gaps among people's concepts of the family. The patriarchal stem family system was abolished after World War II, and legally our family system changed from the stem family system to the nuclear family system. With industrialization, modernization, and urbanization, people's attitude changed from family oriented to individual oriented.

Today it is common that there is a gap among family members who should be included in the family. In 1994, Chizuko Ueno [1] named such a phenomenon Family Identity (FI), which means that each family member does not always identify himself with the same group of people. For instance, a husband thinks his mother who lives with him is his family, but his wife does not think her mother-in-law is her family. What does it mean to long-term care of the elderly? It is quite obvious that those who think the elderly are their family members will accept the role of caregivers, but those who do not think so will not want to accept or will refuse the role of caregivers.

Even if family members' attitudes toward the elderly are not negative, there are differences among them. Here is an example. Recently, a 62-year-old man died of stroke and his kidney was removed for transplantation. According to our organ transplantation law, judgment of brain death should be made twice before transplantation, but only one such judgment was made. Thus, five family members (wife and four children), excepting the second daughter, sued the doctors. The second daughter accepted the use of her father's kidney for transplantation and signed an agreement form. After judgment of brain death, the wife and the first and second daughters signed the form for stopping life-sustaining treatment. However, the fourth daughter insisted that she did not want to stop treatment, and if all the family members agreed about transplantation, the mother should sign, but only the second daughter was there when she signed the agreement (*Asahi* newspaper, March 24, 1998).

This case shows differences among family members. Ideally, the doctors should have asked the opinions of all family members, but if they had asked it would have been impossible to use the patient's kidney for transplantation. The mistake of the doctors in ignoring the second judgment was obvious; they might have been hurrying for transplantation. This case shows the difficulties in achieving agreement among family members and in determining who is the key person of the family.

In long-term care of the elderly, it is quite usual that the first son makes a care plan, but it is his wife who practices this plan. Such a gender gap exists all over Japan; that is, a man decides and a woman undertakes. In other words, a man is a head and a woman is a hand.

Before the war, there was no doubt about who should take care of the elderly; it was the first son, who inherited the entire family property, and in turn he was responsible for his parents in old age and his wife did everything that her husband asked. After the war, our civil code was revised and every child, regardless of gender or birth order, has an equal right of inheritance as well as an equal obligation in caring for their parents. Even today, daughters-in-law are the major primary caregivers, but now they are complaining as to why they should take the role of caregivers although they have no right of inheritance. Recently the number of daughters who take the role of caregivers is increasing. Many say that it is more natural that daughters become caregivers because they can understand the elderly more easily than daughters-in-law. However, reality is not so simple. Average Japanese men still maintain the traditional value of the patriarchal family system. It is not as easy for them to accept the idea of taking care of their parents-in-law instead of their parents. Thus, daughters who are taking care of their parents have to worry about their husbands, especially when they are full-time homemakers and are making no money of their own.

Home Care

There is a myth about elder care in Japan; that is, the elderly used to be cared for by family members and when they became old and weak, they were cared for properly by the family at home. However, recent changes in the family and of women have made home care difficult, and the elderly are either sent to institutions or have to endure low-quality care at home. This is not true, actually. As described in Fumio Niwa's bestselling novel *Iyagarase no Nenrei* (*The Age of Harassment*, 1947), which was written right after the war, the frail elderly were creeping about and stained with excrement and urine although the norm of the patriarchal family system was still in existence. At that time, Japan was so poor that no one had time for caring for the elderly because everyone had to make a living. It is a recent phenomenon that people have come to pay more attention to the quality of care as well as the human rights of both the frail elderly and their caregivers.

In 1972, Sawako Ariyoshi's bestselling book *Koukotsu no Hito* (*A Man in Ecstasy*) described the difficulties the family members were facing in taking care of a senile dementia patient at home. Since then, many surveys have been conducted to find out the actual situation of the family caregivers. For example, the Basic Survey of People's Life conducted by the Ministry of Health and Welfare every year includes special questionnaires concerning the bedridden elderly at home every 3 years, the Management and Coordination Agency conducted a special survey of Life and Care in the Old Age in 1981, 1987, and 1992, and many local governments conduct surveys of family caregivers.

Results of these surveys shows that 80%–90% of family caregivers are female. According to the Basic Survey of People's Life in 1992, 85.9% of caregivers of the bedridden elderly at home were women while only 14.1% were men. The results of the Survey of Bedridden Elders at Home conducted by the National Council of Social Welfare in 1968 showed that 90.9% were women and 9.1% were men. There is not much difference despite a big campaign of improving the status of women after the UN's Year of Women in 1975.

According to the Survey of Preference in Welfare Service conducted by the Ministry of Post and Telecommunication in 1985, among those who have (or had) a person in need of care in their family or among their relatives, 37% of men and 65% of women experienced caregiving. Concerning bathing and assisting in moving about indoors or outdoors, men helped slightly more often than women, but such daily activities as feeding, toileting, and changing clothes are mostly done by women. Men have not only less chance to be caregivers but also have less chance to conduct routine activities, which is quite similar to men's participation in housework.

As is shown in Table 1, if the elderly is male, his wife is the caregiver and if the elderly is female, her daughter or daughter-in-law is the caregiver. This is caused by gender difference in longevity and marriage age; that is, women live longer than men and they tend to marry men older than themselves. Although daughters-in-law still play major roles in caregiving, their share has been shrinking and the share of the spouse (wife) has been expanding. This is caused by changes in living arrangements; that is, more and more old people live separately from their children. Before the high-level economic growth of the 1960s, more than 80% of the elderly lived with their children, mostly with their first son's family. Now a little more than half of the elderly live with children, but those living in

Table 1. The relationship of the caregiver to the bedridden elderly by gender (%)

Year	Totals	Total	Spouse	Son	Daughter	Daughter-in-law	Grandchild	Other unknown
1968	Total	100.0	25.1	2.7	14.5	49.8	2.9	5.0
	Male	100.0	50.1	1.9	8.7	34.4	1.3	3.6
	Female	100.0	7.7	3.2	18.5	60.6	4.0	6.0
1980	**Total**	**100.0**	**36.7**	**2.3**	**18.6**	**28.8**	**0.6**	**13.0**
	Male	**100.0**	**76.0**	—	**6.7**	**10.7**	—	**6.7**
	Female	**100.0**	**7.8**	**3.9**	**27.5**	**42.2**	**1.0**	**17.6**
1990	Total	100.0	40.8	4.6	21.8	28.4	0.4	4.6
	Male	100.0	72.6	3.5	9.0	12.4	0.5	2.0
	Female	100.0	16.3	5.3	31.6	40.7	0.4	5.7

Sources: National Council of Social Welfare (1968) The Survey of the Bedridden Elderly at Home.
Bureau of Welfare, Tokyo Metropolitan Government (1980) The Survey of the Life of the Elderly.
Bureau of Welfare, Tokyo Metropolitan Government (1990) The Basic Survey of Social Welfare in Tokyo.

a three-generation family number fewer than one third (1995 National Census). Many seem to believe that the Japanese elderly are still living in a three-generation family, but more than 40% are living in either a couple-only household or a one-person household.

The ratio of daughters-in-law has been decreasing, while that of daughters has been increasing. This reflects changes in attitudes of both daughters-in-law and the elderly. Today some daughters-in-law refuse to take care of their parents-in-law because legally they have no obligation to do so. Also, people's attitudes have been changing. The result of the Survey of Gender Differences in Attitudes in the Aged Society by the Management and Coordination Agency in 1989 (the sample consisted of men and women 30–70 years old), men preferred to be cared by their wife (75%), daughter (4.5%), son (3.4%), or daughter-in-law (2.5%), while women preferred to be cared by their husband (33.6%), daughter (21.4%), or daughter-in-law (10.5%). It is amazing that 5.7% of men and 11.6% of women preferred to be cared for in an institution, which is higher than the ratio of those preferring a daughter-in-law as caregiver.

Although the ratio of sons as caregivers has increased slightly, it is still a minority. Even if they take the role of caregivers, men help with non-routine activities because of lack of time and ability. Moreover, usually mothers do not want to be cared for by their son because care work is not a man's task. Montgomery and Kamo [2] mentioned that mothers tend to avoid their son as a caregiver because the mother–son relationship will violate a cultural norm of incest taboo.

Motivation to be caregivers is different in accordance with their relationship to the elderly. The Survey of the Family of Day Care Service Recipients conducted by Japan Institute of Labor in 1989 asked the family caregivers to mention factors that enable them to be a caregiver. Most of them mentioned social services because they were receiving such services. The caregiving husbands mentioned social services (57%), obligation (34%), and love (31%), while the caregiving wives mentioned social services (50%), cooperation of the family (32%), obligation (31%), hobby (18%), and love (16%). The sons cited social services (48%), obligation (30%), cooperation of the family (17%), and cooperation of relatives (17%), while the daughters cited social services (44%), understanding of husband (33%), and love (31%). The daughters-in-law mentioned social services (53%), understanding of husband (34%), hobby (31%), cooperation of the family (30%), obligation (26%), and love (4%), which was less often mentioned than patience (8%) or giving up (6%).

The result shows that many people engaged in caregiving are motivated not by love but by obligation. Although the husbands were more likely to be motivated by love, the wives were not. There are not many husbands who are caring for their wives, and those who care are quite an exception. They often mention that it is their turn to repay their wife's contribution when they were young. That understanding by their husband is important to both daughters and daughters-in-law is very interesting. They seek emotional support from their husband rather than direct hands-on care. The psychology of daughters-in-law is very interesting also. There are not many daughters-in-law who have accepted the role of caregivers voluntarily. The Survey of the Family of the Frail Elderly conducted by the Association of Labor Union (Rengo) in 1994 indicates that 46.2% of daughters-in-law, 30.6% of daughters, 24.0% of sons, 33.6% of wives, and 22.4% of husbands had a feeling of hatred. Eighty five percent of daughters-in-law mentioned that there was no other choice but accepting the role of caregivers, while 62.7% of daughters and 59.2% of sons mentioned the same thing.

Those who experienced elder abuse was 47.7% for husbands, 51.7% for wives, 53% for sons, 45.2% for daughters, 54.3% for sons-in-law, and 49.4% for daughters-in-law. Although daughters-in-law take the role of caregivers unwillingly and some hate the elderly, their chance of elder abuse is about the same as others.

In the traditional society where all family members worked to survive, old people helped with housework or child care. Moreover, child care services were poor. Thus, many working women had to depend on their mother or mother-in-law for child care. Therefore, when these older women became old and weak, it was natural to take care of them. Such an exchange has been diminishing because those who were engaged in family business have decreased and child care services have been improved. In Japan, many working women still depend on their mother or mother-in-law for child care, but they prefer their own mother. The life cycle of women who care for their mother-in-law and who are cared for by their daughter-in-law has been disappearing.

Today, many persons prefer to live separately from their children while they are in good health and to live together when they become weak or a spouse dies. This seems to be ideal, but it does not work actually well. The gap between the two generations becomes wider and wider while they are living apart. It is not so easy to match their life style as well as their way of thinking. Especially it is difficult for daughters-in-law to understand their parents-in-law, who are just like intruders to their home. I know one middle-aged woman who began to live with her demented mother-in-law because she became unable to live independently after the death of her husband. That middle-aged woman did not know what her mother-in-law liked or disliked. Moreover, she could not communicate with her mother-in-law because the elder woman was severely demented. She had nothing to repay, but she had to accept the caregiving role because her husband was the first son.

In any society, care of infants, sick persons, the handicapped, and the frail elderly is the role of women. In addition to such universal phenomenon of gender role, in Japan and Korea where there is a tradition of the patriarchal stem family system, this places a heavy burden on the daughter-in-law. As people live longer, so do the frail elderly. Today the elderly are taking care of the elderly. According to the 1992 Basic Survey of People's Life, nearly one-half of the elderly had been in bed for more than 3 years, and nearly half of the caregivers were over 60 years old. Sometimes caregivers are suffering from illness. Thus, caring for the caregivers is an important issue now.

Institutional Care

There are many studies about the elderly in institutions, but unfortunately not much study has been done concerning their families, because many people, including researchers, seem to believe that the role of the family is minimal once the elderly are in an institution. A few studies have been conducted concerning family visits to the elderly in institutions. Hook et al. [3] found that distance traveled, kinship distance, and length of residence were factors that determined frequency of visitation; that is, the shorter the distance traveled, the closer the relationship, and the shorter the length of residence, the more the family visited. Hagiwara [4] found similar results from her study in Japan, but she found that Japanese families visited less frequently than American families. Although some studies indicate the effects of visitation on the elderly's well-being in nursing homes [5,6], frequency itself does not affect well-being of the elderly in institutions. Sugisawa et al. [7] found that correlation between frequency and such emotional support as comfort or encouragement was minimal, and emotional support was significantly related to family relations before institutionalization and the communication ability of the elderly.

To explain the impact of institutionalization on family relations, I would like to use the case of my mother, who is now living in a nursing home. I cannot say my mother's case is typical, but her story will tell a certain aspect of the role of the family whose parents are in an institution. First, my mother moved to a retirement home (a privately paid retirement home, called *yuryo-roujinhome*) about 15 years ago. Before that, she lived with my elder brother's family. As he is the only son, and my father and brother are engaged in the family business of export, it was natural for my parents to live with their son's family. Actually it was my mother who arranged her son's marriage. They lived in separate houses on the same property. The relationship between the two families was not so bad while my father was alive. However, after he died, the power relationship drastically changed. My brother's wife wanted to take over. She asked my mother to leave the house because her house belonged to my brother.

Although my father paid the entire cost of construction, he recorded his son's name as the homeowner to avoid the inheritance tax, and this took place before my brother's marriage. My brother's wife did not know the truth, and thus it was natural for her to claim her right. There were severe conflicts and struggles between mother and her daughter-in-law and among siblings (one son and four daughters, including myself). After a few years of struggle, everybody became sick and tired. Actually, my mother, her daughter-in-law, and the eldest sister became sick physically and mentally, and I also suffered from skin trouble caused by severe stress.

I was asked to find a good place for my mother. My sisters thought that I must have access to proper information, being a gerontologist. Thus, I collected information and visited several places. Finally I found a good place not so far from Tokyo. Although the initial fee of the retirement home was rather expensive, fortunately my mother could afford it thanks to her inheritance from her husband. It took her almost 6 months to move to the retirement home after she paid the initial fee. To her, it must be shameful not to live with her son, and also it must be defficult for her to accept that she was defeated by her daughter-in-law.

Until she moved, there were hot discussions concerning who should be responsible for her. My sisters insist that it was my brother's repsonsibility because it was natural in our tradition to live with the first son, in addition to his inheritance of the family business and most of the family property. However, my brother's wife thought that it was natural for my mother to live with her daughter since our legal system had changed and the first son was not solely responsible for the aging parents. It is interesting that the word "natural" meant different things to different persons. Although the patriarchal stem family system was abolished legally after World War II, many Japanese still maintain traditional customs and values. According to our civil code, every child has an equal right to inherit the family property, and in turn he has an equal obligation to take care of his parents. Although many claim their right, they tend to forget their obligation.

Soon after my mother moved to the retirement home, the trouble in her legs became worse and gradually she became unable to walk. Then she moved to a nearby nursing home because she became unable to manage for herself. Now she is in a wheelchair. Recently she is confused sometimes, but she is still in good shape and will be 96 years old this summer.

Institutionalization has been effective in changing the relationship among siblings. The relationship with my brother has been improved because he became more kind to my mother than he used to be. He was rather indifferent to my mother when he lived with her. He was afraid of hurting his wife if he was close to his mother. That was a typical attitude of the first son in a three-generation household. He did not want to hurt anyone and wanted to be a good boy. He tried to avoid any conflict in the family by escaping taking the initiative.

Now, there are gender role differences among the siblings. My brother plays the role of guarantor to my mother. All important notices of the nursing home are sent to him. He manages his mother's money and property, so others do not know how much she has. He visits only once a month, but my mother clearly remembers when he came and what he brought. To her mind, he is the only one to depend on. She still feels bitter about her daughter-in-law because she was kicked out by her daughter-in-law. She seems to believe that her son is so fainthearted that he could do nothing against his wife.

The sisters, including myself, play the role of housekeeper like changing clothes, putting things in order, and sometimes mending clothes or putting name tags on her clothes. Although the daughters visit her more often than the son, my mother easily forgets their visits or sometimes she is confused who came. My mother's case indicates that there is gender role differentiation among the family members of the elderly in institutions; that is, a son decides, and a daughter follows. In other words, a man is a head and a woman is a hand.

Some families visit the elderly quite often. There is an old lady in the same nursing home whose granddaughter visits her every morning to help her with eating. This is an exception. Most families rarely visit the elderly once they have sent them to nursing homes. Usually nursing homes are located very far from towns because of the high cost of land. Therefore, it is not so easy for the family to visit the elderly. Now many municipalities are planning to build nursing homes, but the number is not enough, There are 2-year waiting lists for nursing homes in metropolitan Tokyo. In addition to the physical distance, psychological distance is important. In the Western societies where there is no tradition of coresidence with married children, old people often voluntarily move to nursing homes when they become frail. However, in Japan where there is a tradition of coresidence with the first son's family, it is not so easy for old people to accept the idea of moving to a nursing home. In Japan, more frail elderly are in hospitals than in nursing homes, because there are more hospitals than nursing homes, payment for the hospital is much less than that of the nursing home, and it is still shameful for children, especially the first son and his wife, to send their aging parents to nursing home. There are severe conflicts and quarrels among family members and relatives until they decide to send the elderly to the nursing home. In the process of conflicts, the family relations become so deteriorated that they do not want to recall their hard experience. How to increase family visits is one of the problems for nursing home staff. Thus, the nursing homes plan family gatherings and publish newsletters to increase family visits.

The most important and difficult decision for the family of the elderly in an institution is the treatment of their terminal stage. Most elderly are sent to hospital when they reach the terminal stage because medical treatment, especially a high level of treatment, is not allowed in a nursing home. However, many families, including myself, prefer not to send the elderly to hospitals, because high-tech medical treatment at the terminal stage will only increase unnecessary pain for the patients. Living wills and informed consent are still premature in Japan, and much information is not available to everybody. Thus, the treatment of terminal patients is usually in the hand of doctors.

Whose Welfare Should Be Respected?

As I mentioned earlier, there are discrepancies among family members. Each family member has a different image of the family and a different idea with regard to who should be responsible for the frail elderly. Government policies for the past decades have been trying to alleviate the burden of family caregivers because they were suffering from such physical and psychological stress that it was often called "caregiving hell." It was urgent to alleviate their burdens. The Gold Plan (Ten Year Strategies for Promoting Health and Welfare of the Elderly) in 1989 and its reform in 1994 focused on home care and tried to increase such services as home helpers, short-term respite care services, and day care services. The long-term care insurance that was enacted in 1997 and will be enforced in 2000 is aiming at improving home care.

Comparing with welfare of the family, welfare of the elderly seems to be neglected. The elderly have been regarded someone to be taken care of and someone to be dependent. Many forget their rights of decision making and of independence. In the field of health and welfare, the family, usually the first son, has played the role of the proxy; that is, he decides everything and what he decides is regarded as the same as what the elderly want. In other words, the family and the elderly form one unity.

However, Japanese families have changed a great deal and there are discrepancies among family members. Under the patriarchal stem family system, the parents' welfare came first. Thus, the welfare of the son's family was often sacrificed in order to realize the welfare of his parents. According to our civil code revised after the war, the welfare of the spouse and children comes before that of the parents. Thus, welfare of the family of procreation takes priority over welfare of the family of orientation.

Recently, autonomy or self-decision making of the elderly has come to be paid more attention, because in recent times elders are more educated and have more money than those of the past, and thus they prefer to manage their life for themselves. Another reason is that the government aims at reducing health care costs of the elderly by asking their independence (not depending on their government), because health care costs are increasing drastically with population aging.

The purpose of the long-term care insurance is supporting independence rather than doing everything for the elderly. The elderly and the family will be asked to choose what kinds of services they receive. The law does not specify who is the family and does not mention whose opinion should be respected. I am afraid that the wishes of the elderly will be neglected. Recently I conducted a small-scale case study (35 cases) of the frail elderly and the family at home. Concerning medical treatment, mostly doctors decided, and concerning welfare services, mostly the family decided. There were a few families in which the elderly made the decisions. Even if they decided, usually they asked the opinion of the family.

The burden of family caregivers is so heavy that it is quite natural for the government to alleviate it. The next step will be to respect autonomy of the elderly at home as well as in an institution. Even in Western societies, it was just recently that people paid attention to the autonomy of the elderly in institutions [8]. Nursing home staff as well as families forget that the elderly have the ability to decide, and the elderly are often treated like children. The attitudes of specialists who think they know everything are quite similar to those of the family. They try to determine the best interest of the elderly without asking their opinion.

It is not so easy to achieve the welfare of the elderly and of their family at the same time. There should be an optimal balance between the two. At present, we do not have much information about what the frail elderly really want concerning their care, life, and death. The first thing we should do is to collect such information so as to improve the quality of care of the elderly.

Institutionalization is effective in realizing the welfare of the family by alleviating the burden of caregiving, while the welfare of the elderly is sacrificed by being separated from their family and home. Is there any solution to realizing the welfare of both the elderly and their family? One is to build nursing homes not so far from the elderly's residence. Compared with the American elderly in nursing homes, the Japanese elderly have fewer visitations of the family and friends [4], which seems to be attributed to geographic distance. Thanks to a drop in the cost of land and decrease in the number of children, especially in urban areas, there are combined buildings of nursery school and nursing home, or of junior high school and nursing home. When decentralization of power from the central government to municipalities has materialized, it is much more easy for municipalities to increase nursing homes as well as social services.

Other solutions will be to change people's attitude toward the nursing home by providing proper information so that they do not have to feel guilty for sending their parents or parents-in-law to a nursing home or experience severe conflict before reaching the decision of institutionalization. Today, institutionalization is the last resort or seems just like being sent to a remote island. If the gap between home and nursing home is not so wide and if it is possible to choose between home and nursing home, the psychological impact of institutionalization on the elderly as well as their family will not seem as disastrous. In addition to change in the location of nursing homes, changes in their image will be necessary for promoting good relations between the elderly and their families.

References

1. Ueno C (1994) The formation and the end of modern families. Iwanamishoten, Tokyo, pp 4–6
2. Montgomery RJV, Kamo Y (1989) Parent care by sons and daughter. In: Machini JA (ed) Aging parents and adult children. Lexington, MA
3. Hook WF (1982) Frequency of visitation in nursing homes: patterns of contact across the boundaries of total institutions. Gerontologist 22:424–428
4. Hagiwara K (1985) Social welfare and distance—the search for coexistence of the elderly and their families. In: The quarterly of social security research. Kikan Shakai Hosho Kenkyu, pp 350-364
5. Neolker L, Harel Z (1978) Predictors of well-being and survival among institutionalized aged. Gerontologist 18:562–567
6. Greene NL, Monahan D (1982) The impact of visitation on patient well-being in nursing home. Gerontologist 22:418–423
7. Sugisawa H, Yokoyama H, Takahashi M (1993) Support from families for residents of public nursing homes. Jpn J Gerontol (Rounen Shakaikagaku) Vol. 15 No. 1:47–57
8. Gamroth LM, Semradekn J, Tornquist EM (eds) (1995) Enhancing autonomy in long-term care. Springer, New York

Further Reading

Sodei T (1994) Family support and case management (Kazoku sien to case management). In: Techniques for support at home (Zaitaku shien no giho). Chuou Houki, Tokyo

Kinoshita Y (1989) Sociology of geriatric care (Rojin kea no shakai-gaku). Igaku shoin, Tokyo

The Relationship Between Informal and Formal Care

CHRISTINE ELISE SWANE

Key words: Aging—Family—Social care—Professional roles

Public responsibility for old age frailty and disability has a long history in Scandinavia. Old age pension was introduced in Denmark in 1891, the first country in the world to establish pension with no frailty criteria, in Sweden in 1913, and in Norway in 1937 [1]. Long-term care developed from the 1950s and on as part of the development of the welfare state. Out of the poorhouse tradition of the nineteenth century grew old age homes. Home help services were established in the early 1950s and expanded substantially during the following two decades, while nursing homes increasingly substituted for the traditional old age homes. The policy of the 1980s was characterized by a change to a deinstitutionalization policy, where sheltered housing facilities, day care centers, district nursing, 24-hour home care, delivery of aids and appliances for handicapped persons—all this partly substituted for traditional institutional care [2].

The 1990s have brought reduction in care budgets. But at the same time there are serious efforts to ensure continuity in social and health care services by improving interdisciplinary cooperation between home care and nursing homes, elderly centers and hospitals, and family and professionals. A well-organized cooperation of professional care and family care has proven to lower the expenses and create better life conditions for the ill, frail, and handicapped elderly.

Complementary Care Systems

Many studies of caregiving in Scandinavia show that formal and informal care are complementary, i.e., that they supplement rather than substitute for each other. A theme in feminist-inspired research has been to show

how dependent the welfare state is on the invisible contribution of women's unpaid family care [3]. A relevant question is what professional care is needed for, if it not to relieve families of some of their obligations and tasks? The perspective in this paper is seeing the ideal of formal care as a kind of substitution of family care, but not a total substitution of responsibility.

According to legislation in Scandinavian countries, adult children are not legally responsible for any dimension of their parents' living conditions. This may appear to be an erosion of the family as a social entity. The assumption here is rather seeing the public care system as giving individuals the right to choose to care for each other according to personal resources (e.g., physical and psychological strengths), affection, etc. In popular terms: as a woman you are not stuck with the care responsibility of a mother-in-law you never got along with. At some level, this should benefit both parties.

One obvious reason behind the need of a high level of formally provided care is the high working rate among women in these countries. In Denmark, 73% of women are in the labor force, compared to 82% of men, as shown by 1996 data [4]. With women working outside the household, which has become the norm in industrialized societies and increasingly among younger generations, the care resources in families are limited. With the population aging, the "sandwich generation" has become a well-known characterization of women 45 to 65 years old who have not only their own children and grandchildren (and spouse) to care for, despite their job outside the household, but also old parents, perhaps even grandparents. Also, the geographic scattering of generations, sisters, and brothers, etc., in modernized societies means that there is no guarantee of someone being around to provide care, so that the responsibility must lie with the formal care system. The children may be there, they may not. In this way the system also sets up a care guarantee for people with no children or relatives.

On the other hand, the availability of informal care, particularly from family, reduces reliance on formal care. Formal care is the social safety net to be used if, and when, family resources are missing, exhausted, or insufficient. The ideal of care policy is formal care substituting for informal care where needed, not vice versa.

There seems to be a general belief that modern families are less willing to provide care because the public care system will cover whatever is needed. Are Scandinavians more heartless than other people concerning their closest kin, friends, and neighbors? Do we have a culture of feeling less obliged to take on responsibility for one another than do families in countries that offer less professional care?

The dynamics of care responsibility can be seen in a more complex way. Research shows that many tasks are still done by family members, and family care postpones the need of professional care (e.g., the point when home help is needed)—or the need of more intensive professional care (e.g., delays a move from home to nursing home). Studies also reveal that the older generations appreciate public care as an option, mainly because of their solidarity with their children, who have busy lives of their own. The elderly's own experience taught them about being overloaded with care tasks, and by this attitude they seem to want to protect their own adult children. This transition in expectations between generations certainly is not unproblematic. Many very old people in need of care are feeling let down by daughters or grandchildren when they receive formal care. But most often it is a problem that diminishes once they get to know their professional caregivers and feel safe in their hands.

Shared responsibility between family and professionals favors both the care-needing person and the carers. Not only physical, practical workloads can be removed from the family carers, but also the psychological strain of feeling overwhelmed by responsibility and forever worrying if you are doing things right. Hence the professional carers can create a partnership in which both the old person and the family can discuss matters of frailty, disease, and everyday life. Despite good intentions among family members, in most families care responsibilities tend to land in one person's hands (mainly the spouse, daughter, or daughter-in-law) and the option of talking to someone who professionally and by experience knows about generational quarrels, about old people's reluctance to receive help in matters they are used to handling themselves, and about specific diseases—dementia, not the least, is of great importance [5].

A Deinstitutionalization Policy

Some of the key words in the deinstitutionalization policy in Denmark were explicitly formulated around 1980: self-determination, freedom of choice, and use of personal resources. Traditional, medically trained staff, who were predominant in institutional care, were not believed to be able to fulfill this philosophy alone. Hence a useful trend in improving formal care services is the integration of traditional health staff (nurses, nurse aids) with occupational therapists and social and health assistants—staff who are trained to see as their major task to help people help themselves, to support their use of own resources. They are trained not to see frail and ill people as merely patients, hence they are also more apt to include the closest family and friends of the care-needing person in their work. Here lies a great potential in improving care by means of making it more clear and explicit what can be the role and tasks of the informal carers—and those of the professional carers. This of course is a negotiation that goes on in each individual case, but the responsibility is and should be the professional's in informing, guiding, and supervising the family carers, friends, and neighbors.

A kind of basic social, maybe human, condition of caregiving lies in the difficulties of becoming dependent on someone else's help and care. This is a process that all frail and handicapped people go through, and some achieve more of an acceptance than others do, and the issue is not solved categorically by offering family care versus professional care. Intimate and personal knowledge makes some care tasks done more easily, e.g., a wife who knows what her demented husband likes to eat—or a daughter who can clean her mother's apartment without insulting her because the mother does not categorize her help as "care," whereas the old woman might feel that she ought to be able to do the cleaning herself if a stranger cleans her house. Some tasks can be easier for an "outsider" to carry out, not the least help with personal hygiene.

The emphasis on establishing long-term care through the 1960s and 1970s stretched at least the Swedish and Danish societies very far in their institutionalization policy—so far in providing equal services for everybody independent of financial or family situation, that the social network of clients and patients was widely neglected as a resource to be dealt with, not to mention frail persons' own resources. In the 1980s and 1990s, long-term care policy has been heading more toward an integration of the care recipient's social network. At the same time the deinstitutionalzation policy aims at more flexible solutions, and hence specific care needs are better met today. Institutions formerly tended to build on routines and had very little flexibility, like most hospital care is or has been organized.

To change a system radically from one care structure to another may very well include strategies that take things too far in one direction (i.e., the institutionalisation of the social welfare society) before the pendulum swings back and finds a more moderate position. Maybe other societies can learn from this experience and head for flexible, network-oriented strategies for the organization of care that integrate filial and other care resources in the local community. I believe that an integration of non-medically oriented staff, more occupational therapists, social workers, pedagogues, etc., who focus on old people as social beings with the need of meaningful activities in their lives, can help with the transition of care policy. Also, the families need to be taught to look differently on the elderly in this transition process, a task that probably is better done by staff with a broader view than medical staff have been taught.

References

1. Daatland SO (ed) (1997) De siste årene. Eldreomsorgen i Skandinavia 1960–95. (The last years. Elderly care in Scandinavia 1960–95, English summary.) Norwegian Social Research, Oslo
2. Swane CE (1994) Payments for care: the case of Denmark. In: Evers A, Pijl M, Ungerson C (eds) Payments for care. A comparative overview. Avebury Aldershot, UK, pp 101–124
3. Lingsom S (1997) The substitution issue. Care policies and their consequences for family care. Norwegian Social Research, Oslo
4. Danish Statistical Department (1997) Statistical ten-year review. Copenhagen, Denmark
5. Swane CE (1996) Hverdagen med demens. Billeddannelser og hverdagserfaringer i kulturgerontologisk perspektiv. (Everyday life with dementia. Images and experiences in a cultural gerontological perspective, English summary.) Munksgaard, Copenhagen

Further Reading

Daatland SO (1997) Welfare policies for older people in transition? Emerging trends and comparative perspectives. Scand J Soc Welfare 6:153–161

Evers A, Pijl M, Ungerson C (eds) (1994) Payments for Care—A Comparative Overview. Aldershot, UK, Avebury

Weekers S, Pijl M (1998) Home care and care allowances in the European Union. Utrecht, Netherlands Institute of Care and Welfare

Summary of the Discussion for Session 1

1. Family Care: Is Caring for Elderly Parents Different from Raising Children?

Family care is important everywhere, but in many respects caring for parents appears more problematical to people than caring for children. Having children or not is usually planned, and once they are born, there is a legal obligation to care for them as dependents. In contrast, caring for elderly parents is a task thrust upon the family and the legal responsibilities are undefined. Moreover, children will become less dependent, but elderly parents tend to get more dependent, for an indefinite and perhaps prolonged period. The fact that older people often feel that they do not want to be a burden to their children also has an impact. However, children generally do feel that they have some responsibility toward their parents, although the degree probably varies among countries and may also be reflected in the inheritance pattern.

In Denmark, as a result of women's participation in the labor force (women, 77%, to men, 80%), there is a growing trend to share and diffuse the responsibility of caring for children among school, after school, pre school, husband, and wife. Thus, although caring for children and caring for elderly parents should be regarded as belonging to different dimensions, there are some similarities. In Japan, such a mixed system, with more private sector involvement, has emerged in child caring. Perhaps, it could also be developed in LTC.

2. The Relationship Between Formal and Informal Care

In a "residual" system, it is assumed that public, formal care picks up only when self-care or informal care is not available; the former British regulation that in-home services would not be provided to anyone who had a female relative within walking distance is an example. Japan certainly fell into this category at least until recently, including resistance to the idea of having outsiders come into the house to provide care. Even in many nations with better services, it is often assumed that families will take the main responsibility for care. On the other hand, in Scandinavia the presumption is that the government has the primary responsibility, with families "cooperating" if they choose to do so. Many do, but it tends to be more psychological support, rather than hands-on care.

Most participants thought that family roles were usually important and positive, even when the elder is institutionalized. Often family members derive satisfaction and have good feelings about providing care. However, the care provided by the family may not always be appropriate, and indeed in Japan there is a tendency for families to provide too much care, which is not good for the older person (this can happen with formal care too).

Preferable is a more complementary model, in which "joint production" between formal and informal care results in better care for both caregivers and the older person. More choice is needed: the main thing is to provide alternatives between full-scale formal care (i.e., in institutions) on the one hand and complete dependence on families on the other. Also, burdens on families can be eased by providing services for them, such as therapy and self-help groups as well as respite care—such programs are inexpensive and often have good results.

The role of formal care is expected to grow in most nations because the supply of informal care is shrinking, with more women working outside their homes. The introduction of LTCI in Japan will be a dramatic shift in this direction because the level of benefits will be the same regardless of how much informal care is available. How this individual entitlement will affect patterns of informal support will become a major issue.

It was agreed that volunteers, whether neighbors or people participating in volunteer organizations, should not be seen as primary care providers, but they can fill important gaps particularly in providing "softer" services. The term "volunteers" has a wide range—neighbors and friends, local grassroots organizations, people who regularly participate in a large volunteer organization, the Japanese sort of "paid volunteers." Elders themselves can make a significant contribution as volunteers.

Among forms of formal care, some participants emphasized the advantage of the free market, which is more efficient in terms of aligning costs and benefits. In Japan's new LTCI system, introducing competition among providers will mean that the services most desired, and those who best deliver them, should expand. Markets have their dangers because individuals (especially the very frail) often are not in a position to shop for the best provider, although families may be able to take on this role. Several participants worried about having large for-profit companies dominating long-term care.

3. Professionalism, Medical and Social

The improvement of long-term care, for individuals and for the entire system, depends heavily on close cooperation among professionals with different specialties. The "geriatric team" is a frequently evoked ideal. However, there is a tendency for people who have formal qualifications to overemphasize professionalism in order to raise their status. A client-centered approach, where the goals are enhancing the security, integrity, self-determination, and dignity of the individual, should always be emphasized as the mission goal to avoid the evils of overprofessionalization. "Cross-training" in which different professionals learn about each others' jobs together is one way to achieve that.

All agreed that it is necessary to carry out research to generate new knowledge, and to use the results of research to improve practice (one suggestion was that 1% of the funds devoted to long-term care should go to research). Some participants thought that the development of more scientific expertise would allow professionals to be more authoritative in deciding what treatments and services are most appropriate for a particular older person. Others emphasized the limitations to "technological determinism" in long-term care; for one thing, such decisions often involve peoples' individual values, their living situations and so forth, and so must be negotiated between the professional and the client.

In general, clients should be more actively involved in decision making than is usually the case, as by including them in case conferences. It is a big mistake to believe that elderly people are incapable of making intelligent choices; even among the very old, those with cognitive problems constitute only a minority. On the other hand, most older people would like to turn to professionals for their expertise and good advice.

Japan has some barriers among professions that can make cooperation quite difficult and, moreover, it has real shortages of professionally trained social workers in particular and care workers in general. It is a hopeful sign that these fields have recently become quite popular, but the new LTCI system will require new thinking in this area.

Session 2
Clinical Aspects of Care

Introduction and Summary

JEFFREY B. HALTER

Clinical aspects of an ideal long-term care system have been discussed in a group of thoughtful and stimulating papers. Professor Chino focused on the importance of rehabilitation medicine in long-term care, and Professors Inoue and Nakayama on nursing. Professor Mauritz reviewed the long-term care insurance plan in Germany as a model and its impact on clinical aspects of care. Professor Mitty's paper discussed the interface of acute medicine and long-term care. My own paper reviewed the multiple roles that physicians can play in a long-term care system, and Professor Orimo discussed the substantial need for physician training in geriatrics and long-term care. Professor Ribbe's paper highlighted the important collaboration between medical care and social services needed for effective long-term care and the role of long-term care specialists. Finally, Professor Whitehouse focused on the long-term care needs of patients with dementia. A number of common themes appeared in this series of papers. As summarized in Table 1, these themes can be grouped according to the perspective: the point of view of the patient and patient care, the point of view of the health care providers, and the point of view of the health care system.

Two issues deserve special attention. One is the importance of interdisciplinary collaboration to provide effective long-term care. Here, collaboration means the close working relationship and communication between professionals who each bring the expertise of their discipline to the care of the patient.

Second, to progress toward an ideal system of long-term care, the design must allow for change and adaptation to accommodate the new knowledge that will only come from research. Research and development are desperately needed to guide the evolution toward an ideal long-term care system. One focus for such research should be on outcomes. Are long-term care services that are provided achieving expected outcomes: better quality of life, improved patient satisfaction, greater mobility? Specific

Table 1. Themes of clinical aspects of care

Patient Perspective
Quality of life
Health outcomes
Patient autonomy
Heterogeneity of patients
Functional status
Care Provider Perspective
Individualized care
Comprehensive assessment
Interdisciplinary team
Collaboration between different disciplines and between medical and social services
Specialist training in LTC
Case management
Health System Perspective
Continuum of care services
Understanding the interface of acute care and LTC
Linkage between evaluation of patients and management

measurable outcomes need to be defined and monitored. The appropriate mix of long-term care services as a system evolves should be based on evidence demonstrating effectiveness in achieving such outcomes. Key outcomes in long-term care that are particularly in need of measurement are functional status and functional improvement. An important dividend of investment in research is that people carrying out research on new models for long-term care and establishing an appropriate base of evidence are ideally suited to teach the next generation of health care providers. Two specific recommendations regarding research were discussed: (1) a proportion of annual expenditures for long-term care insurance should be invested in support of needed research and development; my own view is that 1% of such expenditures is appropriate; (2) expert panels should be formed to define priorities for a long-term care research agenda to guide research expenditures.

Another point of discussion is the challenge of establishing academic programs in geriatrics and long-term care that can have the needed influence on development of an ideal long-term care system. This is one area in which the United States has had more success than many other countries. The papers by Ribbe and Orimo describe some of the problems in the Netherlands and Japan. One of the reasons for the relative success in the United States is its investment in research on aging, beginning with the establishment of the National Institute on Aging (NIA) in the mid-1970s. The annual budget of the NIA now exceeds $ 500 000 000 per year. This research support has attracted the attention of leaders in medicine and provided substantial support for developing geriatrics programs. Another important source of support has been the U.S. Department of Veterans Affairs, which established a group of centers of excellence in geriatrics in the 1970s and has also provided substantial support for geriatrics training of health care professionals. In parallel there has been the development of a formal certification process for physicians in geriatric medicine and geriatric psychiatry in the past 10 years. This has occurred within the existing certification structure for physicians and has been another dividend associated with the research support that established academic geriatrics programs. While this growth initially targeted physicians, these geriatrics programs throughout the United States all emphasize interdisciplinary approaches to health care and have led to a parallel growth at many institutions in clinical and education programs for the many other health professions that focus on geriatrics and long-term care.

Commentary: Preparing Health and Social Clinicians for Holistic Care

ROSALIE A. KANE

Introduction

As a visitor to Tokyo, I had great pleasure yesterday in exploring the city, yet the subway posed a challenge. As a stranger, I had difficulty finding the stops where transfers could be made from one line to another. This experience and the anxiety it engendered is analogous to the experiences of older people with disabilities and their family members when they seek to locate and use long-term care services. Most people have had experiences with physicians and nurses during their lives, but most tend to be strangers in the land of long-term care. Patients often have great difficulty finding their destinations within health care systems and social service systems and moving between them. Health and social services are both vital for long-term care, yet the two systems (to the extent they are systems at all) tend to be poorly articulated. Physicians and other health professionals may speak different languages from social service professionals, and may also have different views of case management.

It is crucial for the well-being of older long-term care consumers that health systems, construed broadly (encompassing hospitals, physicians, primary care, preventive care, and rehabilitation), and social service systems (encompassing personal care, social services, housing, psychological counseling, and financial assistance) be well articulated. If the two "systems" are enmeshed in conflict, it is impossible for either to win unless the long-term care consumer loses.

To emphasize the importance of the full range of clinical services, consider the goals of long-term care. Arguably, two general classes of goals can be described: therapeutic and compensatory. Therapeutic goals refer to measurable improvements or slowing in decline on a range of outcomes, including health status, ADL functioning, psychological functioning and mental health status, and even social well-being. Compensatory goals refer to meeting needs—that is, providing services that allow people with disabilities to live as meaningfully as possible despite their impairments. Both kinds of services are needed, and both are highly valued by consumers.

Medical Versus Social Models

Many of the short papers of this session discussed a tension between broad health goals of long-term care, on the one hand, and social goals on the other. From the medical and nursing perspective, the following problems are often cited and were reflected in the short papers:

- In general, professional personnel, including physicians and nurses, have insufficient knowledge and skill in the diagnosis and treatment of older patients. Specialized geriatric assessment is important and insufficiently available, and it is also necessary to improve the knowledge of generalist personnel.
- Payment systems in acute care do not allow sufficient physician or nurse time for adequate diagnosis, for rehabilitation, or even for pain control with older people.
- Long-term care frontline personnel (the aids, nursing assistants, and attendants in nursing homes and home care) are not qualified for their positions. They permit the clientele to deteriorate. They fail to notice if the user of services has additional needs.
- Taking all these together, the effect on older people is that remediable problems are not identified and unnecessary suffering and disability ensue. Services are provided to compensate for disabilities when the disabilities could have been alleviated in the first place. Using a "social model" to provide compensatory care without first attempting rehabilitation is ultimately expensive and is also inhumane.

From the social side, the following complaints are often heard and were reflected in the short papers.

- Physicians and other health-oriented personnel have too much power as authorizers of services and as gatekeepers. They seldom understand the socially oriented services they are authorizing.
- When long-term care patterns of service change—even in Denmark and Sweden where social models of care are exemplary—physicians are slow to understand the new programs and how to work within them.

- The "medical model," even at its best, has led to requiring older people to sacrifice lifelong interests and goals, and has ignored the very elements of life that give people meaning and satisfaction. Instead, narrow health and functional goals are adopted. A "placement" in various long-term care programs is treated as though it were nothing more than a medicine or treatment regimen designed to achieve narrow goals. Health professionals forget that their *care plans* become *life plans* for the people needing care and their families.
- The "medical model" emphasizes safety. Every fall or fracture is treated as a bad outcome. People are expected to adhere to diets rather than to enjoy meals. Everyday life is turned into therapy—music therapy, dance therapy, conversation therapy, reminiscence therapy, gardening therapy, animal therapy, massage therapy. It can all be scheduled, administered by trained personnel, and evaluated for "progress." At best this is expensive; at worst, it is deadening to the human spirit.

Consumers' Perspectives

The tensions between proponents of the medical and social models lead some commentators to suggest that the medical model has been proved a failure in long-term care, whereas others are lamenting that it has not even been properly implemented. But long-term care consumers, whether clients of social service agencies, residents of nursing homes, or patients in a hospital about to be discharged after a stroke, are likely to find these distinctions meaningless. Often the consumer of services has no voice at all, other than perfunctory opportunities to express their satisfaction with particular services that they have received. Older dependent people are often polite and sometimes timid, and they usually express satisfaction with their own services and care. But from the various studies I and others have done, I believe that consumers would make the following points about health and social services in long-term care:

- Diagnosis, rehabilitation, and active approaches to treatment are important. They are not only important initially but they *continue to be important* when long-term care is being received. Access to specialist care may also be important and is sometimes frustratingly cut off by primary care gatekeepers.
- Speech therapy and physical therapy are highly valued and often are discontinued too soon.

- Practical information and techniques to cope with chronic illnesses and disabilities are also valued. Nurses and therapists often provide exactly the kind of help people crave to minimize fear and increase coping.
- Nevertheless, certain routine and continuing aspects of care such as administration of medicines, catheter and ostomy care, and skin care are too expensive because of requirements that only a licensed nurse can perform these services. Many older patients and their families would welcome programs that make it possible for the helpers who are offering housekeeping assistance and personal care to also provide routine nursing services and assistance with medications. If these tasks are too professionalized, they are too expensive for most privately paying families to purchase in the marketplace and too expensive for public programs to offer at home.
- Whenever possible, consumers seek care that does not disrupt their lives and that does not necessitate moving their residence to receive it.
- If it is necessary to move to receive care, the preference is to move only once and to move to a place that still qualifies as home. In most cultures, this living space should be private (even if it is small), and consumers should not be forced to share it with strangers. Consumers who have moved away from home to get care will want continued communication with family and friends and involvement in meaningful activities. They will wish to decide how to spend their time, to have some control over their space, and to have meaningful symbols and possessions nearby. Safety is important to them, but it is not the only important thing.
- Death cannot be prevented, and most long-term care consumers do not consider death in advanced old age to be a bad outcome.

Questions Posed for Session

How can the impasse between medical goals and social goals be resolved in a way consistent with consumer preferences and needs? Dr. Ikegami and Dr. Campbell raised four general questions for commentators to consider. In taking up these questions, I tried to address them in ways that bridge gaps across disciplines and between health and social services.

Question 1: When Does Acute Care End and Long-Term Care Begin?

Surely, acute care and long-term care are intertwined. Often the first need for long-term care—which is, after all, help with everyday living—begins after an acute care episode, such as a stroke or a hip fracture. But once a person receives long-term care, he or she is likely to have regular and recurrent needs for acute care. In that sense, the need for ongoing diagnostic and treatment interventions and even preventive health care (for example, flu vaccines, screening for disease, exercise and strength development) does not end because long-term care began. Someone needs to be accountable for ensuring that long-term care consumers receive necessary acute care. We must also recognize that long-term care can take place in hospitals and acute care can take place at hoem: the place of the care does not identify it as acute care or long-term care.

Question 2: How Can the Virtues of Rehabilitation and Pain Control Be Brought More Effectively into Long-Term Chronic Care Without Sacrificing the More Holistic Approach That Is So Logical and Important in Long-Term Care?

This "holistic" approach is important not only because of comorbidities as the question is worded, but also because long-term care shapes the lives and worlds of those who need it. Without presuming to know the whole answer to this question, it seems that we should strive to break down programmatic compartmentalization. We need to recognize that consumers deeply care about improving function and about pain control and comfort. They do not want doctors, nurses and other therapists to design their lives, but they do want their expertise. The following strategies may be important to move toward more holistic approaches.

- Rehabilitation does not necessarily require and elaborate, expensive multidisciplinary team. It requires a point of view and diffusion of technologies without regard to the actual disciplines of those who organize the efforts. There should be less expensive ways to make sure that people get ambulation assistance, range-of-motion exercises, and bowel and bladder programs than enrolling them in formal rehabilitation.
- Pain control does not necessarily require a hospice team or specialized palliative care unit. Also, it should not be necessary to agree to forego life-prolonging treatments to get state-of-the-art help with pain.

Principles for pain control and alleviation of discomfort need to be diffused through the long-term care system, and need to include common problems such as constipation, muscle pain, and nausea as well as the pain associated with cancer. Sometimes, however, even hospice patients within months of their death can benefit from a rehabilitative approach designed to improve their functioning.
- Comprehensive assessment tools such as the Minimum Data Set for nursing home residents used in the United States should not be confused with clinical assessments. The former are broad summary statements and are not sufficiently sensitive or specific to an individual's treatments. Similarly, one should not confuse screening tests, such as quick screens for dementia or depression, with diagnoses. Each older person showing signs of confusion and memory loss would seem to merit at least on thorough workup for dementia. At the point when major life decisions are being made, comprehensive assessment would seem particularly important.
- We need to teach paraprofessional workers who do ordinary frontline care how to identify and interpret signs of illness and decline in function. They need to know what to observe and whom to inform about such observed changes, and what to consider as urgent. Family members and patients themselves can also be taught these signs.
- Mental health programs need to be better articulated with other health programs and social services. With the exception of Alzheimer's disease, the mental health needs of older people are often ignored.
- Above all, older people should not be forced to chose between health goals and life goals.

Question 3: What Needs to Be Done to Improve Training for Medical Personnel to Emphasize Interdisciplinary Aspects of Care and Who Will Provide Them with Such Training?

This question could be reformulated to emphasize that social service personnel also need training in medical and health issues. The following specific points need consideration.

- Multidisciplinary training efforts are valuable, especially if they are targeted to professionals at sufficient levels of socialization within their own discipline and if trainees are exposed to role models of clinical mentors who work effectively and respectfully across disciplines.

Multidisciplinary training for those already committed to geriatrics has proven important in the United States where the efforts of Geriatric Education Centers (funded by the Health Resources and Services Administration) and Geriatric Team Training Programs (funded by the U.S. Veterans Administration and, more recently, the Hartford Foundation) have seeded teaching departments and clinical teaching sites with role models for better multidisciplinary collaboration and communication in geriatrics.

- However, the problems of poor articulation across disciplines and organizational positions cannot be completely resolved through training. They must be reinforced by structural change and job redesign. For instance, built-in mediation reviews are an important way to involve pharmacists in care. Similarly, geriatric nurse practitioners need to be given specific authority.
- We should not glamorize or exaggerate the significance of the multidisciplinary team. A multidisciplinary team is not needed to administer most assessments or to arrange most care, and the mechanism is very expensive.
- A care management or case management function can be an important vehicle to assure that disciplines work together effectively and efficiently.

Question 4: How Can We Establish a Better Research Basis for Clinical Problems and Practices in Long-Term Care?

The following components are needed for a better research basis.

- We need better identification of and measurement of outcomes, including quality of life outcomes, satisfaction, and a broader view of functional outcomes to embrace social role performance as well as basic self-care functions such as are incorporated into ADL and IADL measures.
- We need a sense of the desired outcomes for dementia care. As Peter Whitehouse pointed out, the field of dementia treatment has been impeded by lack of clarity or agreement on goals.
- We need databases from clinical practice that combine health and social information and that permit following long-term care patients over time and across settings.
- We need to focus on some key issues where medical and social needs come together and concentrate evaluative efforts there. Examples

include hospital discharge decision making, medications administration and monitoring, and management of pain and discomfort. Targeted interventions should be evaluated according to their outcomes.

All this research should be undertaken with recognition that there is no single right plan for each person. The effort to find the precise "appropriate" service "plan for each person should be abandoned, and instead we should examine the costs and benefits of various interchangeable ways to achieve goals.

Maintaining Physical Functioning of Frail Older People

Naoichi Chino

Key words: Frail older people—Rehabilitation—ADL—Functional evaluation

A recent survey indicates the life expectancy of the average Japanese is 76 years for men and 83 for women. These figures are the highest in the world. In addition to this long life expectancy, the low birthrate is leading to an increasingly aged population in Japan. Estimates show 27% of the Japanese people will be 65 years of age or over in the year 2025. Therefore, it is essential for the Japanese government to prepare for the increased demands on the medical and long-term care insurance systems.

In 1997, a long-term care insurance policy system was adopted and will become effective in the year 2000. Nevertheless, it is important to help frail older people maintain good physical and psychological condition. This will enable them to independently carry on activities of daily living (ADL) for the remainder of their lives.

Rehabilitation medicine was established in 1947 in the United States as one of the medical specialties to treat patients with physical disabilities. With diagnosis and treatment by physical modalities such as electric or magnetic stimulation, therapeutic exercises, and orthoses, patients can be made more independent in ADL and returned to their homes or other social setting. As a result, the community's burden of care becomes less.

In Japan, survivors of stroke continue to increase in number. According to a recent survey by the Ministry of Health and Welfare, about 43% of patients aged 65 years or older who were institutionalized for at least 6 months had suffered a stroke. Not only stroke patients but also frail older people are more likely to suffer from multiple diseases (comorbidities) compared to younger people. During the aging process, the organs begin to degenerate, often leading ultimately to increasing dependence in ADL and being bedridden.

The primary purpose of rehabilitating the older patient is to prevent physical and psychological deterioration caused by unnecessary confinement to bed. To achieve this, the older patient should sit in a wheelchair or stand and walk with a walker as soon as he or she recovers from acute care. It is important to carry out a proper rehabilitation regimen, including for example, range-of-motion therapy to prevent joint contractures, and muscle strength exercises to help patients ambulate safely [1]. A recent study indicated that very elderly people, aged over 90, increased muscle strength 2.5 fold through proper rehabilitation, resulting in fewer falls in nursing homes [2].

To effectively promote the integration of medical and long-term insurance systems, it is vital to evaluate the potential for functional improvement through rehabilitation programs. This is particularly true for older patients. In other words, rehabilitation medicine should be considered before arranging the care system, to not only lessen the burden of care but also increase the quality of life (QOL) of frail older people.

The most important issues in initiating the long-term care insurance policy system on April 1, 2000, are the objective measurement of the category of burden of care and the practical measure of carrying out the caregiving program. The objective, validated measures of ADL and burden of care have been proposed by the Government in six categories. Detailed evaluation programs, however, are still closed or "black-box." Since the pilot study indicates that 25% of the sampling collected by the government in 1997 was erroneously rated, the rating procedure will be specified in such a way as an ordinal or interval scale [3,4]. Last but not least, the implementation of the care system for frail old people must be carried out only with the closest collaboration between medical and social care professionals.

To summarize, by rehabilitation medicine, frail older people can be made more independent in ADL and returned to their homes or other social setting so that the community's burden of care becomes less. Objective measurement of the category of burden of care and the practical measures of carrying out the caregiving program are the most important issues.

References

1. Chino N, Melvin JL (eds) (1996) Functional evaluation of stroke patients. Springer, Tokyo.

2. Fiatarone MA, Marks EC, Ryan ND, et al (1990) High-intensity strength training in nonagenarians. JAMA 263:3029–3034
3. Merbitz C, Morris J, Grip JC (1998) Ordinal scales and foundations of misinference. Arch Phys Med Rehabil 70:308–312
4. Williams BC, Li Y, Fries BE, Warren RL (1997) Predicting patient scores between the Functional Independent Measure and the Minimum Data Set: development and performance of a FIM-MDS "crosswalk." Arch Phys Med Rehabil 78:48–54

Further Reading

Chino N, Melvin JL (eds) (1996) Functional evaluation of stroke patients. Springer Tokyo

Physicians' Roles in the Geriatrics Interdisciplinary Team

JEFFREY B. HALTER

Key words: Medical evaluation—Gatekeeper—Clinical pathways

The physician's role in interdisciplinary care of elderly patients may have many facets and can include a broad spectrum from a very limited participation to serving as a key leader of the team. Many factors may influence how the physician's role evolves. These include the educational background and interest of the individual physician; the requirements for physician participation imposed by insurers, the government, or the health care facility in which the patient resides; the setting in which care is being provided; and the specific needs of the patient. This paper briefly summarizes some of the key functions for a physician in team care of elderly patients, with an emphasis on the long-term care setting.

Medical Evaluation and Management

The physician has a central responsibility for medical evaluation and management of any patient for whom he has primary responsibility. This is the traditional role for which the physician has received extensive training in medical school, at the postgraduate level, and in continuing medical education. Specialists in geriatric medicine have completed additional postgraduate training beyond that of a general practitioner, focusing on medical evaluation and management of complex elderly patients and those who need long-term care services. The physician has responsibility for establishing the patient's diagnosis, for institution and adjustment of appropriate therapy, for ordering appropriate diagnostic tests and procedures and then interpreting their results, and for obtaining consultation from other health care providers and medical specialists as needed for the patient.

The physician's primary role in medical evaluation and management is sometimes viewed as being a "gatekeeper," particularly in the managed care environment. However, this view has a negative connotation, implying that the physician's responsibility is to limit the patient's access to certain services so as to control health care costs. A more positive and appropriate view would be that the physician serves as a "gate opener" to provide access to needed specialty and diagnostic services.

While the physician usually provides medical evaluation and management services directly, the physician may delegate some of these responsibilities to other members of the health care team, usually as part of a close working relationship with a physician's assistant or clinical nurse specialist. Under these circumstances, clinical pathways or algorithms are often utilized to ensure that there is close agreement and understanding between the physician and the colleague to whom responsibilities are delegated. Documentation of the physician's role in medical evaluation and management generally provides the basis for reimbursement for professional services and for review of the physician's performance. Indeed, the many other roles that a physician may play in interdisciplinary care are rarely evaluated and often unreimbursed.

Administrative and Legal Activities

In the United States and many other countries, legal responsibility for patient care is vested in the physician. Even when the physician's role is relatively minor and indirect, the physician of record is legally responsible for the care provided. The physician's signature is a requirement for carrying out care plans for the patient or diagnostic tests in an institutional setting and for the patient to obtain most medications. Physicians also may have legal responsibility, particularly in long-term care settings and acute hospitals, for a review and approval of care provided by others, including all patient orders written. In the long-term care setting a physician is often designated as having administrative responsibility for institutional rules and procedures and for monitoring quality of care provided to patients in the facility.

Education

The physician often plays a key educational role as part of the activities of an interdisciplinary team caring for elderly patients. Education of the patient and family members is an important aspect of the delivery of health services, representing a key part of the physician–patient interaction. In some settings the physician may delegate much of the patient education responsibility to other members of the health care team. The physician also can play an important educational role for other health providers who are members of the team. The physician has the most in-depth knowledge of medical illness, disease course, and prognosis compared to other members of the team. Thus, the physician is in a unique position to educate team members about specific aspects of the medical status of a given patient, thereby assisting the whole team to be more effective in developing and carrying out a care plan.

Physicians often provide educational experiences for trainees in the health professions, especially for physicians in training at various levels. Physicians may also be active participants in educational experiences for trainees in other health professions that participate in team care of elderly patients. Although models for health professions education in team care have not been rigorously tested or described, such settings are now being used for educational purposes to train the next generation of interdisciplinary team members. In addition, long-term care institutions are increasingly affilliating with academic institutions and thereby becoming sites for training of health care professionals.

Team Roles for the Physician

Traditionally, the physician has been viewed as the leader of the interdisciplinary team. This leadership role is grounded in the historical legal responsibility that the physician has for delivery of patient care services as well as the traditional identification of the physician as the point at the top of the health care delivery pyramid. This model for physician leadership also recognizes the strong educational background and clinical experience of physicians. However, this model is an outgrowth of the acute hospital situation in which acute medical or surgical illness is the central feature of the patient's situation. In contrast, in the long-term care setting chronic disease, disability, and psychosocial issues often predominate. Thus, in this setting the physician's role as leader may be less natural, and in fact it may be more appropriate for a nurse or social worker to provide leadership for a given patient with the physician as a team participant. For example, there is evidence that physicians do not do a very good job assessing the patient's functional status, which is often critical in long-term care.

The role of physician as leader also at times relates to the role of the physician as an employer or direct supervisor of other members of the health care team. This role for leadership is based on the flow of financial resources, which are often directed primarily at physicians. However, in the United States and many other countries, physicians are increasingly employees of health care systems, analogous to the status of other members of the health care team. In such a situation, it also may be more natural for the physician to function as an integral participant, but not necessarily the leader, of the health care delivery team.

Summary

The physician may play many important roles in the team approach to providing care to complex elderly patients. In most situations, the physician is a necessary participant in the team. However, the whole concept of team care is based on the understanding that the physician alone either does not have sufficient skills to meet all the clinical care needs of the patient or that it would be inefficient use of the physician's skills and time to attempt to do so. A clear understanding and delineation of the physician's roles is important to the success and effectiveness of the interdisciplinary team over time. Much of the knowledge base about the physician's roles in team care is experiential and empirical. Much remains to be learned about how best to integrate the physician's skills into the health care team to provide the highest quality cost-efficient care for complex elderly patients.

Further Reading

Anderson LA, Persky NW, Whall AL, et al (1994) Interdisciplinary team training in geriatrics: reaching out to small and medium-size communities. Gerontologist 34:833–838

Calkins DR, Rubenstein LV, Clearly PD, et al (1991) Failure of physicians to recognize functional disability in ambulatory patients. Ann Intern Med 114:451–454

Halter J, Campbell R, Furuse T (1995) Geriatrics care and team approach (in Japanese). Gerontology 7:118–125

Klein SM (ed) (1995) A national agenda for geriatric education: white papers. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, Bureau of Health Professions, Rockville, MD

Qualls SH, Czirr R (1988) Geriatric health teams: classifying models of professional and team functioning. Gerontologist 28:372–376

Reuben DB, Beck JC (1994) Training Physicians to Care for Older Americans: Progress, Obstacles and Future Directions. Institute of Medicine, National Academy Press, Washington, DC

The Role of Nurses in Long-Term Care for the Elderly

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Key words: Individualized elder care—Family care—Community-based nursing care

The emphasis in care of the elderly has centered on helping patients live a fulfilling life, even if they suffer from health problems, so this is considered an area in which nurses can exercise their skills. In particular, "well-being," or alleviating the patient's health complaints and helping him or her maintain a better quality of life, is a more important concept for the nurse than aggressive therapy.

With this concept in mind, we would like to briefly discuss some aspects of the role that Japanese nurses ought to play in caring for the elderly and some of the problems that they face in taking on this task.

Individualized Care: Emphasis on Individualized Care in Hospitals and Care Facilities

For reasons of economic efficiency, each unit (ward) in a Japanese care facility tends to accommodate fairly large numbers of patients, sometimes as many as 40. the newer care facilities have been set up to allow residents to maintain their individual privacy and their accustomed lifestyle as much as possible. However, it is not easy for elderly people to maintain their previous lifestyles or independence after entering a care facility (or hospital). As everyone knows, the longer persons are institutionalized, the more they lose their ability to live in the community. An important task for the nurse is to make the stay as short as possible by concentrating on individualized care and finding forms of care that will not impede the patient's ability to handle everyday life.

Family Care: The Need to Support the Entire Family, Including the Elderly Patient and the Caregiver

A special feature of care for the elderly in Japan is that it has long been entrusted to family members. I am speaking in particular of the custom of the daughter-in-law caring for her in-laws, which is not often seen in other developed countries. For that reason, the problems of caring for the elderly in Japan are closely linked with the work that women perform as family caregivers. In rural areas, where there are still plenty of three-generation households, elder care by daughters-in-law is still the norm, but we find situations in which the caregiver herself has grown old, and couples in their sixties end up looking after parents who are in their eighties.

In such cases, the nurse's concern is not limited to the elderly patient, but extends to the entire family. Whether it is support by the currently existing public health nurses or nurses from the visiting nurse center or support through long-term care insurance in the future, it seems to be limited to lightening the burden on the in-home caregiver. What we need in Japan is to include the family who live with the elderly patient, and taking the initiative for doing so will be a huge task family for nurses.

Until now, public health nurses have played a role in family care, but this will be reduced with the reorganization of the Public Health Centers, and we can predict that the financial aspect of dealing with the health problems of the family will become even more difficult in the future. In looking at the situation in the context of the Japanese family system, it is important to recognize the critical significance of setting up a system of family care services.

Liaison Nursing in Continuing Care: A Bridge Between Community Care and Hospital Care

With the revision of the Community Health Act, Japanese nurses who care for the elderly have begun focusing their energies on home care. Thanks to the efforts of the municipalities, there have been tentative experiments in offering 24-hour home care in which nurses play a major role. However, for elderly people who live alone or who live in places with poor transportation, areas prone to heavy snowfall, or other areas where it is difficult to provide services, there is a limit to what in-home care can do, and we must ensure the availability of adequate institutional care.

Therefore, we need a system in which elderly people who need both home and institutional care can receive the appropriate type of care at the right time. A system of care managers will probably be set up to ensure the most effective use of public money, but another task for the nurses will be to develop specialists in geriatric nursing, the so-called liaison nurses, who can effectively serve as the link between home care and hospital care. We believe that the liaison nurse will play a major role in determining when medical attention is needed and providing continuity, to ensure that elderly people make the most effective use of hospital care.

Paradigm Change in Long-Term Care: The Switch from Medically Oriented Nursing Care to Health-Oriented Nursing

In Japan, health has come to mean the absence of illness. However, it ought to be possible even for a sick or disabled person to enjoy the best state of health that is possible for his or her condition. In particular, because elderly people become less healthy as they age and have to live with chronic ailments, promoting their health means striving to keep their condition from deteriorating. We can therefore state that for older people, health promotion refers to maintaining their current state of health, even if they are ill. This idea of health promotion needs to be our first principle when nursing care is provided.

Further Reading

Rader J (1995) Individualized dementia care. Springer, New York

Inoue I (1966) Ninchi shougai no aru koureisha to sono kazoku kaigosha no genjou (Cognitively impaired elderly people and the current state of their family caregivers). Kango Kenkyu (Nursing Res) 29(3):17–30

Murashima S, Horii T, Hollander R (1997) Gyousei ga sasaeru 24jikan Zaitaku Kea (Government supported 24-hour in-home care) (in Japanese). Nihon Kango Kyokai, Shuppankai

Foundation for the Promotion of Exchanges Related to Pioneering Public Health Activities, Subcommittee on Research and Surveys of Overseas Public Health Activities (1994) Henkakuki ni okeru hoken katsudou: eikoku no hoken, iryou, fukushi no renkei (Public health in an era of reform: links among public health, medical care, and welfare in England). Japan Nursing Association, Tokyo

Greene VL, Ondrich J, Laditka S (1998) Can home care services achieve cost savings in long-term care for older people? J Gerontology: Social Sciences 53B(4):S228–238

Greene VL, Lovely ME, Miller MD, Ondrich J (1995) Reducing nursing home use through community long-term care: An optimization analysis. J Gerontology: Social Sciences 50B(4):S259–268

Issues Physicians Must Face Under Long-Term Care Insurance

KARL-HEINZ MAURITZ

Key words: Long-term care—Age restriction—Assessment—Role of general physician

The role of physicians has changed considerably in the last 20 years. Because of an aging society and also as a result of effective acute medicine, more people survive with severe chronic deficits. Care, not cure, is the primary objective in these patients. After introduction of long-term care (LTC) insurance, physician are confronted with new questions, problems, and new administrative procedures. However, they are also offered new ways by the LTC insurance to improve their patients' problems. This chapter mainly focuses on the problems and issues that arose for physicians in Germany [1] after a compulsory LTC insurance was introduced for every citizen. The health insurance system helped to establish the LTC insurance. In fact, each health insurer founded its daughter LTC insurance.

Who Is Eligible?

After the introduction of the new LTC insurance, everybody with severe handicaps and disabilities became eligible. There is no restriction of age (even children are eligible), diagnosis, or employment. Patients are not required to undergo a means test. The latter fact is especially important, since it brought about the support of a broader public for the new law. Everybody is entitled who needs care because of physical, cognitive, or psychological disabilities. For practitioners and hospital doctors, a transferral to a nursing home seemed much easier. New nursing homes were built by private investors, anticipating many new clients, and the financial burden for the relatives of LTC patients was supposed to be alleviated. For physicians it is very helpful that the LTC insurance is not restricted to old age and age-related disease, because many patients who are dependent for long time periods are relatively young patients after severe accidents or patients with multiple sclerosis and other debilitating disease. These patients need intensive care for many years.

Who Is Doing the Assessment?

According to the German LTC insurance, there are three levels of severity depending on the severity of disability/handicap in three categories: body care (grooming, toileting, dressing), mobility, and food intake. Because cognitive aspects are not addressed, there are many care-dependent persons who are not eligible in the current LTC insurance (for example, amnestic patients after delayed cardiac resuscitation). The assessment is base on rather simple ADL tests and questionnaires [2] that are performed by physicians or nurses of the health insurance system. That health insurance is involved in the assessment is because the health insurance was instrumental in setting up the new LTC insurance. Many new positions had to be created for the assessment, and because there is an oversupply of doctors in Germany and most European countries, it was a new employment opportunity for many jobless physicians. According to the law, attending physicians and nurses who are familiar with the problems of the patient should be consulted. However, in reality, there is almost no contact between the doctors and the raters.

Several problems arose after introduction of the LTC insurance. Assessment doctors and nurses were very busy. Waiting times for assessment were of the order of months because several hundred thousand handicapped people had to be evaluated at once. These periods have been shortened, but they are still too long. Discharge planning is hampered by these long waiting periods. Physicians, social workers, and nurses had no experience in the new application procedures. One major drawback of the assessment procedure is, in my opinion, the fact, that the rating person sees the patient only for 15–30 minutes. He or she is not involved in considering further nursing strategies or conceiving a plan, and there is almost no contact or feedback with the attending doctor. Therefore, the patient is left alone. Medical treatment and nursing care are handled in parallel. In addition, quality control for nursing services are deficient. Practitioners would have to be involved as case managers. However, payment by the health insurance is mainly restricited to medical procedures. To make the system more effective, a team approach between practitioner, visiting nurse, physical therapist, and social worker would be advisable. Care management will be necessary in the future to plan and supervise the appropriate services.

What Are the Benefits?

The benefits are granted either as payment for institutional care (nursing homes, day care centers, visiting nurse services, devices) or as cash for the care provider (usually family members). Payment for professional care is higher then cash payment to unskilled family members. The monthly payments are, at level 1 for professionals, 750 DM (= $420), and for family members, 400 DM (= $220); at level 2, $1000/$440; and at level 3; $1550/$720. In very severe cases, payment in level 3 payments can be increased to $2080. However even this amount is by far not enough to cover the cost for a nursing home for very intensive care (persistent vegetative state or locked-in syndrome), which costs about $6700 per month. One of the most important goals of the LTC insurance therefore was not achieved, i.e., to protect the family financially and make the discharge or transferral to a nursing home easier. Payments by the LTC insurance relate only to nursing care and similar expenses. Medical expenses, drugs, and physician services are independently paid by the health insurance.

Cash payments for nonprofessional care providers sometime have a negative effect. Some patients only get minimal care, and somebody else, who does not provide care for the required minimal 14 hours/week, gets the money. These is virtually no quality control. Because family members as care providers have their pension insured, the new LTC insurance is in some cases a means to make some distant relative eligible for pension insurace. It is the role of the family physician in these cases to notify the LTC insurance and to ensure that the patient is not maltreated.

Cure Versus Care

LTC insurance covers only services and technical aids for nursing care. Health insurance covers medical treatment. Because long-term illnesses that lead to disability are most of the time a combination of cure and care, there is often a disagreement who will pay for a procedure or a service.

A very elaborate system of criteria for the question who pays for what is established. It is very complicated for daily routine, since there exist several dozens of different health insurance systems each with different criteria. The family doctor is most often not familiar with the detailed regulations, and neither are the visiting nurses, and therefore the patient and the relatives are left alone. There also have been some complaints that private nursing services overcharge the patient.

There is another aspect of the division between health insurance and LTC insurance. Since payments of the health insurance are not restricted to a maximum amount in contrast to the LTC insurance, it is cheaper for families to have the disabled relative in the acute hospital as long as possible, because everything is covered. Physicians in the hospital are pressed by the family to keep the patient as long as possible and longer then necessary. Considering the oversupply of hospital beds in Germany, there is almost no incentive for the hospital doctor to discharge the patient immediately after the acute phase. The excuse that was raised in former times, that there are not enough nursing homes, is not valid anymore.

Needed: Care Management

Most physicians have not yet accepted that for a huge patient group with long-term deficits a close interaction with nurses, social workers, physiotherapists, occupational therapists, and neurologists is necessary to provide the best care for the chronic disabled patient. There is still a interface problem between health care insurance (= acute medicine) and LTC insurance (= chronic medicine).

References

1. Alber J (1996) The debate about long-term care reform in Germany. In: Organization of Economic Co-operation and Development (OECD). Caring for frail elderly people: policies in Evaluation. Social Policy Studies No. 9. OECD, Paris, France, pp 261–278
2. Mauritz KH, Hesse S, Denzler P (1996) Evaluation of impairment and disability in stroke patients: current status in Europe. In: Chino N, Melvin JL (eds) Functional evaluation of stroke patients. Springer, Tokyo, pp 45–58

Interface of Acute and Long-Term Care: Clinical Perspective

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Key words: Nursing home—Hospice—Subacute care—Assisted living—Transitional care

Long-term care (LTC) in the United States is not so much a system as a multitude of options, each with its own funding stream and eligibility requirements. This is as confusing to the health care professional as it is to the patient and family; thus, our experiences may help Japan avoid the pitfalls without compromising on the programs. There are patients in hospitals, nursing homes, assisted living, day care, and home care whose functionality and mental status, medical, nursing, and physical rehabilitation needs are identical. Why this is so is contingent on several factors with varying degrees of influence: source of payment for care; availability of the service in a geographic area; physician awareness of, and control of access to, a care domain; reimbursement for physician and other health professionals services in each domain; eligibility criteria for each domain of care; nursing home and community resources (e.g., informal caregiving availability); network affiliations (i.e., hospital–nursing home–home care); competition to keep beds filled in acute as well as LTC; goal(s) of care; case management presence and role; and the patient's wishes/preferences.

Nursing homes are only one domain of LTC; there is an extensive array of community options, including day care (social, medical), assisted living facilities, senior housing, and home care. Respite services (that is, care for the caregiver) can be provided at home, in the community via day care, or in a nursing home. Hospice care is available in the hospital, nursing home, and at home. Historically, more than two-thirds of nursing home patients are admitted directly from an acute care hospital. Home care patients, on the other hand, can access services/care through community application as well as post hospitalization or nursing home discharge.

However, access, range, and duration of services provided varies with the payer source (and, hence, patient eligibility). The average length of stay for the "traditional" nursing home patient (known as a "resident") is 3 years, during which time the individual would probably have two or three short-term hospitalizations and return to the nursing home. A growing number of nursing home patients are admitted from acute care for short-term rehabilitation and are discharged home or to a lesser level/domain of care (e.g., assisted living facility; senior housing) after a stay varying from 10 to 60 days, depending on the nature of the illness/ disability.

Traditionally, nursing homes provide maintenance care, some restorative nursing care, some rehabilitative care, and care for the terminally ill and dying. Because it takes, on average, 4 to 6 hours to obtain lab and x-ray reports, many nursing home physicians use hospital emergency rooms as external laboratories and use hospital physicians as a source of support for verification of their diagnosis. This default decision to hospitalize gets complicated, however, when the patient has a DNR (Do Not Resuscitate) and/or DNH (Do Not Hospitalize) order. When the patient's goals of care are inadequately expressed and documented, the confusion and uncertainty generated by those orders generally means that the patients is "ping-ponged" back and forth from nursing home to hospital to nursing home. To no small degree, physician confidence in nursing staff's ability to safely care for the patient (i.e., assess, implement, communicate change) and nursing's own sense of its competence and capacity to manage a complex patient is a formidable influence on the decision to hospitalize. In addition, the under- or unreimbursed costs of care, e.g., IV antibiotics, is another major factor in the decision whether or not to hospitalize.

Many nursing homes hospitalize a patient who is clearly dying because they (or the physician) fear legal or regulatory sanction that they failed to provide the necessary and appropriate care. The hospice philosophy has permeated the nursing home industry. Hospice care as a discrete provider program with special eligibility, reimbursement, options, restrictions, and services has also forced nursing homes to rethink what they mean by palliative or comfort care even if the nursing home does not have a formal affiliation with a hospice provider. We now think about the possibilities of aggressive caring instead of cure. The hospice approach has somewhat reduced the "fear of abandonment" expressed by providers as well as patients. Many nursing homes are proceeding on their own to develop pain and symptom management clinical protocols and to develop a hospice approach for end-stage diseases other than cancer, e.g., Alzheimer's, renal, and cardiac disease. Acceptance that the patient is in fact, dying, has ameliorated some, but not all, dilemmas around whether or not to hospitalize the patient.

The average length of acute hospital stay for a nursing home patient or for a person aged 65 or older admitted from the community is generally 5 to 7 days. Cost containment pressures in hospitals, and greater reimbursement for "nonhospital acute care," has made "subacute care" in nursing homes an increasingly attractive venture. However, its premises are not without its perils. Hospital readmission is not uncommon, however, because some nursing homes are unable to provide the necessary care (especially for a patient who was discharged from the hospital "quick and sicker"). Subacute care requires more as well as better trained professionals (particularly RNs and geriatric physicians), sophisticated equipment, the capacity to perform or obtain lab and X-ray services within a reasonable time, and clinical programs. The advent of subacute care in nursing homes followed a similar but older development in home care; we now have two levels of care in each domain. An individual at home can be receiving hi-tech medical, nursing or skilled rehab services, and maintenance or personal care—each reimbursed under a different program with different eligibilities and cadres of professional and nonprofessional staff! Parenthetically, it should be carefully noted that many nursing homes are reluctant to hospitalize their patients because of the poor care they receive in the acute hospital. The hospital nurses are not specially trained in geriatric nursing nor are there necessarily geriatricians on staff. Nursing home patients all too often return from a hospitalization disoriented, with indwelling catheters, restraints, and bedsores.

In constructing an ideal LTC system the first and most daunting task is to define and describe the programs/services that would (should?) be provided in each domain. This question is invariably linked to "who will control the domain?" Medicine? Nursing? Social services? Will it be interdisciplinary? Where will the patient flow come from? How will the domain/service be reimbursed? For a nursing home patient, acute hospital care is indicated and justified when a diagnostic workup can only be done in the hospital and it will alter the goals and plan of care, or when an intervention/type of care is available only in the hospital and it will restore or enhance comfort or function. Given this construct, the relationship between acute and long-term care (and between any of the domains within LTC) should operate independent of the funding stream and be driven, rather, by the focus of care (first) and the locus of care (second).

Particularly with respect to hospitalization, but appropriate when deciding about any domain or service, is the individual, and often family, feeling about the benefits and burdens associated with that domain/service. What do individuals feel they have to gain or lose by hospitalization? of receiving hi-tech care at home? There is a danger of being overzealous in trumpeting the benefits of home care without due regard for the caregiver's and care receiver's fears and feelings about their changed relationship. Medical and nursing interventions should be congruent with the overall goals of care and the patient's preferences and wishes. The locus of care, then, is the best location for the provision of that intervention or care and services.

Many hospitals in urban as well as rural areas have set aside beds for a "transitional care unit" (TCU), more often than not to compensate for low census and the need to keep beds filled (even if at a lower reimbursement). In many cases, however, the patient is too unstable or too complex to be discharged safely to a nursing home in the area (that lacks subacute care capability). The cost-effectiveness of TCUs in acute care has yet to be established, although data indicate less recidivism after discharge from these units. However, there are no data comparing similar sets of patients discharged to subacute care in nursing homes.

Several demonstration nursing homes are admitting patients directly from the community for short-term subacute care for which the individual would traditionally have been admitted to acute care. This route to appropriate medical care that is less costly than acute care hospitalization has significance for cost containment with quality(!). However, without geriatricians and baccalaureate-prepared geriatric nurses, these kinds of programs will not be safe or clinically successful.

Assisted living facilities (ALF) in the United States are still a virtually unregulated and poorly defined LTC domain. Construction and management is generally in the private for-profit domain; reimbursement is primarily from private sources and not from tax-supported programs. Some ALFs provide extensive nursing home-like services, including skilled nursing supervision, intervention and physical therapy, whereas others offer little more than a "safe" environment with some assistance in personal care (i.e., ADL) and recreational and social services. An ALF can have a service arrangement with a home care agency that provides skilled nursing supervision, utilizing a geriatric nurse practitioner, and physician availability. As such, nursing homes are becoming more like community hospitals and ALFs are becoming like nursing homes of a decade ago. The average length of stay in an ALF is as yet unknown as is the frequency of hospitalization of its residents; it is a relatively new domain of LTC. It would not be surprising if some individuals elected to go to an ALF for the short term (as might occur in rural areas of Japan during the winter).

Health care service, and LTC in particular, operates under the four "R's": reimbursement, regulation, review, and rights. There must be quality indicators and a way to measure them; "utilization review" is only one kind of approach. It is unethical and a misuse of public monies to purport to have a LTC system (or domains) without regulatory oversight and periodic independent external review. There is an extensive literature on quality of care and quality of life measurement and a sufficient number of instruments to begin to develop baseline data that address outcomes. It is interesting to note that nursing home patients and home care recipients have radically different feelings about their quality of life and satisfaction with care based on their age, expectations about health care, where they are in their life span, and their values.

The quantity, quality, and flow of information between LTC and acute care, and within LTC, should be such that interventions/services and critical indicators of patient function are readily available and up to date. When baseline data such as the client's normal ADL self-care status, cognitive and decision-making capacity, and emotional status are not available, or come from diverse and possibly unreliable sources, the goals of care, discharge planning, and need for nursing home, home health care, and/or community support can only be regarded as tentative. This is inefficient at best and poor health care planning at worst.

Assessment of the need for acute care and potential to remain in any LTC setting must consider the least restrictive environment where the necessary and appropriate care can be given safely and effectively. This requires training and education of the professional and paraprofessional caregivers and specially educated practitioners. Nursing homes that employ master's degree-prepared geriatric nurse practitioners (GNP) have better patient outcomes: fewer hospitalizations; less emergency room use; reduced use of indwelling catheters; better behavioral management of patients with dementing and/or psychotic illness; less use of restraints and psychotropic medications; and fewer pressure ulcers. These advanced practice nurses are directly involved with patient assessment, care plan development, monitoring, program development, and staff education. It has been shown that the use of GNPs is cost neutral and, in some studies, has reduced patient care costs. Hospital discharge planning designed specifically for the elderly and carried out by nurse specialists has been shown to delay or prevent rehospitalization and has achieved cost savings. In-home comprehensive multidisciplinary geriatric assessment (often led by a GNP) has delayed or reduced the effect of disability, lowered the number of nursing home placements, reduced hospital use, and improved quality of life.

If LTC is to be a comprehensive, integrated, "seamless" continuum of care that interfaces with acute care as needed, then, in addition to the smooth transfer of information and removal of barriers erected by different funding streams and government bureaucracies, a new professional is needed: the case/care manager. Case management would first pick up that client in acute care who now has long-term care needs, or would follow the individual who first became a client via the nursing home or community. I do not believe that medical health care and social (health) care are two separate entities. The overarching goal is to restore an individual to maximum functionality and sense of "well-being," as perceived by the individual, in the least restrictive environment. Without striking a claim that this is nursing turf, as a practical matter, the case manager approach should be holistic, informed by basic knowledge in health and social science.

Finally, it must be noted that the costs of home care, whether hi-tech or maintenance, can exceed the average daily costs of nursing home care. It could be argued that, for some kinds of medical, nursing, or behavioral interventions, the difference between acute care and LTC is whether to bring the patient to the service or the service to the patient.

Further Reading

Castle NG, Mor V (1995) Hospitalization of nursing home residents: a review of the literature, 1980–1995. Med Care Rese Rev 53(2):123–148

Mitty E (1997) The role of nursing in long-term care. In: Jolt H, Leibovici MM (eds) Health care management: state of the art reviews. Hanley & Balfus, Philadelphia

Naylor M, Brooten D, Jones R, Lavizzo-Mourey R, Mezey M, Pauly M (1995) Comprehensive discharge planning for hospitalized elderly. A randomized clinical trial. Ann Intern Med 120(12):999–1006

Stuck AE, Aranow HU, Steiner A, Alessi CA, Bula CJ, et al (1995) A trial of annual in-home comprehensive geriatric assessments for elderly people living in the community. N Engl J Med 333(18):1184–1189

Wetle T (1995) Ethical issues and value conflicts facing case managers of frail people living at home. In: McCullough LB, Wilson NL (eds) Long-term care decisions. Ethical and conceptual dimensions. Johns Hopkins University Press, Baltimore

The technological tether. Ethical and social issues in high-tech home care (1994) Special Supplement, Hasting Center Report, New York

Training of Physicians for Long-Term Care

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Key words: Geriatric medicine—Health care for the elderly—Undergraduate education—Postgraduate education—Training of geriatricians

Japan's population is aging rapidly. Effective training programs in geriatrics and reliable health care for the elderly are basic requirements for an aged society. Unfortunately, the systems currently in place in Japan are glaringly inadequate for these purposes. It is imperative that they be reformed as soon as possible.

Today, clinical education in Japan's medical schools aims at the training of specialists of the various physical functions or organs. Medical practice is also becoming increasingly specialized by organs. As a result, the system is inappropriate to deal with elderly patients with multiple pathology that impair their ability in daily life. Another problem is the lack of a coherent policy on geriatric education. Only 20% of Japan's medical schools offer programs in geriatrics or have departments of geriatrics, and there is virtually nothing by the way of a standardized curriculum.

Recommendations for Geriatric Education and Medical Care for the Elderly

Undergraduate Education: Establishing a Required Geriatrics Curriculum

To respond to the need of an aging society, we must make training in geriatric medicine much more widely available. Programs in geriatrics must be established as a universal component of medical education in this country. Our first task, therefore, is to institute a geriatric curriculum at each medical school. This curriculum should encompass both lectures and training courses and should cover a wide variety of topics in the areas of basic, clinical, and social medicine. In the area of basic medicine, the program should be arranged to impart an understanding of changes in morphology and function with aging process, the role of genes, factors that influence aging, and the relationship between genetic predisposition and the environment.

Clinical medicine is the most important area in the curriculum. The basic purpose of education in geriatric medicine is to train doctors capable of providing the elderly with appropriate and effective medical care. Accordingly, clinical education in this field should focus particularly on approaches to the diseases that interfere with the ability of the elderly to live independently. These include senile dementia, cerebrovascular disease, and osteoporosis.

The biggest problem in an aging society is the rapid increase in elderly patients requiring long-term nursing care. Long-term home and institutional care is the major focus of concern for those involved in health care for the elderly. Accordingly, this area of health care must emphasize the social aspect of medicine, specifically, the provision of social services. Health care for the elderly must concern itself with the whole individual. It requires not only diagnosis and treatment of diseases but a comprehensive assessment that gauges the individual's overall ability. For this purpose, team work is essential. Doctors need to be conversant in various issues in geriatrics such as immobility, impaired communication, falling incontinence, rehabilitation, emergency care, appropriate drug therapies, and issues of medical ethics in terminal care.

Such a geriatrics curriculum, if it is to be effective, will require not only teaching staffs but also a system of support for geriatrics education from specialists in basic and clinical medicine. In addition, universities need to establish cooperative arrangements with off-campus facilities to provide practical training in the treatment and care of elderly individuals with senile dementia or in need of long-term care. The curriculum should include training in such social service facilities as geriatric hospitals, dementia wards, health care facilities for the elderly, and special nursing homes; it is hoped these institutions, in turn, will work to enhance their own training programs.

Geriatric medicine should be included as an indispensable curriculum in medical school, and questions relating to geriatrics and health care for the lederly should be included on the national licensing examination for medical practitioners each year. A considerable number of medical students these days express an interest in specializing in geriatric medicine. Moreover, Japanese society today is in need of a large number of qualified geriatricians. To respond to these needs, our most immediate task is to make education in geriatric medicine available at medical schools throughout the country.

Postgraduate Education: Practical Training for True Proficiency in Care of the Elderly

Medical education in Japan is moving toward requiring 2 years of postgraduate clinical training that maintains a broad focus. Clinical training in health care for the elderly should be given during this period. Geriatric medicine is primary care, and all clinical physicians, regardless of their specialty, should be versed in it. To this end, we must address ourselves to the following goals.

Establishing Geriatrics as a Formal Speciality

Japan's Ministry of Health and Welfare has yet to recognize geriatrics as a formal branch of clinical medicine. Simply having elderly people as patients does not make one a geriatrician. Geriatrics as a medical specialty focuses on elderly patients with various problems requiring long-term care or likely to require such care in the future. The majority of these patients will be at least 75 years old. Physicians specializing in this field need a broad perspective and extensive knowledge, enabling them not simply to carry out diagnosis and treatment but also to conduct comprehensive assessments of patients' functional impairment and to coordinate team work.

Creating Geriatrics Units in Major Regional Hospitals

Many geriatric patients require long-term care, and the majority will receive this care at home. As such patients are particularly subject to medical emergencies, including infections, fractures, and loss of consciousness, it is important to establish a system of medical and social service support for those receiving home care as well.

Public and private hospitals should establish geriatrics units capable of responding to any emergencies of elderly patients. In addition, the need for a system of long-term care should be met by using the existing long-term care wards and health care facilities for the elderly. If core hospitals in each region have for geriatrics units those units can function as centers of care for the elderly, provide coordination for team work, and facilitate the residents' access to necessary care.

Training of Geriatricians

Undergraduate and postgraduate education in geriatrics should contribute to the training of qualified geriatricians. In 1989 the Japan Geriatrics Society inaugurated a system for the certification of geriatricians. As of April 1997, 1627 physicians had received this certification.

An aged society will have a pressing need for a large number of such physicians who will be involved in every aspect of elderly care, which includes preventive health, medical care, and social services.

Further Reading

Orimo H (ed) (1992) New Geriatrics. Tokyo University Press, Tokyo
Orimo H (ed) (1995) Geriatric disease training manual. Medical View, Tokyo

Long-Term Care: The Need for Special Medical Supervision and Collaboration Between Health and Social Services

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Key words: Physician(s)—Long-term care—Nursing home(s)—Medical training—Medical supervision

Introduction

Demographic trends and age-related rates of chronic conditions, resulting in high levels of disabilities and handicaps, will determine the need for community long-term care and institutional long-term care (LTC). As has been shown for many countries, the segment of the elderly population needing institutional LTC varies in general between 5% to 8% of the elderly population (about 2%–5% of the elderly is in need of nursing home care and 3%–5% of care in residential homes) [1,2]. Each elderly and younger person with severe chronic conditions and long-lasting physical and/or mental disabilities shows an almost unique interface with family relations and support, other informal care, living situations, and social integration. Hence, professional LTC support should be highly person-specific and delivered by specially trained professionals (also medical doctors) in a health and social service system that is flexible and easily accessible, guaranteeing continuity of care and allowing clients to make the best informed choice among services available.

It is well known by all involved that the professionally preferred solution to a problem is definitely not always the preferred strategy of a client and his family. The very complicated relationship between demand and care supply in long-term care favors a specially designed LTC system that deals adequately with most of the situations and problems when caring for frail elderly and younger persons with chronic conditions. At least one consequence is that community LTC and institutional LTC (such as care in residential homes and nursing homes) should be optimally interrelated with respect to medical supervision. It is a common experience around the world that fragmented insurance schemes, insufficient eligibility criteria, problems with availability and type of housing, lack of home care, unclear responsibilities and collaboration between health and social services, failing support for families, etc., explain the variations in use of community and institutional LTC. In addition, the specific functions of institutional LTC services are also poorly defined and its capabilities are unknown to many professionals, inhibiting effective collaboration with other health and social services. As residents in institutional care generally have progressive chronic conditions, comorbidities, high levels of disabilities, and frequently exacerbations of medical conditions, special medical care and supervision in this area are needed to avoid unnecessary hospitalizations and to keep the patient at home as long as possible.

Medical Supervision in Community Long-Term Care

With respect to medical supervision in community LTC, several steps can be made to deliver good quality medical care:

- Whenever possible, a general practitioner (GP) functioning as gatekeeper to higher and more intensive levels of medical care, such as care in hospitals
- A GP with expertise that is based on adequate training programs in geriatric medicine, psychogeriatrics, long-term care, and case management during medical school and during the period of specialization in general practice; at least a small part of the GP's specialized training should consist of practicing medical care in a nursing home, a residential home, and a day-hospital
- Practicing according to the principle of keeping the frail elderly (and other disabled age groups) at home as long as possible, having community nursing, paramedical care, (intensive) home care, home helps, day-hospital care, respite care, social work and/or case management available, thus allowing a multidisciplinary community LTC that is person-specific and well balanced with and complementary to family and other informal support
- Delivering to the elderly population a type of medical care for chronic conditions that is preferably based on Consensus Practice Guidelines

(an example is the Medical Standards of the government-supported Dutch Society of General Practitioners with medical guidelines on topics such as COPD [chronic obstructive pulmonary disease], dementia, diabetes mellitus, hypertension, congestive heart failure, depression, arthritis, incontinence, etc.)

- Practicing "friendly visiting" (regular visits to the home of the frail elderly and other disabled age groups) to monitor chronic conditions and disability levels, and advising on (and reducing, whenever possible) professional care according to the needs and preferences of the client
- A GP that is able to consult (also in the client's home), among others, with a specialist in geriatric medicine (geriatrician) and a physician who is specifically trained in LTC (an LTC physician, for example, based on the Dutch model of the "nursing home physician"; see later)
- In consultation with the family, the GP can extend the consultation of the LTC physician to a level where the LTC physician sets up and monitors (preferably for a limited period) multidisciplinary care at home, needed as a result of severe chronic conditions, physical and mental disabilities, and heavy care needs. Expertise and professionals from institutional LTC settings, such as a nursing home, can be made (temporarily) available at the client's home. Client, family, and multidisciplinary care team members can also be supported with day-hospital care and respite care. If a GP is not available, the LTC physician should be able to set up community LTC in the client's home on request of the client (and his family) and other professionals involved.

When a frail elderly person is referred to a hospital, this should only be for diagnostic procedures and short-term medical and surgical treatments, avoiding the development of institutional LTC in hospitals. Medical insurance for hospital care should be distinct from the insurance for LTC, having incentives for proper and early discharge from hospital. Geriatric medicine and geriatric nursing should be available in hospitals, both in a geriatric ward and via geriatric consultation to handle the almost inevitable physical and mental problems so often seen during a hospital stay. A geriatrician with a special training in geriatric medicine (similar level of internal medicine) should also be able to function as a consultant-geriatrician to general practitioners and LTC physicians.

Special attention has to be paid to chronic pain management. Although malignant pain management is a well-known topic, but nevertheless poorly managed in quite a number of patients, medical treatment of chronic pain from nonmalignant diseases is even worse and not infrequently a forgotten area. Special training programs during the specialization period of physicians is definitely needed, e.g., using the WHO pain protocol as a basis for guidelines, adapted to specific pain syndromes. Special pain centers (delivering care, and for teaching and research) should be established on a hospital level for inpatients and for ambulatory patients, for example, as part of a department of anaesthesiology. In addition, from these centers, consultation and treatment should be possible on the spot (at home and in institutions), either on the level of advice to other physicians, or on the level of actually treating (and monitoring) the patients, or both. Training in pain management should also be a substantial part of the training of LTC physicians.

Institutional Long-Term Care

There are no universally accepted definitions for the different long-term care institutions. Nevertheless, to facilitate discussions on functions and positions of institutions in LTC, the following definitions can be adopted. A residential home for elderly people (home for the aged) is an institution providing living conditions adjusted to the needs of residents usually requiring no more nursing care than that can be given by a visiting nurse, who is preferably employed by the residential home. In general, admission results from an inability to manage at home because of difficulties with (instrumental) activities of daily living and the need of relatively frequent supervision and support to organize independent living. In residential homes, assistance should be available for basic activities of daily living, including assistance with dressing and bathing, assistance with mobility from a private room to a communal room for meals, and limited assistance with appliances such as urinary catheters. Most care in residential homes should be provided by nursing aids and personnel who are specifically trained for the job in relatively short training programs. In many countries, residential homes are building complexes (apartment buildings) where elders reside in private apartments of single rooms.

When a resident is gradually deteriorating, more intensive care should be available and, in addition, be supplemented with multidisciplinary care from a nearby nursing home (for example, nursing care and paramedical care from nursing homes available in residential homes). Transfer to a nursing home should be kept to a minimum, whenever possible. Rehabilitation can be an indication for a temporary nursing home admission. Nevertheless, it is evident that the strict boundaries so often seen between residential homes and nursing homes have to disappear, at least with respect to legislation, insurance schemes, medical supervision, collaboration, and exchange of expertise and personnel (for example, "substitution of nursing home care from a nearby nursing home to a residential home," with the goals of avoiding transfers from residential homes to nursing homes and improving quality of life and independence of the residents in a residential home should be possible). At the same time, privacy, freedom of choice, and respect for autonomy also should definitely be improved, in nursing homes as well as in residential homes, without denying the importance of medical and paramedical care. This multidiscplinary care should be available in institutional LTC settings that are homelike as much as possible.

A nursing home is an institution providing nursing care 24 hours a day, assistance with activities of daily living and mobility, psychosocial and personal care, and paramedical care such as physiotherapy and occupational therapy, as well as room and board. Availability and type of services in nursing homes reflect more intensive levels of care. In addition, nursing home care should have a diversity of treatment and support goals. To take the Netherlands as an example, residents are admitted to Dutch nursing homes for several reasons: 50% require intensive long-term institutional care (for physically and/or mentally disabled [dementia] residents), 40% use predominantly rehabilitative services, 5% are in need of terminal care, and another 5% require special services such as the care needed by comatose people and those on respirators. Many nursing homes in the Netherlands also provide respite care.

The rehabilitative services provided by Dutch nursing homes include physical therapy, occupational therapy, speech therapy, and activity therapy (six paramedical staff per 100 beds). Such intensive rehabilitative efforts result in approximately one in three nursing home residents (35%) being discharged home after a shorter or longer nursing home stay [2].

In addition, medical care in nursing homes in the Netherlands is provided by specially trained physicians, who are employed by the nursing home with an average ratio of one full-time doctor per 100 nursing home beds. The training program to become a nursing home physician takes

2 years (after finishing medical school). Each physician-in-training is working 4 days per week in a teaching nursing home for practical training under the supervision of a senior nursing home physician. One day per week, the trainees receive theoretical training at a specialized university department. The training was implemented after a 15-year discussion with the nursing home sector, the government (Ministry of Health, Social Welfare and Sports), and the Royal Dutch Medical Association [4]. Recognition of the need for good quality medical care in nursing homes convinced all parties to agree on the development of this training program, which is collectively paid for by all the nursing homes in the country. In 1997 there were almost 1000 registered nursing home physicians and physicians-in-training in the country's 325 nursing homes with 55 000 beds for a population of just over 2 million elderly (2.5% of elderly are in nursing homes). Almost all nursing homes also have special collaborative care projects with nearby hospitals (hip fracture and stroke rehabilitation, care for comatose patients, and special terminal care, etc.)

Medical Supervision in Institutional Long-Term Care

As mentioned earlier, a small percentage of the elderly population will most likely be in need of institutional LTC, whatever long-term care system is designed. Nevertheless, this percentage can be kept low if community LTC is well developed and care in institutions such as nursing homes incorporates rehabilitative services and adapts a more active discharge policy. In addition, the most important elements in institutional LTC—residential homes and nursing homes—have to be interrelated to a level of less heavy and more supportive LTC in residential homes (including care for mild to moderate severe dementia patients without severe behavioral problems) and more heavy and specialized care in nursing homes. It is suggested that medical supervision of residents with chronic conditions and related complex health problems should be delivered by specially trained LTC physicians, practicing in institutional and co-practicing in (complex) community LTC.

Hence, when developing medical supervision in a new LTC system of which residential homes and nursing homes are a part, it is essential to have the following.

- Clear definitions of LTC homes and their service potentials, so as to position these homes adequately in the total spectrum of health and social services and to effectively balance collaboration

- A LTC physician who is specially trained for the medical supervision of chronic conditions in residents living in nursing homes and residential homes (employed by these homes and having 24-hour medical responsibility)
- A LTC physician functioning as a consultant and copractitioner to general practitioners and—if applicable—giving supplementary medical supervision for clients living at home and in need of (complex) community LTC
- A LTC physician who is practicing proper assessments of residents and regularly monitors chronic conditions and health problems (for example, according to the methods of the Resident Assessment Instrument [RAI] [3]
- Coordinating a multidisciplinary team consisting of nurses who are specially trained in LTC, and of professionals in paramedical and psychosocial care
- Setting up and evaluating care plans that are characterized by an individually adjusted balance between cure and care, avoiding overmedicalization and underdiagnosis (these aspects are an important part of the 2-year training program of the LTC physician)
- Treating current disorders and health problems in the community and institutional LTC setting itself (for example, exacerbations of congestive heart failure, urinary tract infections, pneumonias, etc.) to keep the number of hospitalizations to an adequately indicated minimum
- Implementing rehabilitation programs and resocializations at a level that would enable an active discharge policy from the nursing homes to the community
- Functioning as a consultant to hospital specialists to structure early discharge policies for patients in hospitals that are in need of institutional LTC and to establish collaborative care projects within the LTC settings.

In addition, adequate long-term care should focus on flexible collaboration between the different care segments and services, replacing institutional care for community care and gradually introducing more competition between services and, thus, increasing innovations. Central in developing an LTC system is the principle that it is not the (survival of the) service or institute itself that is the core of the health care system, but the flexible provision of care at a place and time that is optimal in balance with the patient's/client's care needs and preferences. So, the concept of established services and institutions should be replaced by the concept of "thinking in terms of care functions that are flexible and person-specific, rather than thinking in terms of fixed institutions and services" [5].

Conclusions

Much attention should be paid to the medical curriculum at universities and the specialist trainings of physicians with respect to the medical supervision of chronic conditions. There is need for a specially trained long-term care physician who performs the medical supervision of residents in institutional LTC settings and functions as a consultant and co-practitioner to general practitioners and hospital specialists. Based on the Dutch experiences with the AWBZ (Exceptional Medical Expenses Act), it can be expected that the above-described developments are very possible when there is a specific and distinct insurance scheme with objective eligibility criteria, performed by independent indication committees [5].

References

1. Ribbe MW (1993) Care for the elderly: the role of the nursing home in the Dutch health care system. Int Psychogeriatr 5:213–222
2. Ribbe MW, Ljunggren G, Steel K, Topinkova E, Hawes C, Ikegami N, Henrard JC, Jönson P (1997) Nursing homes in 10 nations: a comparison between countries and settings. Age Ageing 26 (suppl 2):3–12
3. Steel K, Sherwood S, Ribbe MW (1997) The future: a person-specific standardized assessment instrument. Age Ageing 26 (suppl 2):83–85
4. Ribbe MW (1992) A new professional challenge: the two year post-graduate vocational training programme for nursing home physicians. Paper presented at the WHO Regional Office for Europe symposium "Contribution of Prevention and Rehabilitation to Healthy Aging," Heidelberg, Federal Republic of Germany, 4–7 October 1992
5. Schrijvers AJP (ed) (1997) Health and health care in the Netherlands. A critical self-assessment by Dutch experts in the medical and health sciences. De Tijdstroom, Utrecht

Long-Term Care and Dementia

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Key words: Dementia—Long-term care—Special care units Alzheimer's disease—Ethics

Individuals with dementia require long-term care (LTC), i.e., "a variety of on-going health and social services provided for individuals who need assistance on a continuing basis because of their cognitive impairment" [1] (also see chapter by J. Campbell, this volume). We agree with the premise of the conference that the goal of LTC is to improve the quality of life of these individuals and other affected members of their family and community. In this paper we review the characteristics of dementia that require special consideration in designing an ideal LTC system. We believe that, with some exceptions, the system should not include dementia-specific components, but rather be judged as dementia-capable or dementia-friendly. We begin by reviewing the dementias as medical and social entities and their different characteristics that should be responded to in our LTC systems. Next we consider current initiatives to provide LTC to patients with dementia, including community and institutional basis LTC. Then we examine the kinds of programming that are thought to be important for patients with cognitive impairment. Finally, we conclude by discussing characteristics of an ideal LTC system that would meet the needs of patients with dementia, although many of these characteristics will overlap with the general characteristics of an ideal health care system.

Dementia—What Is It?

Dementia is the loss of more than one cognitive ability in a person who was previously intellectually at a higher level occurring in a clear consciousness. Thus, dementia is differentiated from a brain lesion that leaves the individual with essentially a single modality of intellect affected, such as language in an aphasia due to a stroke. Dementia is also differentiated from mental retardation, where an individual was born with lower intellectual abilities than normal, and delirium, which is an acute and often reversible form of cognitive impairment often caused by medical illness. Dementia can coexist with both mental retardation, as in older Down's individuals, and with delirium, in individuals who are demented but then become additionally impaired by a medical illness. The definition of dementia does not require the condition to be progressive, although the most common causes frequently are. For example, dementia could be caused by a static lesion such as head injury. Moreover, dementia can affect individuals of any age, although it is more common in older individuals. The most common cause of dementia in the United States, and probably in Japan, is Alzheimer's disease (AD), a neuropsychiatric condition that begins insidiously and progresses slowly to where it may cause complete dependence on other individuals. Some dementias are potentially reversible, such as those caused by hypothyroidism or vitamin deficiencies, but all dementias should be viewed as treatable in one way or another.

The degenerative dementias are characterized by loss of nerve cells, often with specific pathological hallmarks such as senile plaques and neurofibrillary tangles, as in AD. Overlap occurs among degenerative dementias in clinical and pathological features, for example, AD and Parkinson's disease. These different degenerative dementias have specific features that would affect care systems. For example, patients with dementias associated with movement disorders such as Parkinson's disease or Huntington's disease have greater care needs because of their motor dysfunction. Moreover, frontal lobe dementias, of which the classic is Pick's disease, are increasingly being identified. In these diseases, executive functions, i.e., goal setting, planning, monitoring one's own behavior, and social skills are dramatically affected by the disease. These patients require much greater energy from the caregivers to both initiate and monitor behavior. These patients also frequently have behavioral and psychiatric symptoms, such as hallucinations and delusions, although these kinds of symptoms can be found occurring later in the course in a variety of dementias including AD.

Dementia can devastate the individual's ability to perform both personal activities of living and social roles. Thus, as the dementia progresses the patient needs increasing help in functioning in daily life. The patient with dementia becomes particularly vulnerable in terms of allocation of social resources. Such an individual depends largely on their past participation in society and current social relationships to defend a niche for themselves in society and a place in the health care budget. Some have even described that dementia involves a loss of self or personhood; thus, there is a danger in debates about LTC policy that individuals with dementia would even be excluded by virtue of losing their humanity [2,3].

Long-Term Care System for Demented Patients

A discussion of the evolution of LTC for patients with dementia is beyond the scope of this paper. A variety of informal and formal health care services have been offered, including mental institutions, geriatric hospitals, nursing homes, assisted living, community-based programs, in-home programs, and, of course, informal family care. The relative importance of these different institutions has shifted through time in both Japan and the United States, and services vary in different countries [4].

In both countries there has been a spirit of innovation in LTC focusing on patients with cognitive impairment. In the United States, the National Alzheimer's Association Respite Demonstration Program, which this author chaired for a number of years, provided resources to chapters of lay individuals to develop a variety of programs largely to help maintain patients in the home. The Robert Wood Johnson initiative in day care and the Medicare demonstration for case management in the community built on this initiative. Day care and home care have expanded rapidly over the last several years, although firm, quantitative evidence to support its improving the quality of life of either patient or caregiver is scant. A revolution has also occurred around the world in the development of environments to better care for patients that require some form of institutionalization. The term Special Care Unit (SCU) has been used to label these entities, although what is referred to as an SCU varies considerably [5]. Some nursing homes in the United States have merely reshuffled some beds and developed a marketing plan, whereas other organizations have developed completely new buildings with architecture and programming designed to enhance the quality of life of the cognitive impaired. Research clearly demonstrating the value of these health care interventions in comparison to more traditional forms of institutional LTC is lacking despite attempts to generate such an empirical foundation [4]. Currently, a new spirit of innovation also exists in an important and neglected stage of Alzheimer's disease, i.e., end of life. In the United States, hospice programs were designed principally around models for patients with "terminal" illnesses, such as cancer. However, it is increasingly recognized that the philosophy of hospice could well serve individuals with other chronic diseases, including dementia [6].

One of the difficulties in assessing these LTC interventions in AD has been the lack of a well-developed field of outcomes research in dementia [7]. Particularly, there has been a lack of attention paid to the assessment of quality of life [8]. Most recently, however, new initiatives have led to the development of dementia-specific instruments to assess quality of life using self-ratings, even in patients who have moderate dementia. Thus, the assessment of quality of life of both patient and caregiver is being incorporated into more trials of therapeutic intervention in dementia. Ultimately, such a focus on function and quality of life outcomes may allow us to compare interventions of different kinds, not only community- and institution-based care, but also medications. Perhaps the use of common assessment instruments such as the minimum data set would facilitate this comparison of biological and social interventions. Moreover, the assessment of quality of life in cost utility analysis allows pharmacoeconomic studies to be conducted, particularly to measure the effects of medication.

Programming: Specific Interventions for Dementia

Attention has been paid in LTC to both environmental design and programming for patients with dementia [5,9]. The traditional nursing home developed in the United States and modeled after a hospital has been judged to be inadequate. For example, long halls with a central nursing station did not permit adequate monitoring or allow, for example, patients to have privacy. Wanderers can end up entering into rooms at the end of the hall. Many new nursing homes use different designs, including, for example, circular tracks for patients to wander and specific means by which patients can recognize their rooms, for example, including a display case outside the room with photographs and personal mementos. A considerable amount has been written on programming for patients with dementia specifically. These include attempts to improve communication such as keeping routines structured and predictable, and include appropriate numbers and types of patients [9].

Two approaches we have been evaluating are attempts to improve communication, which is essential to providing care to patients with dementia. The first is a program called FOCUSED [10]. The second approach, validation therapy, developed as a reaction to perhaps the most common form of programming, called Reality Orientation. Reality Orientation is designed to bring the patient back into the world of the caregivers by orienting them to time, weather, and organizational activities. Validation therapy, developed by Naomi Feil, asks the clinician to try to enter into the cognitive world of the patient and to work with the specific issues that the patient is dealing with at that stage of their life development [11]. Other more specific programming approaches such as music therapy are also being developed.

Characteristic of an Ideal Long-Term Health Care System for Patients with Dementia

Integration of Medical and Social Models

The Alzheimer academic and clinical world can be torn apart by conflict between those who wish to find a cure (biological treatment) and those who wish to care (psychosocial treatment) [12]. Of course, we need to do both, but because of professional antagonisms and competition for funds, fruitful dialog is not often possible. I agreed with the organizers that a long-term health care system that builds on principles and approaches of both medical and social models would be best.

An example of such integrated approaches is the use of teams. We are working, for example, to improve the development of interdisciplinary team care through the development of geriatric learning teams in which teams of professionals identify specific learning goals for themselves designed to improve care of patients with dementia.

Increasing numbers of drugs are being developed for patients with AD, which may provide a modicum of benefit in enhancing cognition and will also lead to more effective treatment for the psychiatric symptoms. Many studies are now under way to assess whether various drugs can slow the progression of disease. Although these promise to have significant impact on care systems, we must be cautious in exaggerating the likelihood of profound benefits. We will need to use these medications in LTC integrated with psychosocial programming.

It is also important to enhance the dialogue about therapeutic goals between those that work on medication development and those who focus on psychosocial programming. Using common assessment instruments in trials of different kinds of interventions might assist this discussion. Moreover, people who are producing new medications frequently justify the cost of such medications on the basis of preventing nursing home placement. It is not clear whether preventing nursing home placement will save money (i.e., patients in the community may use more acute services), or in fact whether it is a desirable goal at different stages of disease. Severely demented patients may be best cared for in an institution.

Coordination of Care

The needs of patients with dementia and their families should encourage the development of a seamless continuum of care. Patients with dementia frequently evolve from needing minimal extra health care to becoming completely dependent. Thus, they need integrated seamless systems, which include common case care coordination and financial and information systems. In the United States, the National Chronic Care Consortium is promoting such efforts at integration.

Use of Information Systems Technologies

In the future, the use of information systems will be critical in integrating health care systems by providing such features as common care plans and financing. They will also serve as educational tools. The use of multimedia technology to educate caregivers (lay and professionals) will increase. For example, in our geriatric interdisciplinary team training grant mentioned earlier, we are developing a CD-ROM to teach nurses, social workers, and physicians about the complexities of the ethics of genetic testing in dementia. Moreover, it is possible that information systems can be used as an important part of programming for patients with dementia. In the homes and LTC facilities (in Japan and the United States), the television set is ubiquitous. Can we not replace the television set with a computer video camera and monitor that monitors the environment, responding to the needs of the individual patients? Could we not imagine a CD-ROM constructed for somebody in the early stages of dementia that would include favorite photographs, movies, and vacation trips? As the dementia progresses, the computer can modify the interactive CD-ROM to respond to the specific needs and abilities of a patient at different stages. Can a computer become a carer (or at least assist with care)?

End-of-Life Care

Although strictly speaking end-of-life care fits into our concerns about providing a coordination of care across systems and of integrating medical and social models mentioned earlier, we list it separately because of the current neglect and its importance for the future. Hospice philosophies and programs work well for patients who are dying of a variety of illnesses, but have not been developed specifically for dementia. How does one work in end-of-life issues in patients with a disease that has been referred to as the funeral that never ends? Such patients often cannot communicate well, or at all verbally, with family or staff.

Moreover, we will increasingly face cost constraints on our health care system and will have to ask how much care can be offered to patients in the end stages of disease. My own belief is that the placement of a feeding tube in a critical decision in end-of-life care. As we think more about individual clinical goals, as well as social policy goals of our health care system, we will likely offer less care to severely demented terminal patients than is currently provided. The use of antibiotics and feeding tubes will likely decrease. It is important that such reflections of our goals of care be based on ethical deliberations and attention to the results of research rather than purely financial motivations.

Summary

In the future, more people will have dementia and our health care systems will be stressed. Integrated biopsychosocial models of care will be key. We need to develop models of long-term care that are dementia capable and responsive to the needs of caregivers as well as patients. Ideally, outcomes research can guide some of these efforts to define what is key to successful community and institutional long-term care. Attention to quality of life and not merely duration of life, particularly in profound dementia, will be essential. Attention to spiritual needs of patient and caregivers should be included in our programs of care [13]. Integration of medical and social models will be difficult but is important to optimizing use of resources.

References

1. Improving the quality of care in nursing homes (1986) National Academy Press, Washington
2. Sabat SR, Harre R (1992) The construction and deconstruction of self in Alzheimer's disease. Ageing Society 12:443–461
3. Whitehouse PJ, Deal WE (1995) Situated beyond modernity: lessons for Alzheimer's disease research (Editorial). J Am Geriatr Soc 43:1314–1315
4. Butler RN, Kiikuni K (eds) (1993) Who is responsible for my old age? Springer, New York
5. Holmes D, Ory M, Teresi J (eds) (1994) Alzheimer Dis Assoc Disord 8 (suppl 11):S1–S434
6. Post SG (1995) The moral challenge of Alzheimer disease. Johns Hopkins University Press, Baltimore
7. Whitehouse PJ, Maslow K, Smyth K (eds) (1998) Alzheimer Dis Assoc Disord 11 (suppl 6):1–198
8. Whitehouse PJ, Rabins PV (1992) Quality of life and dementia (Editorial). Alzheimer Dis Assoc Disord 6:135–138
9. Gwyther LP (1985) Care of Alzheimer's patients: a manual for nursing home staff. Alzheimer's Association, Chicago
10. Post SG, Ripich DN, Whitehouse PJ (1994) Discourse ethics: research, dementia and communication. Alzheimer Dis Assoc Disord 8(4):58–65
11. Feil N (1993) The validation breakthrough. Simple techniques for communicating with people with Alzheimer's-type dementia. Health Professions Press, Baltimore
12. Kitwood T, Bredin K (1992) Towards a theory of dementia care: personhood and well being. Ageing Society 12:269–297
13. Keck D (1996) Forgetting whose we are: Alzheimer's disease and the love of God. Abingdon Press, Nashville

Further Reading

Improving the quality of care in nursing homes (1986) National Academy Press, Washington

Butler RN, Kiikuni K (eds) (1993) Who is responsible for my old age? Springer, New York

Post SG (1995) The moral challenge of Alzheimer disease. Johns Hopkins University Press, Baltimore

Kitwood T, Bredin K (1992) Towards a theory of dementia care: personhood and well being. Ageing Society 12:269–297

Summary of the Discussion for Session 2

1. Difficulty of Balancing

Long-term care poses a difficult issue for professionals. For example, physicians do not want to get too involved in the social aspects of care. On the other hand, they do not want to delegate too much of their professional role to nonphysicians, whether nurses, social workers, or families, etc. While physicians have been accused of treating patients too aggressively in the acute sector, in the LTC sector they have been criticized for underdiagnosing and undertreating conditions, such as chronic pain, which can be improved (if not cured) by appropriate medical interventions, just because the patient is considered to be too old. Thus, striking the right balance too much medical care and too little medical care is tricky.

Physicians specializing in geriatrics and rehabilitation should be able to act as the ideal interface between acute medical care and LTC. However, their role remains poorly defined and they tend to be caught up in the middle of the struggle between the medical and social service sectors and to have difficulty obtaining adequate resources. Physicians in acute, mainstream medicine tend not to have a high regard for rehabilitation medicine because they think that the results are often uncertain and lacking in scientific basis. Conversely, those working in the social sector criticize the medical rehabilitation performed in hospitals because they believe it is often poorly suited for the actual living conditions found in the community and nursing homes.

Several practical questions thus remain unanswered. Should rehabilitation be financed by health insurance, LTC insurance, workers' compensation, or pensions? Should entry into LTC occur only after all rehabilitation efforts have been exhausted, or should active rehabilitation treatment continue to be provided as part of LTC?

Nurses working in LTC often have an ambivalent role too. On one hand, they wish more responsibility would be delegated to them from physicians. On the other hand, they are hesitant about delegating specific nursing procedures, such as handing of medications, to care workers. Legal liability issues become tangled up with professional turf battles in both. The problem becomes more pronounced in home care because nurses and care workers are very often on their own when providing care. LTC nurses are also faced with an uphill struggle to gain recognition from their peers working in the acute sector. The education and training of nurses has been dominated by the acute care model, and, in the case of Japan, a considerable part of the teaching is still done by physicians.

The dividing lines between LTC and acute medical care, and that between nurses and care workers, are constantly being redefined, which adds to the difficulty of establishing precise boundaries. In an ideal model, geriatrics and rehabilitation and geriatrics are fully recognized, and the difficult task of maintaining the balance is achieved. Then, the physician could become a gate-opener to social care, which would substantially increase service access to elders because they are more willing to visit health care facilities.

2. How Countries Have Struggled to Maintain Balance

The marginal, and difficult, roles of physicians and nurses working in LTC are common to all countries. In the United States, LTC tends to be dominated by the medical model, mostly for funding reasons. However, more by accident than by design, acute care and LTC are separately funded: acute care by Medicare, and LTC by Medicaid. This independent funding has helped to increase resources for LTC, as LTC tends to lose out to acute care if they share a common funding source. Recently, efforts are being made to integrate acute and LTC by managed care organizations, as the boundaries have shifted. Many nursing homes have taken on the function of hospital care, although they continue to be largely managed by nurses, not physicians.

In Sweden, after the ADEL Reforms, LTC was moved out of medical care, under the responsibility of the counties, and became part of social care, under the responsibility of the municipalities. Physicians have had difficulty in working under these new conditions. To prevent municipalities from dumping their responsibilities onto the counties, if the patient is ready to be discharged from hospital, the municipalities are obligated to find an appropriate placement. Should they fail to do so within 5 days, they must pay for the rest of the hospital stay.

On the other hand, in the Netherlands, physicians are very prominent in nursing homes. In a country of 2 million elderly and 50 000 nursing home beds, there are 1000 nursing home physicians. Nursing home medicine is a recognized specialty of medicine. However, rehabilitation specialists are concentrating more on young people and less on the elderly, leaving the elderly to nursing homes and nursing home physicians. The funding source for LTC is clearly separated from acute care.

In Germany, the new LTC insurance does not cover medical treatment. Rehabilitation therapy is being provided before the provision of LTC insurance or pension so that the benefits level could be lowered. Thus, once the individual starts receiving benefits from LTC insurance, it becomes very difficult to receive rehabilitation. However, the new insurance has made available LTC to the young, who had faced particular difficulty in obtaining care. This advantage would not be available in the new Japanese system because of its age limitations.

In Japan, under the new LTCI system, the original intention was to move away from the present medical model, which has created such problems as having most institutional care take place in hospitals. However, the medical community realized that unless they had some input in designing the new scheme, they would be left out. Physicians and nurses will accordingly have a substantial role in providing services, and a basic question for the success of the new system is whether their participation will actually improve the lives of frail older people.

3. Policy Implications

Keys to making the clinical dimension of LTC more effective include careful diagnosis of the problems that cause frailty, assessment of the extent to which they can be corrected, and judgment on how that should be accomplished. At present in Japan to a still greater extent than in other countries, it is not possible to do large numbers of full-scale geriatric assessments because there are not enough doctors with appropriate training.

The curricula in medical schools should be revised, and good courses in geriatrics and rehabilitation should also be developed for in-service training for practicing physicians, aimed particularly at diagnosis of chronic illness and appropriate treatments. The ideal would be to have all those providing LTC, including care workers and families, share a basic common knowledge of the underlying medical conditions. At the same time, learning of the social aspects of care should be made compulsory to all health care professionals. Cross-training is the key to better communication and the ability to work effectively in teams.

The dividing lines between acute care and LTC should be drawn so that at the level of individual patients, they are able to move between the facilities and reimbursement mechanisms for each. However, at the organizational level, it may be more appropriate to divide the responsibility between two different systems so that the funding for LTC would remain protected. The flow of money and patients must be carefully managed and monitored.

Investment in research is the key to establishing the status and defining the role of rehabilitation and geriatrics. The use of rehabilitation and other aspects of LTC could be improved if outcomes were to be measured more systematically, focusing on quality of life and utility. Such research might borrow from the pharmacoeconomics approach to estimate quality-of-life years. In setting the research policy agenda, the following issues should be noted. First, at least in America, there tends to be too much R and not enough D in Research & Development. Second, research into the social aspects of LTC and into how particular programs work should also be undertaken, since there appears to be an overemphasis on research related to biological aspects of aging and pharmaceutical products. Third, outcomes research should be used to improve systems, not just provide the data for stricter and stricter guidelines on what can be reimbursed. This can be done. For example, the use of restraints in the United States is being abandoned due to the results of such research.

Session 3
The Macroeconomic and Macropolitical Setting

Introduction and Summary

PETER HICKS

The papers in this session situate long-term care in its economic, social, and political setting. This introductory statement attempts to provide a context by summarizing trends in these broader areas.

The Overall Macroeconomic Implications of Aging

The macroeconomic implications of aging in OECD (Organisation for Economic Co-operation and Development) countries flow from the combined effects of individual aging (the growth in longevity as a consequence of declining mortality), population aging (more people in older age groups as a result of declining fertility), and changing patterns of activity within age groups (particularly earlier retirement). If existing trends persist, the combined results will be that, in most OECD countries, employment will grow as a percent of the population until about the year 2010 and then will begin to decline.

Unless something changes, this decline will pose a fiscal challenge. In 1960 there were four employees to support the pensions and health care of each older person. There are now three employees for each older person, which will persist for another decade. Then there would be a slide; by 2030 there will be only two employees for each person aged 65 and over. The result would be higher taxes for workers, lower benefits for retirees, or both. The same trends pose a threat to material living standards, with relatively fewer people working to produce the goods and services to be consumed by the whole population. Assuming a continuation of current productivity trends, the rate of increase in GDP per capita will be cut in half in the years after 2010.

A reduced rate in growth of material living standards would not be a problem if it resulted in a socially desired outcome—more leisure time in retirement. However, the evidence indicates that choices toward early and abrupt retirement are considerably influenced by unintended incentives built into social programs and labor market practices. If these were changed, many people would choose a less abrupt retirement and would spread work later in life. As well, existing arrangements are leading to a misallocation of society's resources. For many, living standards already increase on retirement. Living standards for retirees are already higher than for families with young children. Also, the periods of time spent in retirement are becoming much longer. There is a loss to the economy and society of the contributions of growing numbers of healthy, skilled people.

The Macroeconomic Implications of Long-Term Care

Across OECD countries, about 20% of older people need formal care, about a third of it in institutions and two-thirds in homes. Because the numbers of very old people are growing particularly rapidly, the fiscal implications of supporting long-term care might initially seem to be formidable. This does not seem to be the case in reality, however. Spending on long-term care is relatively low. For example, a 50% increase in the cost of care would result in an increase in spending of about 1% of GDP—a large figure, without any doubt, but still considerably smaller than costs associated with pensions and health care. Further, the growth in long-term care costs may not be as high as once thought. Recent data, including recent analysis by the OECD, suggest that incidence of severe disability is decreasing and is likely to significantly mitigate the pure effects of aging on long-term care costs.

The conclusion is that the overall macroeconomic implications of aging and long-term care may be relatively small. As well, OECD analysis suggests that the form of financing (such as the balance between pay-as-you-go and advance-funded elements) is unlikely to have major effects at the level of the economy as a whole. This in no way, however, minimizes the financing challenges for a country such as Japan that is planning a major expansion of the system over a short period of time. And, as noted in Professor Yashiro's paper, financial arrangements can have a large micro effect on the incentives that operate within the long-term care system itself.

Uncertainty About the Future

The foregoing comments assume that existing trends will carry on in the future. This is a risky and, indeed, unlikely assumption. The data needed to support projections of the demand for, and supply of, long-term care are weak. There is much uncertainty about the demand for long-term care. The extent of disability depends greatly on medical breakthroughs that cannot be predicted. There are potentially important cohort effects that cannot be easily quantified. That is, future generations of older people will have quite different nutritional, family, labor market, and educational histories.

There is also much uncertainty about the future supply of long-term care. With respect to family caregiving, a new generation has been added to the typical child–parent–grandparent structure with consequences for caregiving that are not yet clear. Traditional expectations based on implicit trade-offs involving inheritances and caregiving may change as a result of this added generation (and as a result of changes that are occurring in the relative income and wealth positions of different generations). Uncertainty is compounded by the effects of greater marital instability and rapidly changing labor market patterns for both men and women.

There is equal uncertainty about the supply of formal caregiving. The long-term care system is heavily driven by labor (as opposed to health care where technology plays a much larger role). Also, considerations about the supply of labor are, as indicated in Professor Seike's paper, not simple; they are influenced in part by the education and training systems. There are many questions about the speed with which the labor market can adapt to changes in the long-term care system, particularly given the scale of change now being considered in Japan. And, as noted, medical technology can make a large difference to the type of long-term care that will be required. Changes in housing and social services policies would also have effects that are difficult to anticipate.

Macropolitical Trends Affecting Social Policy Generally

A similar lack of data, and hence much uncertainty about future trends, exists in most areas of social policy, not only in long-term care. Indeed, throughout the OECD world, social policies are being reformed in similar ways in response to common trends and uncertainties.

A central direction in reform in social policy is the gradual introduction of a new life-course emphasis, with the focus on a more active role in helping people contribute to the economy and society over the course of their lives. The OECD has referred to reforms in this direction as *active aging.* Active aging reforms involve reducing the provisions that now exist in much programming that reduce flexibility in how people allocate time over their lives to work, learning, leisure, and caregiving. It also involves strengthening support to people in making life choices. The most pressing priority is on increased choice during the work–retirement transition, but similar trends apply in most areas of social policy.

These changes can be cast in terms of the active "citizen" who has complex, interacting social and economic relationships over the course of life, including use of government services and income transfers. This is in opposition to the image of a passive "client" who is seen as the recipient of a particular public service taken in isolation (or of a "customer" choosing among a set of such predetermined services). The result of this changed perspective is more emphasis on providing information to allow citizens to make better life choices in areas such as health, training, or retirement planning, on preventative as opposed to remedial services, on getting nearer to the individual through decentralization, aging-in-place and case management, on a variety of market-like instruments for providing greater choice and efficiency.

Other examples include new priority to lifelong learning, human capital formation, employment-oriented social policies, and policies that focus on transitions in life such as those from school to work as well as from work to retirement. There is more emphasis on a better integration of family and institutional arrangements, on a better balance between lifetime benefits from programs and contributions to the cost of those programs, and a better balance between policy priorities and the actual lifetime risks faced by individuals and families. Such newer approaches will, however, only be sustainable in the long term if they are supported by good data on outcomes. In most areas, such data unfortunately do not exist and, as a consequence, there tends to be an element of faddishness in these trends. They move in cycles that can be driven as much by ideological as by empirical factors.

Because of this uncertainty, a key challenge is therefore to develop systems that can adapt flexibly over time—that can allow learning based on new evidence as it develops. An important element in providing flexibility is to build systems (both in terms of financing and delivery) around multiple instruments and approaches. An even more important element is to start collecting (and using) data on outcomes—on what is working best in reality.

In some cases, and especially in the absence of good data on effectiveness, a call for flexible systems based on multiple instruments might have a perverse effect. It could be taken as an excuse for inaction, or for action that is driven by fiscal concerns alone. It could be seen as a defense of a fragmented approach to social policy where various players do not talk to each other and may indeed work at cross purposes. What is needed, therefore, is a balance between this kind of flexible, evolutionary change and a more radical change in paradigms—in the way that the problem is formulated and tackled. In many OECD countries there does appear to be a new willingness to tackle social problems from a longer-term, more-integrated approach. There is an emerging awareness that such action would make sense from the perspective of both social and economic policy.

Implications for Long-Term Care

Many of these broader policy trends apply directly to long-term care as described in the papers in this session. These papers nicely illustrate the balance that is needed between making radical change toward an ideal and developing a flexible system that takes account of what is already in place. The papers by John Campbell, Mathias Schulenberg, and Naohiro Yashiro stress the importance of taking rational action now to develop an ideal system. Social insurance principles are seen as a central element of the ideal system—at least in its larger macroeconomic and macropolitical dimensions. John Campell provides the general rationale for social insurance, along with some potential problems. Mathias Schulenberg shows that the new long-term care system in Germany (based on social insurance) works well in practice. Naohiro Yashiro emphasizes the importance of social insurance for a sound market approach and regrets that, given a clean slate, the Japanese reforms did not go even further. Taken together, these three papers present a strong case for the social insurance approach as a basis for an ideal system of long-term care. The papers are balanced; problems are not ignored. However, the disadvantages of social insurance that they outline are relatively small and manageable, certainly no greater than those that are inevitably encountered in any system of financing.

Other papers tend to concentrate more on the incremental elements of change. As already noted, Atsushi Seike deals with the constraining realities of the labor market. Reform must take account of the existence of skilled people in different categories and of the speed with which the people can be trained and recruited. Kieke Okma stresses the need to take account of the complexity of the systems in which long-term care is situated, including the extent of public support for change and the broader cultural perspective of old age. These systems, attitudes, and values change only gradually. Her line of argument suggests that the choice between tax-based and social insurance systems may not be all that fundamental. Yasanori Sone elaborates on the importance of the political system in shaping reform and in sustaining it. He uses the example of the role of executive and legislative branches in the Japanese reform to illustrate that the political process is complicated and slow. There are many interests to be negotiated and the process must be evolutionary.

My paper also expresses doubts about the wisdom of searching for a single ideal approach, especially one that could apply in all countries. There are many uncertainties and a corresponding need for flexibility and evolution. I implicitly suggest that social insurance might not so obviously emerge as the ideal solution if the papers in question had been, for example, based on Scandinavian or Canadian experience. The paper does, however, identify some more general principles for reform that do appear to be held in common in OECD countries. These have been endorsed by OECD ministers after much discussion by officials and experts. They may, therefore, provide a useful consensus statement on which further discussion can be based.

Commentary: Macroeconomic and Macropolitical Setting

DAVID CHALLIS

In this session I have tried to identify cross-cutting themes. Within the papers raised there are a number of broad issues which link with a range of long-standing issues focusing upon supply of long-term care.

1. There is a commonality of trends within social and health care systems. This is particularly evident in Hicks' work where debates about policy indicate the pressure for substitution at the margin of institutional by community-based modes of care.
2. There is a similarity of specific problems identified in different societies. One can argue, as one cross-national study did, that there are three broad trends in the care of older people: namely, a reduction in institutional-based care reliance, a greater focus on community-based modes of care, and the use of mechanisms of coordination and case management to achieve more intensive modes of home-based care. This would indeed be a fairly precise description of the policy changes emerging within the UK.
3. Intersectoral relationships. These factors have assumed a growing importance. For example, there are substitution effects which are meant to occur for any one individual who might previously, under old policy regimes, have received nursing home care may now be expecting to receive intensive modes of home-based care. But at the more macro level there is also a substitution of home care investment for nursing home investment. Coupled with this is often a degree of substitution across systems of care. For example, in the UK the division between health and social care has meant a shifting of the boundaries between the responsibilities of those two agencies. Social care is seen as the driving agency for the implementation of new community-based services while health care has withdrawn from the provision of long-stay care toward a more clearly defined acute focus.

Another intersectoral relationship is the role of social security; indeed, it is the very allocation of social security funding to distort incentives in the provision of long-term care away from community based provision that led to major reforms in the United Kingdom. Finally, housing is a crucial factor in the provision of effective long-term care for older people, particularly if that long-term care is to be provided within a domestic rather than an institutional environment. Failure to make necessary investments in housing fabric will of itself diminish the probability of any success in policies that are concerned with shifting the balance of care. Hence it would be reasonable to ask whether the parameters for long-term care policy should be discussed in narrow terms, such as the balance between health and social care, or more broadly as related to housing, pensions, and employment policies.

4. Implementation. The factors associated with successful or less successful forms of implementation are raised by at least three papers. Implementation is concerned less with the end state but the process itself, and there are major implementation factors which must be addressed. These include changes in numbers and roles of service providers and the relative security of their position. How fast, how many, and how changed is it possible for service providers to be in the short term? Second, there are questions about the feasibility of the expected rates of growth of providers and possibly rising marginal costs of expansion. Third, there are problems of the effects of targeting upon the most vulnerable. This is the policy goal in most societies, but there are costs that may include more rapid deterioration of less vulnerable individuals and possibly a withdrawal of support for those vulnerable individuals by the informal sector if the formal sector contracts its role. One way of handling this issue of targeting and in what ways targeting is to be achieved could be by developing a more sophisticated conception of period risk of events such as hospitalization against which such investment goods as rehabilitation may be set and thus evaluated.

5. The concept of seamless care. This is the desired experience of most service users, but it is equally inevitable that seams will exist and divisions will occur between responsibilities, budgets, and units of production. These separations take the form of divisions between health care and social care; acute care and long term care; hospital and community; and social security versus health and welfare. Seamlessness may be a goal, it may be a desired experience, but in reality, as in the preparation of a quality garment, it is the less visible, less obtrusive, and less problematic

joints between the sector that should be the focus of policy intervention. The seamless garment will never in practice exist. The key question which we must always address remains what are the incentives that arise from where boundaries are located within the long-term care system.

6. Balance of care. We have previously noted that there are marked policy similarities between different societies reflected in the shift in emphasis from institutional to community-based care. Increasingly, this is a less appropriate description of patterns of provision as the system moves from a simple binary institutional community system to one where there are many levels of care which arise from such phenomena as the growth of special housing. Thus reaching a new balance of care will almost continuously require a reshaping of policy goals. In the Australian context this is reflected in the long-term care policy review processes. We could thus say long-term care policy is not static and cannot be static because the system to which it relates is itself not a static environment.

7. Integration of care. Integration seems to be a key phenomenon in all the areas of policy debate but integration has very different meanings within different settings and it is possible to distinguish integration occurring at different levels. This ranges from integration at the level of funding, at the level of organizational systems such as health and social care through integration of units of management down to the integration of care at the level of hands-on providers—separating the divide between home care workers and nursing assistants. A second level of integration might be conceived as a distinction between horizontal integration and vertical integration. Horizontal integration would reflect the integration of different modes of production such as the integration of a health care system and of a social care system. Conversely, vertical integration would reflect patterns of integration that are the integration of linear points in the provision of care. For example, this might be reflected in the development of a dementia care service or an integrated form of care for highly vulnerable older people that provided the same set of care providers from rehabilitation hospital through to community-based support. It is interesting to note the extent to which some of the trends emerging in policy change in care of older people represent a shift toward more vertically integrated modes of care.

8. Thus, to conclude we might argue that moves toward the creation of a long-term care system, which almost by definition represents an integrated care system, would require both a move toward vertical integra-

tion and also a move toward integrating the different levels of care so that they remain logically consistent, so that incentives arising from patterns of funding do not distort logical modes of care such as more integrated hands-on care providers. Integrated care might thus be seen to mean consistent, coherent, multilevel modes of care that offer continuity of support for highly vulnerable people.

Financing the Ideal Long-Term Care System Through Social Insurance

JOHN CREIGHTON CAMPBELL

Key words: Japan—Social insurance—Policy for the elderly—Welfare

My view is that payment for long-term care (LTC) should be financed by social insurance rather than private insurance on the one hand or tax revenues on the other. My assumption is that the main goal of an ideal LTC system is to improve the quality of life for the frail older person and for the caregiver. That ideal requires a considerable change from present patterns of caregiving. A social insurance system for LTC is one in which everyone with an income pays premiums, and all are eligible for benefits if they meet specified criteria—certainly disability, perhaps also age. The government would set the premium rates, manage the funds, determine eligibility, and oversee the provision of benefits.

Couldn't private insurance do the job? It is well known from both theory and practice that simply encouraging voluntary private LTC insurance would not change the present situation much. A more workable system, once well established, might be mandatory private insurance under which individuals are compelled to build up an account in which benefits are related somehow to past contributions. However, people who need LTC now or in the near future would not be eligible because they had not contributed enough, so younger people today would be paying for care both for their own and the previous generations—too big a burden.

What about a tax-based system, where the costs of LTC are covered from ordinary government revenues? Such systems have developed in Scandinavia and work well. However, in my opinion, in most countries the social insurance approach is a better choice than a tax-based system, mostly for reasons having to do with "rights" (or, as critics call them, "entitlements"). There are several dimensions. In most countries, social insurance is seen as more an individual right than are tax-based government programs. People have a sense that they paid their premiums and are entitled to benefits from them even when (as in American Social Security) the financing is "pay-as-you-go" so that people are not really drawing on their own funds, and when (as in health insurance in most countries) benefits are not related to the amounts of premiums paid.

Tax-based social programs often are means-tested, which inevitably will carry the stigma of "welfare" for poor people, or even if not will still require an application to the government that will be evaluated on the basis of regulations and bureaucratic judgment. Particularly middle-class people commonly feel they are asking for a favor or for special treatment rather than exercising a right. The way in which Scandinavian countries have been able to build a culture of rights to tax-based services among the general public probably takes a long time to develop. In most countries, making it clear that the new LTC system is a sharp break from means-tested social assistance or Medicaid programs of the past will go a long way to convincing the public that the system is for everyone. Moreover, such a radical change may be necessary to stimulate new ways of thinking among the public, a shift in the "culture" of caregiving.

A principle of individual rights also becomes embodied in the government's administrative machinery. When the money comes from taxes, it passes through the budget, usually as an annual appropriation, where the LTC program will have to compete with all other public programs. In flush times, or when the elderly are popular for some reason, the program might be made too generous. In tougher times or when there is a backlash against waste or easy living, budgeted funds can be cut relatively easily. Social insurance is based on a fund that in principle should be kept in balance. Any increase in benefits requires an explicit decision about contributions, encouraging sober thinking about expansion. On the other hand, the chances of cutbacks by political whim are lessened when a designated fund is established. Of course, the fund cannot and should not be completely independent from economic changes and political choices, but a degree of insulation is desirable.

A social insurance program in which "ownership" lies with the citizen rather than the government also fits naturally with an ethic of "consumer sovereignty." A tax-based system tends to go with government deciding what services are needed and delivering them directly or by contract. The experience of many countries (including Scandinavia) indicates that such services may well be managed more for the convenience of the provider than for the interests of the client, and there is not much direct incentive for improvement. Incidentally, social insurance financing does not necessarily mean that the benefits must be paid in cash, although that is the main way the new German system operates. In fact, to achieve substantial changes in existing caregiving practices while still maintaining consumer sovereignty, benefits can paid in the form of vouchers for purchase of services.

Three types of objections are commonly raised to social insurance compared with a tax-based system. One type has to do with its "tax base." It might be too narrow, if contributions are limited to people with earnings (perhaps a shrinking group in the population), and the financing will be somewhat regressive because premiums are usually a fixed percentage of income up to some ceiling. Having premiums deducted from old-age pensions as well as earnings will mitigate the first problem. The second one can be mitigated by subsidization of LTC insurance from tax revenues—so long as the insurance portion is at least half, it is likely that social insurance principles will prevail in people's minds.

A second common objection is that establishment of a social insurance system does not in itself create new services. Particularly if the benefit is in vouchers, however, we can anticipate that in response to an explosion in demand, existing organizations will expand their services and new providers will quickly appear. Both commercial and independent not-for-profit organizations are likely to be more flexible with regard to both consumer preferences and labor market conditions than the traditional public or contracted services in a tax-based system.

A final objection to the social insurance approach is that it is "wasteful" in that a large portion of the benefits go to people with adequate incomes—or worse still to their heirs, who will get the money their parents would otherwise have spent on a nursing home. That point is of course quite correct: means-tested programs are by definition targeted on those who cannot afford to buy services for themselves. These days, an argument that most social programs, including pensions and health care, should be means-tested by one mechanism or another is quite popular among conservatives. I reject that view, and believe that some risks their extent to be decided by society should be socialized for everyone rather than borne by the individual. I think that disability in general and old age frailty in particular should be included in those risks, and that the best method in both ethical and practical terms is a public, mandatory long-term care insurance system.

Further Reading

Campbell JC (1992) How policies change—the Japanese government and the aging society. Princeton, Princeton University Press

Campbell JC, Ikegami N (1998) The art of balance in health policy: maintaining Japan's low-cost, egalitarian system. Cambridge University Press, New York

Learning from Other Countries' Experiences in Designing the Ideal Long-Term Care System

PETER HICKS

Key words: Aging—Long-term care—OECD—Policy—Economics

From the perspective of the Organisation for Economic Co-operation and Development (OECD), the timing of this conference is ideal. Ministers of OECD member countries met in Paris at the end of April 1998 and discussed a report prepared by the Secretariat on the policy implications of aging. This report, *Maintaining Prosperity in an Ageing Society*, concerns a wide range of issues: pensions and financial markets, the retirement decision, and health and long-term care. A summary can also be found in a series of articles in the June/July 1998 issue of the *OECD Observer*. The long-term care sections build on major work in the OECD in recent years on caring for frail elderly people. (See list of additional readings for references to these and other OECD documents referred to here.)

Several weeks later, in June 1998, a meeting of social policy ministers from OECD countries reviewed findings based on a detailed survey of a range of social policy concerns and recent reforms in member countries. (This will be published later this year as *A Caring World: National Achievements.*) Again, long-term care issues figured prominently in country responses to this survey.

Let me first discuss the questionnaire. First were questions asking countries about the nature of their concerns. In most cases, the main concerns reported in the area of long-term care related to the quality of the service more than to cost issues. Next were questions about the roles of various actors—central governments, local governments, the private sector and, of course, families—and about financing. Next were questions about qualitative aspects—ways of escaping the "patchwork quilt" that now characterizes so much of long-term care. A final set of questions related to cost containment.

Cast at a high level of generality, one can conclude that long-term care is a relatively recent area of policy attention by OECD countries. There are shifts toward community-based care, more tailored services for the elderly, and the introduction of private provision for greater consumer choice. There has been devolution of greater responsibility to local government to introduce greater structural coordination of services. Setting up multi-disciplinary teams of professionals is one of the popular approaches to achieve tailoring of services to individual needs in actual practice settings. Diversification and streamlining of services has been introduced to enhance the quality and efficiency of long-term care systems.

Financial aspects of long-term care have been one of the major concerns of many countries. Some countries are setting up funding schemes specific to long-term care, either based on general taxation or social insurance. Cost containment has been built into these systems, through the application of strict needs-based eligibility criteria, imposition of user charges, shifts toward greater reliance upon community-based care, etc. As part of the general shift toward community-based care, many countries are also providing increased support for family members taking care of the elderly.

In summary, there are lessons to be learned from other countries, as all are struggling with much the same problems. Both the common ground, and different approaches being taken, are much more apparent from a detailed review of the responses provided by various countries, then from this short summary. Is an ideal system emerging? Most countries (inevitably) reported that they are satisfied with their national approaches, but I do not think there is yet any sense of a single ideal system. And that ideal would vary depending on country circumstances. Japan is certainly a leader rather than a follower here.

What is the OECD proposing in these circumstances as part of its work on the policy implications of aging? Although there is no single model, commonly agreed principles are emerging that, if followed, would lead to good systems. The basic principle is that a stage of frailty in old age should be treated as a normal part of the aging process, subject to explicit policies and financial arrangements, even if this can be done through using resources from previous health care and pension arrangements. More specific principles call for these concepts:

- Treating long-term care as a normal risk of life that requires sharing mechanisms, with the burden of financing shared by the working age and older populations
- Providing coverage against catastrophic costs, while ensuring a balanced access to home help and institutions
- Encouraging a multiple-pillar system of delivery, with more emphasis on supporting people in their own home and less in nursing homes. Provision of long-term care in hospitals should be avoided
- Harmonizing long-term care policy with health reforms to support the best mix of health and caregiving elements, and with pension reforms to provide coherent mechanisms for diversifying the risks of longevity and frailty.

This set of general principles appears to be a reasonable reflection of the best experience in OECD countries at this stage in the development of long-term care systems. The reports being prepared for the social ministers' meeting in June will provide a guide to more specific practices.

I would like to end with three personal observations. First, while the concept of an "ideal" system is an excellent device for organizing a conference such as this, it may be less useful when thinking about the design of systems of long-term care themselves. I say this because, too often, the concept of an "ideal" is used in a static sense. Yet long-term care systems are best thought of as dynamic—and likely to evolve in ways that are not fully predictable.

Indeed, the concept of a separate system of long-term care was barely known a few decades ago. Its roots were in a desire to provide a kind of care ("aging in place") that could not be easily be provided by the health care or social services systems alone. Its roots were also in a large projected growth in the numbers of very old people and in a concern about the potential burden of caregiving on families. However, the health care and the social services systems are also in process of evolution, as are family structures. Patterns of longevity and healthy life expectancy are evolving; a medical breakthrough in, for example, the area of senile dementia could change our view of long-term caregiving in a fairly dramatic fashion. This idea suggests we should also expect that the evolution of the long-term care system is far from complete. We should design systems that are flexible and that can evolve easily with changing circumstances.

My second observation is related. It is that the energy devoted to developing an ideal long-term care system should not be so all-consuming that reform activities outside the system are ignored. I am thinking about prevention in particular—including active lifestyles and medical research. As noted, some of the biggest changes to caregiving could result from medical research and technology that was more directly focused on the reduction of dependence associated with conditions such as dementia or arthritis.

My final point is also related. If the long-term care system is to be flexible and to evolve with changing needs, then it is important to have a good understanding of how it in fact relates to other systems and how needs are in fact changing. Here, a great deal of basic information is missing. For example, I think it would be most useful to have data that showed the various degrees of dependence (and obstacles to independence) in the whole population at different ages and over time—as well as the type and intensity of care provided in these circumstances by all systems including the health care system, the long-term care system, by disability programs or workers' compensation, and by families (including care for young children, care of family members during sickness throughout life, care for frail elderly people, or others who are chronically dependent). Collecting such data would be neither simple nor quick, but it is nevertheless entirely feasible and would be of relatively low cost when compared with its potential benefits in supporting a more effective system of caregiving. Ideally such data would be comparable internationally. With this achievement, we then could really begin to learn deeply from the experiences of other countries.

Further Reading

Maintaining prosperity in an ageing society. OECD, 1998
Caring for frail elderly people: policies in transition. Social Policy Studies no. 19. OECD, 1996
The caring world: national achievements. OECD (forthcoming, 1998)
The caring world: an analysis. OECD (forthcoming, 1998)
Various articles in OECD Observer, no. 212, June/July 1998

Long-Term Care Within National Social Policy

Kieke G.H. Okma

Key words: LTC in social policy—Ambitions—Governmental decision making—Stakeholders—Changing images of elderly—Multipurpose policies

Policy makers and academics regularly share far-fetched, and unattainable, ambitions. The title of this conference reads "Long-Term Care for Frail Elderly: Reaching for the Ideal System." In real life on this earth, both groups know there is no such thing as an ideal system, but we feel an urge to try, to strive for the unattainable. In fact, as Graham Allison observed more than 25 years ago, most policy analysts (implicitly) use the rational actor model which depicts government as a homogenous and rational decision maker, weighing options and outcomes, and choosing the best alternative [1]. Allison remarked that government itself consists of a wide variety of departments, divisions, and agencies, each of which have their own standard procedures, rules and regulations, and rationales. Thus, he argued, we need an additional model—the bureacratic model—for analyzing government policies in terms of bureacratic processes. Furthermore, government is not the only player in the policy arena, but faces many other organized interest groups that seek to influence government policies. Allison therefore proposed an another model to supplement the other two: the political model. The three models are not mutually exclusive, he added, but will help in understanding the shaping and outcomes of public policies.

Now, why are the different models or approaches of Allison relevant for the topic of this conference? At first glance, there seems to be broad agreement on the need for providing care for frail elderly people. Who would dare to disagree? But, like any other social policies, the funding and provision of long-term care entails many allocational and distributional effects. Most if not all policy decisions affect incomes, decision-making authority, and power of certain groups in society. To start with, there are many government agencies that have a stake in systems for long-term care: central, regional and local authorities; ministries of health, social affairs, commerce and finance. In some countries, there are separate bodies for advising and administering social insurancers [2]. Then, there are (elderly) consumers of long-term care, and other consumers paying for such services (they may overlap). Next, central or regional governments, and public and private health insurance agencies provide coverage for acute and long-term care to the entire populations or to certain groups [3]. And finally, there is a wide range of providers of care, ranging from state institutions to not-for-profit institutions run by churches and charities, to private for-profit retirement communities or home care organizations. All these groups have certain stakes and positions in the policy arena, and are gaining or losing by certain decisions.

In many industrialized countries, long-term care is a relatively young branch of national social policy. Most modern welfare states started with mandatory participation in income protection schemes for wage earners covering risks of unemployment, disability, old age, childbearing, and large families [4]. These schemes were usually based on a traditional family model with one major income source, and two or three generations living together. Changing social relations, increased numbers of women entering the labor force [5], and changing consumer preferences have broken up this pattern. The prime responsibility for taking care of the frail elderly gradually shifted from family to the state, even though in many countries or rural areas the extended family model still is widely in place.

Changing Images

The last decades have seen important changes in the image of the elderly [6]. The traditional, 'biblical image' of elderly as a source of wisdom and advice has all but disappeared. It has been replaced by the 'policy image,' which sees elderly citizens mostly as objects of government policies, and by the 'modern image,' which depicts the present generation of persons over 65 as healthy, wealthy, and spending. And, more recently, we see the 'negative image' of elderly as an increasing burden to society. These changing images have affected social policies. The oil crises of the 1970s, economic stagnation, and high levels of unemployment ushered in a period of questioning the affordibility of the modern welfare states. In the

1980s and 1990s, the debate increasingly assigned a negative image to the elderly, depicting pension schemes and social programs for the elderly (even while such programs usually are not limited to elderly citizens only) increasingly as unaffordable. Reports by the OECD and World Bank carry alarmist titles and use alarmist terms: "Averting the Old Age Crisis," and "The Old Versus The Young." These terms and labels reflect changes in societal ideas and ideologies regarding the elderly [7].

Images and Social Policies

This shift in policy emphasis is important in the discussion about long-term care. Policies (implictly) based on the biblical image regard the elderly as a deserving population group, and support general and non-means-tested pensions and other benefits. The policy image of elderly takes a more paternalistic view, and may lead to services in kind such as home care, nursing homes, or retirement homes. The shift toward the modern image of relatively wealthy and independent elderly has created confusion and raised many questions. On the one hand, elderly are seen as capable and independent decision makers themselves. Many can afford to hire personnel or contract services, or live in luxurious housing or retirement communities offering support for independent living. On the other hand, even while wealthy, some groups are in need of professional medical and social support in institutions or at home. Here, the general insurance principle of income protection seems at odd with our intuitive sense of justice and with efficiency considerations. Why would social services be available at no cost for people who can afford to pay? Why would social services be denied to some elderly only because their income surpasses a certain level? Will targeting services to specific low-income groups increase the efficiency of the system, or will such targeting erode support by middle-income and higher-income groups and thus undermine solidarity altogether?

Multipurpose Policies

There is no easy or universal answer to these questions. Over time, social arrangements have developed to address a variety of concerns: income protection of families, universal access to health care and social services, stability in society, and others. The range of services for the elderly serves more than one purpose. General old age pensions have been very succesful in alleviating poverty among elderly citizens. The extension of employment-related schemes to other population groups have provided elderly access to health care services that they otherwise could not afford. Public funding of provision of long-term care offers an alternative to dependency on families or charity. In most industrialized nations, long-term care has become part and parcel of the modern welfare states even while variations in funding mechanism and organizational features still reflect specific cultural, historical, and institutional developments. Designing new arrangements or adjusting existing schemes requires a good understanding of such variety in policy concerns and of country-specific developments.

Institutions and Interests

For example, the introduction of a new long-term care insurance involves many governmental agencies and nongovernmental organizations. How are the different levels of government involved in the funding structure, allocational decisions, and the planning of these services? Which level of government serves as the ultimate insurer, bearing the financial risk and laying down the rules of the scheme? Will existing providers have access to the funding, and will they see this as replacement of their former income sources or as an additional stream? Who is responsible for the administration and supervision of the long-term care insurance, and what are the sanctions for nonadherence to the rules? Will the new scheme require new administrative bodies, or can existing ones take on the additional tasks? How will the new administration collaborate with others? Are there different bodies for the supervision of financial flows and of the quality of services and, if so, how do they work together?

The foregoing questions serve to illustrate the fact that the design and implementation is not a matter of government only (or for that matter, the health ministry or the social ministry alone). They serve to underline that changes (or extensions) of social policies require a careful mapping of existing institutions and interests to assess to what degree they may be expected to eagerly embrace a new scheme, or to overtly or covertly seek to thwart plans or to block changes altogether. In social policies, there are many examples of such strategic behavior, and of policymakers who are surprised and frustrated by successful opposition of organized interests.

Finally, to be successful, public policies need a reasonable degree of public support. In general, as Pierson observes, the expansion of social services will meet with more public support than retrenchment [8]. Expanding social services usually brings benefits to a limited group, while the burden is spread over many contributors who will hardly feel the effect of a very small increase of their contributions. Retrenchment usually has the reversed effect: a very small benefit to many, but concentrated and visible burden to few. And if these few are well organized as strong constituencies, they may be effective in opposing change.

References

1. Allison G (1971) The essence of decision. Explaining the Cuban missile crisis. Little, Brown, Boston
2. (Germany and the Netherlands are examples of neocorporatist societies, where traditionally organized employers, labor unions, and other interests have participated in centralized discussion and negotiations with government on policy matters of mutual interests.) See Heidenheimer AJ, Hecol H, Teich Adams C (1990) Comparative public policy. The politics of social choice in America, Europe and Japan, 3rd edn. St Martin's Press, New York. Freddi G (1989) Problems of organizational rationality in health systems: policy controls and policy options. In: Freddi G, Bjorkman JW (eds) Controlling medical professionals. Sage Publications, London. (In Dutch health care, this neocorporatism reflects in tradition of a wide variety of advisory and administrative bodies with formal representation of organized interests in the administration of social health insurances. This has provided consumers, insurance agencies, and in particular, physicians and other health care providers with strong opportunities to influence government policies, and to block changes.)
3. The reform of health care. A comparative analysis of seven OECD countries. Organisation of Economic Cooperation and Development, Paris, 1992.
   The reform of health care: A reviwe of seventeen OECD countries. Organisation for Economic Cooperation and Development, Paris, 1994
4. (The health insurances in the United States provide the only exception to this general development in OECD countries, with Medicare offering health insurance to the elderly, and Medicaid to the poor. There still is no form of mandatory health insurance for the working population.) Marmor TR, Mashaw JL, Harvey PL (1990) America's misunderstood welfare state. Persistent myths, enduring realities. BasicBooks, Boston
5. (There is not much evidence that increased labor market participation of women has reduced the willingness to care for aging parents or relative. A recent study by the Social and Cultural Planning Bureau of the Netherlands found that working men and women are at least as much if not more inclined to provide voluntary services, including caring for elderly relatives or neighbors.)

6. Borst-Eilers E, Okma KGH (1996) Priorities in health care of elderly people: conflicting images, conflicts of interests? Journal R Coll. of Physicians Edinburgh 26:553–558
7. Marmor TR, Okma KGH (1998) Societal interventions affecting elderly citizens: a comparative approach. In: Schulz, Maddx, and Lawton (eds) Annual Review of Gerontology and Geriatrics, Vol. 18
8. Pierson P (1995) Dismantling the welfare state? Reagan, Thatcher, and the politics of retrenchment. Cambridge University Press, Cambridge/New York

Further Reading

Averting the old age crisis. Policies to protect the old and to promote growth. Research report. World Bank, Washington, DC

Coolen JAI (ed) (1993) Changing care for the elderly in the Netherlands. Experiences and research findings from policy experiments. Van Gorcum, Assen/Maastricht

Immergut EM (1992) Health politics. Interests and institutions in Western Europe. Cambridge University Press, Cambridge

Wiener JM, Hixon Illston L, Hanley RJ (1994) Sharing the burden. Strategies for public and private long-term care insurance. The Brookings Institution, Washington, DC

Financing Long-Term Care: What We Can Learn from the German Experience

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Key words: German social security—Long-term care insurance—Benefit in kind—Economic and financial aspects

Introduction

In all industrialized countries, issues surrounding population aging have captured the attention of policy makers. Among its manifold ramifications, disability-related poverty and the projected growth in public funding of long-term care demand close attention. In Germany, legislation on mandatory and universal dependency care insurance has gone into force recently. In May 1994, the German parliament passed the social long-term care insurance (LTCI) act, which became Chapter XI of the German Social Security Law (Sozialgesetzbuch SGB XI). It is the fifth and newest social insurance program, after the implementation of the statutory health insurance in 1883 (SGB V), social accident insurance in 1884 (SGB VII), retirement insurance in 1889 (SGB VI), and unemployment insurance in 1922.

The LTCI act responded to limited market insurance against financial risk of long-term care, deficiencies in serving long-term care dependents, the aging of the German population, and the fiscal crisis of German communities (cities and counties), which had served as a lender of last resort for destitute care clients. After 3 years of operation, LTCI is technically in place and financially (still) healthy. However, the new program is a baby that will grow up in size and problems.

German Social Long-Term Care Insurance

Everybody who earns less than DM 6.300 (443 500 Yen) per month (in West Germany and DM 5.250 in East Germany; all numbers for 1998) has to be covered by LTCI managed by the sickness funds. The contribution rate for this social insurance program is currently 1.7% of the working income. Half is paid by the employees and the other half by their employer.

In 1994 it was estimated that about 1.65 million persons will need long-term care whereby 1.2 million will remain at home and 450000 will receive institutional care. In 1997 about 1.7 million people received benefits from LTCI, which is just what was predicted; 1.24 million are at home and receive up to 1300 DM per month in cash or benefits in kind up to 3750 DM. Also, 453000 institutionalized patients receive DM 2000 to 3000 per month.

The LTCI has reduced social aid by DM 11 billion because many patients received social aid before the program. The long-term care insurance program has also created new jobs, especially in newly founded home service companies. The government estimates 75000 new jobs. It is remarkable that most of those who receive benefits from LTCI are at home; the reason is that the benefits for home care are relatively high compared to institutional care. The program also started providing help first for home care and later for institutional care because the government expected the LTCI to increase demand for hospital care and nursing homes. Indeed, many new nursing homes have been built during the past few years. After having a shortage of nursing home beds in 1990, this has changed to a surplus of nursing home beds. LTCI employs a pay-as-you-go financing as do all other German social insurance programs. However, it has accumulated a surplus of 8.9 billion German marks, which is much more than expected (Table 1).

Evaluation of German Long-Term Care Insurance

So far, the experience with the LTCI has been very positive. However, the program has a number of shortcomings and bears some risks.

- Germany is currently in a recession with high unemployment and high transfers to East Germany. The contribution rate of gross work income is already quite high: for pension funds, 20.3%; for health insurance,

Table 1. Benefits of the German long-term care insurance

	Care at home		Nursing home care	
Statutory health insurance	Benefits (in DM)[a] cash benefits/ benefits in kind	Number of receptions (in %), July 97	Benefits (in DM)	Number of receptions (in %), July 97
Intensity of care		**1.17 million**		**430000**
Level 1	400/750	532011 (45.6)	2000	135318 (31.5)
Level 2	800/1800	490401 (42.1)	2500	172976 (41.9)
Level 3	1300/2800 (3750)	143369 (12.3)	2800 (3300)	114522 (26.6)
Refusion rate (in 1996)		28%		23.8%
Private insurance		66000		23000

[a] 100 Yen = 1.42 DM.

13.4%; and for unemployment insurance, 6.5% (half is paid by employer, half by employee). LTCI increases total contribution rates to 42%, which lowers the incentive to work, increases incentive for moonlighting, and decreases the international competitiveness of the German economy.

- Auditing of quality of care is insufficient. Reports on low quality of care and fraud are quite frequent.
- The development of a comprehensive "cash and counselling" concept is needed.
- Demographic changes will cause severe problems for all social security programs that are financed by pay-as-you-go. Economists have strongly recommended fully funded financing.
- LTCI is a uniform system for all Germany. It should be tested if competition between different funds offering different benefit packages for different premiums would increase the efficiency of care provision.
- LTCI is financed only by contributions from work income. One could halve contribution rates and stabilize financing if all income sources were taken as the tax base to finance LTCI.
- The benefits of LTCI are not yet sufficient to provide full coverage for the cost of long-term care. Many recipients still apply for public assistance.

- Who receives benefits and at what benefit level is decided by insurance doctors. The process is not transparent, causes a lot of dissatisfaction, and is very restrictive.
- The distinction between cash benefits and benefits in kind provides incentives for fraud and moral hazard.

Further Reading

Bundesministerium für Arbeit und Sozialordnung, sozialpolitische Information, vol XXXII, 2 (January 13, 1998)

Cutler DM (1993) Why doesn't the market fully insure long term care. NBER working paper no 4301

Frankfurter Institut (ed) (1997) Rentenkrise—und wie wir sie meistern können. Bad Homburg

Greiner W, Schulenburg J-M Graf von der (1996) Leitlinien für eine Systemkorrektur in der Pflegeversicherung. In: Siebert H (ed) Sozialpolitik auf dem Prüfstand. Mohr, Tübingen

Pauly MV (1990) The rational nonpurchase of long-term-care insurance. J Polit Econ 98:153–168

Scanlon WJ (1992) Possible reforms for financing long term care. J Econ Perspect 6:43–58

Zweifel P (1996) Long-term care insurance and bequests as instruments for shaping intergenerational relationships. J Risk Uncertainty 12:65–76

Long-Term Care and the Labor Market

ATSUSHI SEIKE

Key words: Labor market—Human capital—Professionals—Volunteer workers—Market competition

The Labor Market as Key

The feasibility of the proposed Public Long-Term Care Insurance (PLCI) will depend on the amount of long-term care services that could be provided, which will in turn depend on the size of the workforce the service providers can take on and sustain. This chapter outlines the reasons why labor is one of the most important factors in assessing the feasibility of the PLCI.

In the market economy, the labor market is the only source of the necessary workforce. As in the current situation, in which there is general difficulty in persuading people to work for long-term care service providers, the only solution would lie in obtaining the necessary care workers in the labor market by offering the right economic incentives. If the number of care workers is not sufficient, higher wages may have to be offered to attract people into the sector. It is not possible or fair to regard any kind of workforce as being in short supply unless and until wage increase has been considered and implemented (i.e., market price of that labor has been increased) in respect of that workforce.

A clear case that showed a disregard of this important concept is the case of the so-called "shortage of nurses problem" of several years ago. At that time, the management of many hospitals and doctors in private clinics complained of the shortage of nurses and demanded that the government increase training facilities for nurses or even allow foreign nurses from developing countries to work in Japan to reduce the shortage. However, there is no evidence of any increase in the wages of nurses over and above the average wage increase observed across the total workforce. This meant in effect that the "shortage of nurses problem" was not a problem of shortage of nurses as such but was merely a reflection that without an increase in the level of wages for nurses, an insufficient number of people wished to become nurses.

The "mobilization" or "allotment" of workforce is not allowed in the market economy, i.e., workers cannot be allocated to provide specific tasks. Therefore, as care workers can only be obtained through the labor market through the market mechanism, the PLCI will not be able to achieve its purpose without giving serious thought to the conditions that prevail in the labor market.

The Cost of Providing Care Workers

It would be impossible to employ a sufficient number of care workers immediately. In addition, it will be difficult to have immediately highly skilled workers who would provide specialist services because they would require a longer period of training at a high cost. For example, a medical doctor must attend medical school for at least 6 years before becoming eligible to practice.

In this sense, an appreciation of the skill requirements for each kind of long-term care services is important in assessing the availability of care workers in the labor market. The time period necessary for obtaining sufficient numbers of care workers and the necessary wage level to attract people to supply labor for care services will depend on the skill requirements in each kind of care service.

Major services expected to be provided by the PLCI are as follows: (1) care services provided by certified care workers, (2) nursing services provided by nurses, (3) medical treatment or rehabilitation provided by medical doctors, and (4) care management services provided by care managers.

Generally speaking, the more complex services such as care management services and medical services require a longer period of time and higher cost of training before people are able to provide those services, although it should be noted that there is a certain cost in time and training even to train people to provide the most basic services if certain professional standards are to be maintained. Because an individual can use their resources to acquire other kinds of skills rather than care services, this investment by the individual in human capital for care services should have enough return to attract people. Therefore, the difficulty of obtaining care workers depends on the amount of resources sacrificed by individuals, that is, the time and money required to train in each kind of care services.

Among the different types of care workers, workers of the type whose skills are relatively basic and easy to perform can be employed with relatively low wages without waiting for a long period of time. Eligible workers to provide this kind of service can be recruited from other sectors relatively easily, and they can easily move from one employer to another who offer better working conditions. In other words, this type of care worker will be more susceptible to the demand and supply conditions of the labor market and generally their wages. On the other hand, care workers whose jobs require a longer period of training time and cost cannot be recruited without paying higher wages that would cover at least the time and money cost of human capital investment paid by them. The other aspect of this, however, is that these professionals do tend to stay in their profession as they have invested so much in terms of human capital and wish not to lose it. They are less likely, therefore, to move to another business, and their wages may not increase easily even though the labor market as a whole may be tightening.

Allocation of Labor

Of course, care workers in the labor market are not the sole source of supply of long-term care services. For example, family members can provide care services to some extent. In fact, historically the family has been one of the most important sources of supply for care services for the elderly in Japan. One of the reasons why long-term care has been provided by family members is that nothing like the proposed PLCI had been introduced before and only a limited source of care services has been available outside the home. Traditionally, therefore, family members have had to provide care even if they were not willing to do so. In some cases, the elderly also preferred to be taken care of by the family even where outside help was available. In cases in which the family members are willing to provide care, the family will be an important ongoing source of care and there should be no problems in their doing so to the extent of their competence.

However, it should be noted that the supply of long-term care by the family can be expensive from both the individual and the social point of view. This is because the productivity in providing care services is lower for family members than for that provided by professional care workers. The family members providing care often sacrifice opportunities to earn wages themselves. This opportunity cost is particularly expensive for family members who have accumulated their own professional skills. The society then loses the insurance premiums and income taxes that could have been levied on their earnings.

Volunteer workers may also be able to provide long-term care services. In fact, many volunteer organizations have already started providing various kinds of care services. However, as in the case of family members providing care, the use of volunteer organizations may have a cost to society. Volunteer workers also tend to be less dependable than the professionals in the labor market. The fact that the provisions of services by them is purely dependent on their goodwill also means that there is not real element of choice for the consumers. This means that improvement in the quality of services offered is unlikely to be achieved by market competition.

The other important source of care services may be equipment. Equipment has already been introduced to support care services to a certain extent, and an increase in the demand for equipment may induce the manufacturers of the equipment to invest in R&D to enhance progress in technology in the field of care services. In this respect, the labor market mechanism that would increase the wages of care workers when they are in short supply is very important, because increases in the wages of care workers in the most powerful incentive for care service providers to introduce as much equipment as possible to replace expensive labor. In turn, if care service providers introduced more equipment, the incentive for the manufacturers to invest in R&D would increase. Because the Japanese society is projected to suffer a labor shortage in the years to come, it is important for us to maximize the use of equipment where equipment would suffice and to use people for services that only human beings can provide. This concept would apply across a whole range of businesses, not just to long-term care services.

Further Reading

Seike A (1995) Development of care system and its methodology (Kaigo shisutemu no kochiku to sono hoho). Q Soc Security Res 31:1

How the System Can Be Sustained Politically

YASUNORI SONE

Key words: Social insurance—Enactment process—Ministry of Health and Welfare—Japan Medical Association—Council deliberations

If asked to identify the main policy questions facing Japan, for the short run most people would probably mention the monetary system and massive defaults, for the medium term financial and administrative structural reform, and for the long term, the aging society and social security. There would be general agreement on the importance of the social security problem and on what needs to be done from now on. Even those who call for small government and "personal responsibility" have not gone so far as to call for cuts in social security spending.

At the general level, the various political parties do not differ much in thinking about social security in the context of fiscal restraint, but there are differences in their more specific approaches and a lot has yet to be decided. Moreover, methodologically speaking, economists can make a powerful argument for fiscal constraints, but the sorts of claims made in opposition by the Japan Medical Association (JMA) or people in the welfare field, such as "medical care is a special case," do not have much theoretical basis. Because political decisions must be made among such competing claims as "agriculture is a special case" and "education is a special case," the old debates about medical care—"equality vs. free-market" or "fairness vs. efficiency"—are not enough, and advocates will have to explain precisely why "medical care is a special case." Here, as well as debating the content of medical policy, we have to think about the government's decision-making system itself. The process of enacting the public Long-Term Care Insurance Law provides a good case study.

The Public Long-Term Care Insurance Law (LCTI) passed the Diet in December 1997, after revision and supplementary resolutions. Most likely no one believes that the enactment of this law has solved the majority of the care-related problems that Japan faces in its aging society. Even people who are in favor of this system think it is insufficient and predict system overload in the future. Most people seem to view it in terms of setting up an absolute minimum safety net, but opinion is split on the question of whether this really is the minimum.

Naturally, it takes a long time to introduce such a new system, and a lengthy decision-making process ensued. We need to look at the various opinions that surfaced and see how the advantages and disadvantages of each proposal were weighed and reconciled. In doing this, we need to distinguish the discussions associated with the formal decision process from the mere expressions of opinion in the mass media and other forums. Here we concentrate on formal policy making with less attention to public opinion and the media. Note incidentally that although future medical insurance and health policy reforms will not necessarily go through this same process, this case study does reveal the basic pattern of Japanese policy making today, as can also be seen in other policy areas.

It would be a mistake to think that debates about health policy in Japan get started in the legislature, but it would also be wrong to assume that the Ministry of Health and Welfare (MHW) and the JMA just decide everything on their own. To analyze actual decision making, it is helpful to divide the process into two parts: from initiating a proposal to drafting a bill, and then the formal process of enactment.

A peculiarity of the Japanese policy formation process is that the administrative arm of government is more active in drafting legislation than are the political parties. One cannot see what is really going on without looking inside the bureaucracy, but it is possible to get an idea of the various proposals being considered by looking at advisory committees. The JMA and other groups are members of these committees and so can put forward their views and interests there. However, informally, a powerful group like the JMA is also in constant communication with the MHW behind the scenes, and so can learn about ministry thinking and convey its own views quite easily.

Even when a policy direction is decided by a ministry after all these council deliberations, it can be changed in the political process. In the case of LTCI, local government opposition resulted in postponing introduction of the bill in the 1996 legislative session. In 1997, the views of the Democratic Party along with the need for some adjustments within the ruling coalition led to a political accommodation. In the end, the bill passed the Lower House in the 1997 regular session, but it was held over in the Upper House until the fall 1997 special session.

We should not disregard the influence of this kind of political horse trading at the end of the process on the actual decision. However, we certainly cannot assume that the key questions were really resolved at this stage—for example, what are the real conflicts of interests, what problems will actually result from implementing LTCI, what difficulties come with taking a social insurance rather than tax-based approach? The key here is that the basic outlines of the program were not really altered in the political process, but by and large remained as decided by the MHW.

When it comes to future reforms of the medical insurance system, problems with the pension system, and other problems of the aging society, we will inevitably have to depend on nonmarket (political, administrative) decisions, even if our goal is to introduce market mechanisms. In such cases, it is somewhat unrealistic to treat the government in Japan as a single unit, and we should assume it to be composed of two units, political and executive. In addition, policy decision making is influenced by the contributions of interested parties, including the Medical Association, insurance groups, and welfare groups, as well as public opinion.

Furthermore, unlike the era when the Liberal Democratic Party had a solid majority in the Diet, the decision-making process is further complicated by the need to coordinate interests within the ruling coalition. At times, negotiations with some ruling or minor party that has taken a vague political position, as the Democratic Party of Japan did in 1997, enter into the picture, and the decision is delayed or modified.

What is a "politically sustainable program?" As we have seen, it is necessary to start with a sustainable bill, and then it is a matter of how political parties and interest groups get together in the political process and whether public opinion support can be gained. Clearly, with respect to LTCI, most of the arguments are about things that will happen only in the future, so the debate has not really sharpened. As Japan ages, however, the new system will be put into effect, people will be making judgments, complaints will be coming up from practitioners and clients, and LTCI will become a future political focal point.

Market Elements in Financing and Delivering Long-Term Care

NAOHIRO YASHIRO

Key words: Long-term care insurance—Fee schedule—Market equality

This paper overviews major issues with the Public Long-term Care Insurance (LTCI) scheme in Japan that is to be introduced in the year 2000. Unlike other public insurance schemes on pension or health, which are mainly based on already-established individual occupational categories, LTCI is newly established and thus one could have painted an ideal picture on a blank canvas. Nevertheless, the actual outcome is quite complicated, mainly because of to a series of political compromises. Thus, let us first draw an ideal fiscal scheme of LTCI and find the way to be back there.

A prominent feature of the LTCI is a mixed nature of the essence of health pension insurance schemes. Currently, both health and pension insurance schemes are under severe restructuring for meeting with the fiscal pressures with the aging of the population. They have several common problems:

- First, social insurance schemes are divided between those mainly for self-employed and those for wage earners, and the latter are also fragmented by occupational groups. Substantial fiscal transfers are needed mainly for adjusting the different ratios of the elderly between different schemes.
- Second, while the social insurance schemes for self-employed are based on individuals, those for wage earners are on family units, i.e., the benefits of dependent spouses are covered by the contributions by the household's head. This causes an inequality of benefits between the families of the spouses with their own earnings and those without. Those benefits to dependent spouses unmatched by the contributions also bring about an "implicit tax" on their working beyond a certain earnings.

- Third, contributions are flat for self-employed while these are earnings related for wage earners, which are shared equally between firm and the employees. The different fiscal schemes by employment status and occupations make the pension and health insurance schemes more complicated, leading to the need for fiscal transfers between them.

Thus, an "ideal" social insurance on a blank canvas should have been an uniform scheme covering all the people in the country regardless of their occupation or employment status, the flat contribution and benefit schedules on an individual basis, and no contributions by an employer. The actual outcome of the LTCI scheme, however, is quite complicated, mainly because it is based on the current health insurance schemes. Also, using age as a critical factor in dividing both contributors and beneficiaries makes the scheme more complicated.

For those 65 years and older, it is individually based with their contributions deducted automatically from their pension benefits. They are also qualified for benefits with a certain eligibility criteria. For those 40 to 64 years of age, the contributions of both self-employed and wage earners are based on their health insurance schemes. Those for wage earners are family-based, and the half the contributions are paid by the employer. The beneficiaries in this age group are subject to the condition that the cause of being frail should be age-related. Those employed under age 40 are neither contributors not beneficiaries, unlike the case in other social insurance.

A major issue here is why those who are in need of LTC should not be treated equally regardless of the cause. Also, contributions should also be imposed on those below age 40, as LTCI is not only for frail elderly, but for the family members who actually take care of them.

There are alternative scenarios for the actual implementations.

- First is the case when the basic package of LTC is set to be quite generous. The costs for LTC services would rapidly increase with an expansion of demand for visiting home services, and the eligibility criteria are likely to work as de facto quota for LTC services. Then, the middle-income class may have to shift to market services, just as part of medical services of top quality currently are being provided without using health insurance.
- Second is the case when the basic package covered by LTCI is mainly targeted to those who are seriously handicapped, away from those who need complementary services to ordinary life. A simple criterion of the

expenditures for LTC is based on the "shadow prices" of hospitalization; as the terminal care in hospitals is quite costly, those who are in equivalent status have priorities in LTC. However, the "costs" here should not be solely judged at a point of service provision. Appropriate supply of rehabilitation or precautionary measures could save the lifetime LTC costs substantially.

- Third is the ratio of co-payment at the point of serve provision. With the current 10% co-payment ratio, the induced-demand effect by the establishment of LTCI should be larger, accounting for subjective needs in LTC services. Ideally, the co-payment ratio should be higher with the waive for those with very low income, i.e., the introduction of means-tested in LTCI only for the co-payments.

One of the major purposes for LTCI is to shift the provision of LTC services from the public sector to the market. The market for LTC has been underdeveloped for many reasons: one, most of the services used to be provided by family members with intrafamily "implicit contracts" tied to the transfers of incomes and assets between generations; and two, the costs of LTC services in welfare programs are financed by general revenues, and are directly paid to the providers, so that beneficiaries are not considered as consumers choosing from alternative service providers.

Establishment of LTC in the framework of social insurance stimulates better utilization of the market.

- First, there is competition between suppliers toward lowering the costs and/or improving the quality of services, by shifting from the supplier-oriented schemes of public welfare. Consumers subsidized by the LTCI have freedom to choose as in the cases for ordinary services in the market.
- Second, scale economies for provision of LTC services could be expected by uniting the current fragmented demand by both low- and high-income peoples into a single large market. Thus, there should be a mechanism that "good suppliers" can expand their business while bad ones exit from the market. An example is a franchised network organizing independent suppliers that provides uniform qualified services nationwide under the same brand name.
- Third, the role of government is important not as a controller of the market by regulations but as a supervisor for the market to work efficiently by securing the information on the quality of LTC services

provided by various suppliers as well as the protection of consumers. Providing information for promotional purposes should be widely allowed, unlike medical services.

Setting appropriate national fee schedules in LTCI is crucial.

- First, fee-for-service payments have inherent incentives to overtreatment, and bundling of fees needs to be applied more widely in LTCI. Also, the qualification of providers should be accounted for based on their experience.
- Second, the unit of care services should not be directly linked to the time spent for that consumer to provide incentives for efficiency. Also, fees should be set for series of care services among which alternative items can be substituted flexibly. A uniform fee schedule for services is necessary to guarantee profits for those suppliers with lower costs.
- Third, costs of using equipment (leased or purchased) should not be treated separately from that of services, so that there can be substitutability between the two, as well as avoiding induced demand. Inclusion of capital costs for providing a barrier-free home environment in LTCI is questionable, because it increases the value of one's assets and should therefore be financed privately.
- Finally, a prepaid system like the Health Maintenance Organization can be applied in LTC, which provides incentives for preventive measures and rehabilitation of this members to reduce the lifetime costs of LTC.

Use of the market mechanism is a key for efficient LTC provision, because LTC is a part of ordinary life of the elderly, and the average elderly in Japan are no longer poor as has been generally perceived [1].

Reference

1. Yashiro N (1997) The economic position of the elderly in Japan. In: Hurd M, Yashiro N (eds) The economic effects of aging in the United States and Japan. University of Chicago Press, Chicago

Further Reading

Ikegami N (1997) Public long-term care insurance in Japan. JAMA 278:1310–1314

Summary of the Discussion for Session 3

1. Equality and Long-Term Care, and Housing Policy

As the OECD has agreed, frailty should be seen as a common and normal aspect of aging. It is one for which governments already bear a substantial burden—even in the United State some 40% of people turning age 65 face a lifetime risk of spending some time in a nursing home before they die, and, of those currently institutionalized, some 70% are being covered by Medicaid. Why should it be that it that if diagnosed with cancer, one's medical costs are covered without limit, but if Alzheimer's disease one pays until impoverished?

The degree of equality varies widely in long-term care. For example, in the Netherlands, nursing home care is very egalitarian. People are not allowed to pay extra for more nursing or for a better room, although this may change. At the other extreme, in American private market "assisted living" housing facilities, the "room" part of the prices charged are partly determined by real estate values (size, location), and packages of services are offered at quite different price levels.

Japan is moving somewhat in the direction of more differentiation. Under the new LTCI system, it should be possible to cover the services portion of assisted living, leaving the lodging portion up to the individual (although the fact that a large amount was paid up front in existing facilities complicates the situation). And if clients desire more services than their eligibility level will pay for, and they have enough money, they are free to purchase them.

Participants agreed that if LTC is to be provided on an insurance model, a comprehensive system is necessary. In Germany, the government initially tried to encourage and subsidize private LTCI, but the industry rejected these overtures, saying that it did not know how to calculate the risks. American private insurers were also initially cautious; although now more than 100 companies offer such policies, their future is uncertain.

Private LTCI is inherently plagued by moral hazard and adverse selection problems unless made mandatory and heavily regulated, in which case there would not be much difference with a public system. Most participants agreed that the benefits for public LTCI should be a "national minimum," but not at a bare bones level—it should be sufficient to cover the needs of average people. Incidentally, it would seem that if this source of risk in old age could be insured, then either pension levels or savings rates could be somewhat lower than otherwise.

2. Manpower Issues: Where Will Workers and Skills Come From?

Other than family or volunteer care, the work needed for LTC will be supplied from the labor market, in competition with other industries, so both numbers and quality of workers will be influenced by the wages paid. Of course, the overall state of the economy matters. In Germany, public LTCI is said to have created some 75 000 new jobs, a plus in a nation of chronic unemployment. Japan is often short on labor, and manpower issues may be serious, although if the economy is still in recession when LTCI starts that would ease wage pressures.

LTC work is very gender related everywhere in both informal and formal care (the latter somewhat less so in the United States recently). Since in most countries outside of Scandinavia women's labor participation rates are well below those for men, a substantial pool of workers may be available. Experience in the Netherlands indicates that the number of women working part time can go up quite suddenly.

Other working conditions, such as job status and autonomy, are important along with wages in influencing labor supply. Surveys of former nurses indicate that their reasons for leaving the field are usually not so much wages as job dissatisfaction, particularly having to work under physicians without real professional authority. It is notable that the number of nurses delivering home care in the private sector rose rapidly in Germany when LTCI provided the opportunity to work without a doctor's supervision (something of the same phenomenon can be seen in Japanese Visiting Nurse Stations in the 1990s).

The supply of nurses seems to fluctuate between shortage and oversupply rather rapidly, in Germany and elsewhere, perhaps caused more by changes in the overall economy than changes in particular programs.

In several countries highly educated nurses seem to have priced themselves out of the labor market. LTC may require a relatively small number of highly trained nurses (although a high proportion of these will be given real responsibilities); larger numbers of care workers at the lower level will be needed. It is unclear what the impact of more market-based delivery will be on wages and working conditions.

In Japan, social welfare work in general and the new "care manager" job in particular have become quite fashionable, especially among young women, with new schools opening up and textbooks for the various examinations selling briskly. Once the unformulated and sometimes idealistic motives of the new entrants to the field come up against the real difficulty of the work, the dropout rate is high. Those who qualify for the national examinations through on-the-job experience rather than schooling do tend to stay on at higher rates. New opportunities that will be offered by LTCI should make the field more attractive.

3. Politics and Policy in Long-Term Care

The process leading to passage of LTCI in Japan was marked by widespread but perhaps rather shallow support, and surprisingly little opposition. That was partly because the "small government" point of view is not very strongly represented in Japanese politics (despite the serious deficit problem, few call for real cuts in social security expenditures).

The main choice Japan faced was between a tax-based system with the government providing services more or less directly, and a social insurance system in which beneficiaries choose the services and providers. Most social welfare specialists preferred the tax-based "Scandinavian model" but this view did not prevail, partly because the needed large tax hike was seen as unfeasible. In the opinion of many experts outside the social welfare field, social insurance is better because of the greater element of consumer choice.

It is interesting that in Japan arguments about the cost of the new LTCI program did not play much of a role in the debate, although this was by far the most important issue in Germany. The result was a smaller program and much more stringent limits on expenditure growth. In both countries proponents tried to show that LTCI spending would be offset by savings elsewhere (mainly social welfare funds in Germany, and health insurance in Japan); these arguments may have been more convincing in defusing potential opposition in Japan. Actually it may be Germany that is more exceptional in this regard—OECD ministers, in a recent survey, saw cost issues as less salient for LTC than in pension or health care policy.

More generally, it was recognized that passage of a new welfare state program of this size in Japan is a remarkable development. Americans in particular noted how resistance to taxes and big government as well as specific interest group opposition had defeated President Clinton's proposed health care reform, and today these pressures inhibit consideration of major reforms in LTC.

Session 4
Program Design

Introduction and Summary

JOSHUA M. WIENER

While the previous section addressed the macro issues in constructing long-term care programs (such as whether the program is means-tested or provides universal coverage), this segment discusses the "nuts-and-bolts" program design decisions that must be made. In general, program managers must operate under the dual constraint of meeting the needs of the disabled elderly while at the same time keeping expenditures within politically acceptable levels (remembering that the politically acceptable level varies greatly around the world). Although there are an endless number of program design issues, there are five issues that stand out in importance: eligibility determination, the role of care planning and case management, what services are to be provided, how services are to be reimbursed, and quality assurance.

Eligibility and Allocation of Resources

The first issue is establishing the eligibility criteria and deciding who is empowered to determine who is eligible. The most important design element is whether the program is means-tested or available to persons independent of financial status. Beyond that, some countries (such as Japan) have opted to limit eligibility primarily to the elderly population, while most others including Germany, the United Kingdom, Germany, and Sweden) provide services to persons with disabilities of all ages. The advantages of limiting eligibility to the elderly is that it reduces expenditures (because fewer people are eligible), and it sidesteps many difficult and complex eligibility and service decisions concerning people with mental illness and mental retardation. The main problem with this approach is that of "intergenerational equity." It is difficult to rationalize why elderly persons with relatively minor disabilities should be eligible for services, while younger persons with spinal cord injuries are not. In addition, younger persons may resent paying taxes or premiums for benefits that they cannot receive.

Another component of this issue is whether eligibility will be restricted to persons with very serious disabilities (as in Germany, the United States and, increasingly, the United Kingdom), or whether the program will cast a broad net, seeking to provide aid to people with relatively modest levels of impairment (as in Japan). The rationale for a strict disability criteria is that it controls expenditures by limiting the number of people eligible and, by definition, targets resources to people with the most severe disabilities. However, this approach leaves some people with significant needs without services (especially if informal care is not available) and creates a "cliff" in which individuals who are eligible for the program potentially receive a great deal of services, while those who are only slightly less impaired receive nothing at all.

A related issue concern is how disability will be measured in determining program eligibility. Measuring disability is not "rocket science," and there are many different ways to do it. In countries where benefit decisions are separate from eligibility determinations, the measurement of disability is of lesser concern than it is in countries (such as Germany and Japan) where the individual's level of disability determines the amount of benefits the person can receive. In these countries, individuals have a strong incentive to "game the system" to appear more disabled than they actually are to obtain more services (or, in Germany and Austria, higher cash payments).

Once the eligibility criteria are decided, some individuals or organizations must be assigned the tasks of evaluating individual applicants to assess whether they meet the eligibility criteria and, in Japan and Germany, what level of benefits they will receive. A problem facing countries seeking to greatly expand their long-term care services (such as Japan) is the absence of an infrastructure capable of doing these assessments. One possibility is to allow providers, who often have the technical expertise, to perform these assessments. However, they also have a vested interest in finding the applicant in need of the services that the provider can supply. Another possibility is to have agents of the state or the insurance entity perform the assessments. The problem is often that capable staff often do not exist, at least in the numbers needed, and many countries are reluctant to increase dramatically the number of government employees implicit in this strategy. While these workers do not have a financial conflict of interest in the same way that direct providers do, they may find themselves under pressure to alter their assessments if program costs increase faster than anticipated or if savings must be found.

Care Planning and Case Management

Once eligibility has been determined, the question is who decides what services the client will receive. The relationship between care planning and case management is discussed in depth in the paper by D. Challis in this volume. In the new program in Japan and in Germany, once the maximum level of benefits are determined, individuals have a free hand in deciding what services they will receive. Although individuals may use case managers if they wish, at least in Germany, mandatory case management is viewed as inconsistent with insurance principles because it would result in two people with the same level of needs receiving different levels and types of services. In contrast, the United Kingdom and the United States depend heavily on case managers to develop care packages and to allocate resources.

Whether case management is viewed as a good idea and an efficient and effective use of resources depends largely on what goals it is being evaluated against. One goal is for case management to be the agent of the person with disabilities and their family. This approach assumes that the disabled individual is not an expert in long-term care service delivery and financing and needs help in picking among services and making arrangements. Especially if the delivery and financing systems are fragmented or if there are a large number of competing service providers, this need for somebody to coordinate the service package may be especially strong. A competing conception views case managers as cost control agents, making sure that individual clients use the most cost-effective services available and do not use more than is necessary. In this model, case managers have broad discretion in determining how much and what kind of services individuals receive. These goals of advocacy and cost containment conflict, and policymakers must balance the two.

Services to Be Provided

Both eligibility determination and care planning are preparatory to actually providing long-term care services. Thus, it is impossible to overstate the importance of deciding what services are to be covered and who will supply them. The paper by J. Wiener in this volume addresses the balance between institutional and home and community-based services. Countries around the world have sought to expand the supply of noninstitutional services. The policy rationales for this expansion are that people want to stay in their own homes if at all possible (see the paper by R. Campbell), that many disabled people in the community have unmet needs, and that it will result in a lower cost overall system. Extensive research in the United States casts doubt on whether expanding home care will save money—usually large increases in home care use more than offset small reductions in nursing home utilization.

Establishing what home and community-based services should be covered can be difficult because individual needs and preferences vary greatly. To limit expenditures, policymakers are often tempted to narrow the range of services available, but that can result in needs not being met or in the misuse of more expensive services. For a sampling of the variety of needs and service options for elderly people with disabilities, see the papers by F. Miura on people with dementia, by A. Tham on the role of housing in long-term care, and by R. Kane on the importance of service flexibility in satisfying consumers. If people are entitled to services, the difficulty is that the broader the set of services covered, the harder it is to control expenditures. The crux of the problem is that individuals cannot be entitled to everything, and deciding what and what not to cover is difficult and often arbitrary.

The other broad question in this area of services concerns who actually will provide the services. (See the paper by M. Eto for a discussion of this issue in Japan). In Scandinavian countries, for example, most services are provided by the public sector, which has the potential advantage of avoiding wasteful duplication, enhancing coordination, and limiting administrative expenses. It also runs the risk, however, of service rigidity and a lack of responsiveness to consumer preferences. In other countries, such as the United States, services are mostly provided by private organizations, which compete for business, enhancing choice and perhaps efficiency. This approach also runs the risk of wasteful duplication and an emphasis on profit maximizing rather than service to clients. In Japan, an enormous expansion in the number of service providers will be necessary to accommodate the expected explosion in use of home- and community-based services. The new insurance plan largely assumes that private providers will be there to fill the gap, but services must be profitable to encourage the for-profit sector to enter and a labor force must be recruited and trained to supply these services, neither of which is guaranteed to occur. The paper by M. Eto also notes that the use of the competitive market in Japan has a political dimension as well as an economic one and is likely to disrupt the existing relationships between municipalities and social welfare providers.

Reimbursement

Program managers must also decide how to reimburse providers for their services. Both the level and the method of reimbursement are important. The absolute level of reimbursement is especially critical because adequate reimbursement is necessary both to maintain adequate quality and to attract enough providers to supply the services that policymakers want delivered. Controlling the level of reimbursement is also a principal mechanism that policymakers have to control expenditures. It is noteworthy that Japanese government bureaucrats are being given wide latitude in designing the reimbursement systems for long-term care providers for the new system, which otherwise has few incentives for cost containment.

Less often appreciated is that the reimbursement methodology provides incentives to providers to behave in certain ways. For example, flat-rate reimbursement systems, in which all providers receive the same payments regardless of their quality, costs, or level of patient disability, provide incentives for providers to serve lower cost clients. In addition, because providers maximize profits by spending less money, quality also may be adversely affected in flat-rate systems.

Quality Assurance

Long-term care program managers bear a special quality assurance responsibility because the frailty and cognitive impairment of many disabled elderly make them especially vulnerable to abuse. (See the paper by Y. Takagi on achieving quality in institutional and home-based care.) The difficulty, of course, is that measuring quality of care is extremely hard and those aspects of care that are most easily measured (e.g., width of corridors, whether a home care worker has completed a certain training course) are the least important in actually assessing whether an institution is a good place to live or whether the home care worker is kind.

Moreover, a particularly thorny point for quality assurance in home care is determining the home care worker's level of responsibility for what goes on in the client's household. In an institution, the facility can reasonably be held responsible for all aspects of a resident's life because the individual spends virtually all their time there. In contrast, the home care worker may only be in the client's house for 5 or 6 hours a week, and it is difficult to hold the worker responsible for what may occur when the worker is not there.

Conclusions

Program managers must make innumerable decisions in actually designing and implementing long-term care programs. These decisions touch on issues of eligibility for services, case management and resource allocation, deciding what services to provide, reimbursement of providers, and quality assurance. The situation is particularly daunting in Japan where a major new financing system is premised on a the provision of home- and community-based services that currently do not exist. With such a dramatic change, information is critical to successful implementation. All too often, policymakers lack the data systems necessary to provide the information—both research and regular program data—that they need to make decisions.

Commentary: Cross-Cutting Themes in the Provision of LTC

YASUO TAKAGI

Seven themes have been chosen for this session, concerned with program design for the care of the aged, all of which involve difficult problems, and include the following:

1. Which is better for the users, to provide them with direct services or to give them cash or vouchers?
2. What method should be adopted to determine the recipients of the services?
3. To whom should the care manager offer their services and what should they do?

Seven papers have been presented by British, American, Swedish, and Japanese researchers on these themes, but few of them deal with the problems directly. This demonstrates the difficulty of the task of designing programs for the care of the aged and the fact that no ideal model exists in any country. Nonetheless, valuable analyses and suggestions have been put forward in the seven papers, and, taking these into account, I would like to present a few of my own views.

First of all, there is the question of how to offer services, that is, the problem of whether services should be offered in kind or through the provision of cash or vouchers. Although cash payment is not envisaged under the care insurance system in Japan, I think it should be adopted for the following three reasons:

1. To provide all services for the care of the aged in kind requires a great number of service providers, but it is difficult to secure a sufficient number of personnel and develop the infrastructure for providing such services.

2. Even though a social system for care insurance has been created, the system should not be operated in total disregard of the care through the family; I feel there can be a system under which cash is paid as a form of

compensation for the care thus provided. Although care insurance is a system of social support, it should nonetheless be structured under the principle that supplementary support is to be provided where sufficient services cannot be secured through the care provided by the family alone.

3. From the point of view of cost control, cash payment is considered to be more effective than provision of services in kind. As is stated in the report from the United States, home care in particular, unlike institutional care, is preferred by the aged, and the costs for this care are gradually increasing. In addition, home services tend to be expensive because there are a great variety of services involved.

The second problem is determining the purpose of care management and the role it should play in a program for the care of the aged. In this respect, a detailed report on the situation in Britain has been presented in which an important suggestion is advanced, namely, that care management has two functions; that is, the function of securing the quality of services for the users and that of efficient management of the entire system for the care of the aged.

Certainly, care management enables the system to secure the provision of a variety of services and the different sources of revenue necessary for it through the evaluation of the needs of the aged, but it is impossible to provide all the services required by each aged person. A discrepancy can arise between the care management adjusted for each aged person and that at the system level, because there is inevitably a limit on the level of personnel and financial resources that can be offered under the social system for the care of the aged. Therefore, care management must be conducted laying particular emphasis on allocating the limited resources available to each user in an efficient and impartial manner.

In practice, it is extremely difficult to adjust services for each aged person, and the services that can be purchased vary depending on the assets and income of the individual concerned. It is a matter of great importance that appropriate and comprehensive service programs should be formulated and implemented through the introduction of care management. Even so, it would be shortsighted to assume that all the needs of the long-term care of the aged would be covered by such programs.

Throughout the history of social security, various systems of social support have been designed to meet the needs of various life cycles, such as child welfare and the welfare of the handicapped, as well as medical and unemployment insurance for the working population and annuity insurance after their retirement. Under these programs, it was possible to provide uniform and impartial services because the people targeted and the nature of the services required were clearly defined. However, the program for the care of the aged targets people whose levels of assets and incomes, family structures, friendships, attitudes toward life, and values vary enormously and have been uniquely shaped by their experiences, and it is difficult to provide the uniform and impartial services that are provided under the social systems for children and the working population. The two functions of care management, that of the user and that of the system, will play an effective role in designing a program for the care of the aged that balances "efficiency" and "impartiality."

Finally there is the problem of evaluating the quality of the services provided. In this respect the question of the organizations involved in providing the service is significant. The conditions differ to a great extent depending on whether the services are provided by private enterprises or government bodies, or by professionals, families, or volunteers. It is reported that in Sweden, with respect to the question of housing in long-term care of the aged, the roles of provincial and municipal governments are differentiated depending on the degree of necessity for care services and the degree of destitution. It may therefore the assumed that the system for evaluating the quality of services differs depending on the nature of the services provided and the organization that provides those services.

For example, for the protection of the rights of the aged and the settlement of their grievances, such as is performed in Tokyo, it is important that evaluation of the quality of services be conducted in the localities or municipalities where the person concerned actually lives. However, with respect to the quality of private service providers, the evaluation by families and local governments alone will not be sufficient to check whether or not payment is made over and above the cost of the provision of the services in cases where extensive profits are derived through competition and excessive gains are made. This is a questions of the legal framework and operation of the system by the central government that designs the program for the care of the aged, and in Japan where a care insurance system is being launched, it is necessary to give sufficient consideration to the question of evaluating the quality of the services. In addition to evaluation based on care management, it is important to develop third-party evaluation mechanisms, in parallel with the evaluation mechanisms of municipal, prefectural, and central government organizations.

In any event, the formulation of programs for the care of the aged is not a simple matter. As has been mentioned, these people have lived for many years and, therefore, their personal circumstances vary enormously from individual to individual. Since the structuring of a social security system for the aged is so complex, this section of the population has been left behind. Each country is promoting various measures toward the creation of an ideal program for the care of the aged. In this connection, it is important to promote a scientific approach overcoming the differences between countries and, taking into account the problems common to the fundamental elements for the structuring of programs, including manpower, facilities/services, and financial resources. Before long an answer will be produced as to how close Japan's care insurance system is to the ideal model.

Effective Care Management

DAVID CHALLIS

Key words: Care management—Balance of care—Coordination—Home care

Origins and Rationale

There are broad similarities in the changing pattern of services for older people in numerous countries. All involve shifting or maintaining the balance of care in the face of rising demand. These changes may be characterized in simple form, as first, a move away from institution-based provision of care, second, the extension of home-based care, and third, for individuals with more intense needs, the development of mechanisms of care coordination, usually through the medium of case or care management [1].

There is a particular role for care management in the process of shifting the balance of care. Its purpose in policy is frequently to provide a context to improve targeting of individuals into appropriate care options so that institutional care is reserved for the most disabled and, by extending the capacity of home-based care, the rate of growth of institutional care for an aging population may be reduced. Thus, it functions to extend the capacity and extent of home care so that the boundary between maximum home care and the level of support in institutional care is narrowed. A second and less specific use of care management in fragmented care systems is to link a wider range of people in need of support with services which by the nature of the care system comes from a variety of providers and possibly through multiple funding sources. There can be seen here a simple distinction emerging between intensive care management—a highly focused and targeted activity—and coordinative care management, received by a larger population of service users to achieve effective service allocation.

Hence there emerges the need to relate care management and notions of what constitutes effectiveness in this area of activity to its precise purposes and target population. In general it is reasonable to postulate a simple axiom—the more fragmented the care system and its funding mechanisms, the lower the threshold of intervention where care management is seen to be required.

A discussion of effective care management in long-term care needs explicit focus upon the key question: Who receives what kind of care management to achieve what goals with what resources in which setting? Herein lies a source for some of the difficulties in care management implementation in long-term care. Does it constitute coordination of services for a wide range of needy individuals or a specialized approach for a smaller number? an attempt at definition so as to differentiate approaches may assist.

Definition

A variety of definitions of care management may be found in the literature that permit variability of interpretation. For example, the UK Department of Health defines care management broadly as the process of tailoring services to needs, and then specifies a range of care tasks such as assessment and review as core activities [2]. It may be more helpful to offer a multivariate definition of care management for the purpose of providing long-term care as a means of resolving some of the difficulty.

It is helpful to identify six criteria, which together enable a more precise definition to be formulated. These are the performance of a set of core tasks; the function of coordination; explicit goals for care management; a focus on long-term care needs; particular features that differentiate care management from the activities of other community-based professionals; and the dual function of care management at client level and system level [3]. These are shown in Table 1 and are discussed further. They attempt to answer these questions:

How is care management done?
What is undertaken in care management?
Why is it care management employed in the care system?
For whom is care management provided?
What makes care management different from other community-based work?
What impact does care management have on the service system?

TABLE 1. Defining care management

Key attributes of care management	Distinctive features
Core tasks	Case finding and screening; assessment; care planning; monitoring and review; case closure
Functions	Coordination and linkage of care services; tailoring resources to needs
Goals	Providing integrated care with continuity; increasing the feasibility of care at home; promoting client well-being; making better use of resources
Target population	Those with long-term care needs; multiple service recipients; those at risk of losing community tenure
Differentiating features	Intensity of involvement; breadth of services spanned; duration of involvement
Multilevel response	Linking practice-level activities with broader resource and agency-level activities

Most definitions of care management tend to begin with the performance of a series of core tasks in long-term care. Although the precise number of tasks and the label given to them may vary, they are broadly similar. The core tasks included case finding and screening, assessment, care planning, implementing and monitoring the care plan. The core tasks are designed to achieve a greater degree of integration of care, and hence the second element in definition is that of achieving coordination. This is based upon an assumption that care management provides continuity of care, and in most of the more intensive definitions of the role this involves continuity of support by a dedicated individual or team who will organize, coordinate, and sustain a network of support.

The integrated care that the performance of the core tasks is designed to achieve is seen as linked to achieving specific goals. These goals have been most commonly concerned with the shift in the margin between institutional and home-based care, cost containment, community tenure, and individual independence, but have also been related to the enhancement of the capacity of social networks and the improvement of clients' utilization of support systems.

The specification of a clear target population constitutes the fourth aspect of a definition of care management, which is most usually operationalized as a concern with meeting the needs of people with long-term care problems or multiple needs. This perception of its role as a mechanism for providing long-term community-based care, and therefore relevant to a specific target population, is an element that helps to differentiate care management from the activities of other community-based workers. This lack of clarity of differentiation is at times debated in the literature, and the role is often seen as closely linked to that of social workers and nurses who in practice are the occupational groups commonly acting as care managers. There elements which do appear to differentiate the activities of long-term care case management from activities such as key working have been identified as "Intensity of Involvement"—reflected in relatively small caseloads; "Breadth of Services Spanned"—covering more than one service, team, or agency; and "Length or Duration of Involvement"—a long-term commitment.

The distinction has also been made between single agency coordination and comprehensive case management, the latter involving an inclusive examination across a person's needs and resources, linking them to a full range of appropriate services, using all available funding sources, and monitoring the care provided over an extended period of time. The final factor that can be seen to differentiate care management approaches from others is the focus of operation both at the client level and the system level. Care management is seen as relevant to providing care for the individual but also for shifting the pattern of services in ways that are more client-centered and thereby effective. In purchasing terms this is based upon the assumption that the aggregate of a myriad of individual care provision decisions may exert pressure for change on patterns of provision themselves. Thus the degree of horizontal integration that may be achieved by care management at the practice level requires a corresponding degree of vertical integration into the system to be effective.

Hence, care management is too broad a concept in the absence of precise definition. Using this definition most research findings relate to a narrow conception of care management in long-term care, with the more precisely defined programs tending to have the more evident outcomes.

Effectiveness and Features Associated with Positive Outcomes

Most evaluation research of care management programs has been concerned with the intensive support of high-risk or high-need groups in both mental health and aging. These studies have focused on populations with high probability of admission or readmission to hospital or nursing home settings. Despite this diversity and the difficulty of producing reliable and robust definitions of attributes such as severe mental illness or risk of nursing home placement, there is a considerable degree of consistency in the findings. From these studies, several factors may be identified which appear to be associated with effective outcomes in long-term care management (Table 2). As can be seen, these include integrated funding for the program, clarity and precision of target population, clear service objectives, continuity of involvement, and logical linkages between the model of care management, its objectives, and the incentives which the structures present to the practitioners implementing the program. At the practice level, this may refer to such factors as appropriate caseload sizes and the means to be able to respond creatively to identified needs, through such mechanisms as devolved budgets.

Integrated funding can avoid some artificial boundaries and perverse incentives arising from organizational pressures to remain within narrow budgetary confines. Clarity of target population, combined with systems of screening and assessment, can ensure that care management with its inevitably higher overhead costs is provided to those for whom it is most appropriate. Clear service objectives provide a focus for managing and monitoring care management programs, whether in terms of needs of recipients, service processes such as costs, or outcomes such as hospitalization, community tenure, or quality of life. Continuity of involvement offers the basis of practitioners remaining responsible for assessing, monitoring, and reviewing cases and gaining the benefits of feedback from effective and ineffective strategies, whether at the individual case level or more generally. Logical linkages between program goals, environment, and practice incentives reflects the necessity for congruence between practice environment and overall objectives. For example, such components as flexible patterns of response, perhaps by means of developed budgets, need to be available to care managers if a program goal is for individually tailored services. In the absence of such flexibility, or where

TABLE 2. Some factors associated with effective outcomes in care management

Integrated program funding
Logical linkages between model of care, objectives of program, and practice-level incentives
Clear service objectives
Precision and clarity of target population
Continuity of involvement

there is marked difficulty in providing other than standard responses, the incentive for practitioners will be to respond in a very standard fashion rather than to individualize care.

Key Aspects to Be Addressed in Long-Term Care Systems

There are some key aspects of care management that need to be addressed if it is to operate as part of an effective long-term care system.

The need for a differentiated response: The degree of apparent confusion between care management as simply a description of the organizational process involved in assessing and providing services to people in need and care management as an activity undertaken by a designated worker for a specific client group has been observed in the UK. The need for a further distinction between "coordinative care management" and "intensive care management" was made earlier in the paper. Discussion of the role of care management in long-term care cannot be conducted until specific types of care management are related to specific types of need groups. For much long-term care provision, it is care management of the intensive kind which is likely to be required, characterized by a more professional orientation among staff, smaller caseloads, and resource-rich responses to need.

A focused and effectively targeted client group: Differentiated response to need implies targeting of response and the presence of adequate screening mechanisms to implement this. Effective targeting appears to have been a crucial factor associated with positive outcomes in care management. In many of the programs, particularly for older people, targeting has been associated with the propensity to enter institutional modes of care. This has reflected the desire to shift the balance of care from institutional modes toward community-based care. However, while current policies may wish to shift the balance of provision of care, in the longer term some desired balance may well be achieved. In a context of maintenance of a balance of care, targeting may have to be sharpened further, so that the investment of expensive services to coordinate care, such as intensive care management, are focused on those who would make most gain from the provision of such service. This is a problem in social care analogous to the concept of "health gain" in health care.

Balance of activities: assessment, monitoring, and review: Although care management in the UK has been associated with assessment as one of the cornerstones of the implementation of community care policy, the precise contribution of health care and of particularly secondary health care services such as geriatric medicine and old age psychiatry to this process are not clearly specified and are subject to local arrangements. Care management systems devised in agency isolation and lacking access to appropriate expertise for assessment are unlikely to be fully effective, particularly when concerned with individuals with complex problems. Where screening is lacking, care management systems may become unbalanced with excess staff time devoted to the assessment of new cases and insufficient time to review of existing cases. A consequence is likely to be a growing mismatch of resources to needs.

Early monitoring of the development of care management in the UK suggested that because large numbers of people had entered the care management process and the assessment procedures were making heavy demands on scarce practitioner time, it was becoming increasingly difficult to undertake review processes. This was particularly so with the buildup of reviews of elderly people placed in nursing and residential care homes in the nonstatutory sector. There could be a real risk of program distortion if the growth in demand for reviews in institutional settings was such that staff time was diverted from support of individuals in the community.

Program consistency: Linking care management system and practice. The critical importance of care management systems possessing a degree of organizational integration more than just at the practice level appears clear, as is evident in some mental health programs. Coherent links between funding, contracting, and individual case decisions can enhance this. In this way, a degree of vertical integration of care for very vulnerable individuals may be achieved, which may indicated future roles for geriatric and old age psychiatric services in relation to the development of care management.

Related to the linking of system and practice, it would appear that effectiveness requires a logical coherence between expected outcomes, staffing, setting, target groups, service models, and the day-to-day pressures and incentives on practitioners. Lacking this internal consistency, an apparently rational model of care management may well fail to achieve its goals.

Conclusion

An appropriate starting point for debate about the effectiveness of care management in long-term care systems must be in a context where target populations are explicit, goals of care management clear, programs logically integrated, and flows of demand and activity adequately estimated.

References

1. Challis D, Davies B, Traske K (1994) Community care: promise, imperative and ambition—an international agenda. In: Challis D, Davies B, Traske K (eds) New agendas and challenges from the UK and overseas. Ashgate, Aldershot
2. Social Services Inspectorate/Social Work Services Group (SSI/SWSG) (1991) Care management and assessment: managers' guide. HMSO, London
3. Challis D, Darton R, Johnson L, Stone M, Traske K (1995) Care management and health care of older people. Ashgate, Aldershot

Further Reading

Challis D (1994) Care management. In: Malin N (ed) Implementing community care. Open University Press, Buckingham

Japan's Long-Term Care Insurance System: The Likely Impact on Service Suppliers and Their Staffs

MIKIKO ETO

Key words: Service provision system—Supplier's reaction—Cooperation

The Long-term Care Insurance (LTCI) system that is scheduled to start in April 2000 will change the existing Japanese welfare system in two respects. First, the basic principle of eligibility will be altered. Under the 1963 Welfare for the Elderly Law, services have been based on a means-tested poverty program model, mainly aimed at older people without families. In contrast, the new system is based on the principle of universality, under which all insured elderly people are qualified to receive services, based not on their economic or family conditions but only on their needs arising from disability.

Second, the institutional arrangements for service supply will be revised. Under the present system, either municipal authorities or nonprofit "social welfare corporations" (shakai fukushi houjin) provide welfare services for the elderly, such as nursing homes, day care centers, and home help services. Under the new system, medical facilities, private enterprises, and other kinds of nonprofit organizations will also be able to provide welfare services. This reform is intended to expand the number of suppliers and thus the supply of services, and to give recipients more freedom of choice and suppliers more competition. Naturally, many existing suppliers are quite worried about the change.

I would like to focus my attention on the latter aspect of the expected changes; namely, what dynamics will occur among the suppliers, how each supplier will cope with the new situation, and who will grasp and who is likely to miss these new opportunities. I also briefly discuss the changing relationship between medical and welfare specialists under the new system.

Service Provision Under the Present System?

The current system is managed by the municipal authorities. They control the balance between demand and supply, selecting from among many applicants using criteria such as how well they can get along in daily life, personal and family income, and family composition. An applicant who earns a low income and lives alone is likelier to get benefits than someone else with the same disability. The beneficiary receives services from the supplier designated by the authorities; the recipient is unable to choose his or her favorite supplier. The suppliers are managed either directly by the municipality or, most often, by a social welfare corporation, operating with a subsidy from the local authorities.

The welfare corporations are public sector entities prescribed by the Social Welfare Programs Act of 1951. They are prohibited from offering any services other than those assigned by the authorities. While many of them are philanthropic organizations established by religious or charitable groups, recently corporations established by the municipal authorities themselves have increased as a result of financial difficulties that arise from directly providing services.

How Will Service Provisions Change?

Under the new LTCI system, the municipal authorities must establish a committee to assess eligability and level of need. This committee must be in the third sector, independent of the municipal authorities, and be made up of professionals and experts related to health and welfare services, appointed by the mayor. The committee first assesses whether or not an applicant is qualified or not, and if so, at which of six dependency levels. This decision is based on statistical analysis of a questionnaire administered by an interviewer dispatched by the municipal authorities, the interviewer's brief qualitative report, and the opinion of the applicant's home doctor.

At the request of a beneficiary, a care manager may write up a care plan for the amount of services allowed at that level of dependency. The beneficiary can select the supplier, and if he or she needs several services, each can come from a different supplier. Moreover, the beneficiary can purchase services at their own expense to supplement the services provided by the public insurance. It is said that this freedom of choice is one of the important merits of the LTCI system. Because it means that the beneficiary is responsible for their own choices, it is important that an adequate system for advocacy and consulting be established for service recipients.

The LTCI market is open to all suppliers that meet a fixed standard, which varies according to the kinds of services; for example, the standard for approving the provision of nursing home services is stricter than those of various in-home services. The regulation of suppliers will be much looser than with the existing system. Now, private enterprises that have been barred from the existing system because they are profit-making, and also nonprofit organizations that have not qualified under the rules for welfare corporations, will be able to enter the new market. Medical facilities too will be able to participate in the LTCI system. Although competition among various suppliers brings the merit of cost-effectiveness, it is feared tat excessive competition will work to the disadvantage of conscientious suppliers and possibly force them out of the market. The question has been raised whether or not market mechanisms can coexist with an ideal of welfare.

How Will Suppliers React?

What will be the reactions among old and new suppliers to the situation caused by the creation of LTCI? By seeing the actions that they have already taken, we can try to predict what they will do under the new system.

Municipalities

It is the municipalities that actually are in change of the insurance. They are faced with three problems: (1) how to collect the premiums, (2) how to ensure a sufficient supply of services, and (3) how to manage the system. With regard to the first problem, because low-income elderly and self-employed people may not pay their premiums, the municipalities where the rate of aging is high are particularly afraid of being unable to obtain the funds they need. Also, many municipalities worry that they will not be able to secure a sufficient supply of services to meet the needs of the insured.

On the other hand, if the market mechanism works well, the more the needs increase, the more the supply of services should grow. In the mean-time, management problems are likely to be the most difficult for the municipalities: how can they control the increase of expenditures, what advocacy system is needed to protect the rights of beneficiaries, and how can they control "dishonest" suppliers? There are two possibilities for the municipalities: they can elect to focus on only the revenue and expenditure of insurance funds, or they can try to extend their management to the total system.

Social Welfare Corporations

Under the current system, municipalities have protected the social welfare corporations. On the one hand, municipal regulations have restricted the activities of the social welfare corporations, but on the other hand, their subsidies have provided stability. The existing system has provided so much protection to the social welfare corporations that the prospect of deregulation throws them into confusion. While some corporations are trying to adapt themselves to the new environment in a positive way, so far most are not really responding. If they cannot reform themselves and find new direction, they may be forced to withdraw from the LTCI market.

Medical Facilities

Hospitals and clinics would seem to be offered some new business chances just when the government is moving sharply toward restraining medical expenditure. As mentioned, doctors provide an opinion in the assessment process, but they are at the same time service suppliers. One point is that long-term care hospitals with elderly patients will in effect become nursing homes paid by LTCI benefits. Moreover, even beneficiaries living at home will be needing some services from medical facilities. If these facilities provide not only medical services but also social services, they would be able to capture large numbers of clients.

Nonprofit Organizations (NPOs)

A few NPOs have begun to provide community-based social services since the 1980s. Their activities vary from nursing homes to meal delivery services. For example, a large NPO in Kanagawa Prefecture has established a social welfare corporation that manages a nursing home and a day care center, with a subsidy from municipalities. Such an example is, however, a rare case. Most NPOs are small groups and are always worried about shortages of funds, because they have not been approved as public sector corporations under the present system. They may be able to find good opportunities in deregulation, but it is uncertain how many of them will really be able to succeed in enlarging their activities.

Private Enterprises

Private enterprises are powerful rivals for the social welfare corporations and NPOs. They seem likely to try to become suppliers of multiple services. Just as customers prefer a supermarket to a retail store because of the convenience of one-stop shopping, a beneficiary may wish to choose a commercial all-inclusive supplier.

Who Will Take the Initiative? Cooperation Rather Than Confrontation

This competition may become confrontational. Under the existing welfare system for the elderly, social workers and care workers, namely, welfare experts, have played the central role. Under the new system, medical doctors may insist on taking over the leadership in interactions among LTCI providers. While the welfare experts would like to remain independent of doctors' control, they are also very cautious about the prospect of private enterprises becoming involved, because they doubt that companies will have the true "welfare spirit."

It seems clear that, to implement the LTCI system successfully, cooperation between medical and welfare experts is essential. Providers should not worry so much about who is going to take the lead, and should be concerned with how to cooperate among themselves.

Further Reading

Public Participation in Policy-making Process of Health Care (in Japanese). Shinzansha, 1993

Continuity and change of the policy on the health system in Japan (in Japanese). The Annuals of the Japanese Political Science Association, 1997, pp 135–153

Transformation of the "Japanese-style welfare" under the coalition period since 1993; the process for the establishment of the long-term care insurance system in Japan (in Japanese). Leviathan, 1998, pp 68–94

Models of Long-Term Care That Work

ROSALIE A. KANE

Key words: Consumer focus—System development—Assisted living—Cost-effectiveness

In the United States, as is probably true elsewhere, long-term care often seems to fail to "work" in the sense of meeting the interrelated cost, access, and quality criteria by which health and human services programs tend to be judged. Access and cost (that is, price) are particularly intertwined. A relatively low price for services is important regardless of whether payment is made by the consumer, by governments in a tax-supported program, by governments for low-income people, or by private insurers. If prices are low, access is improved because more services can be provided and more people are helped per dollar expended.

Quality is the most important and the most ambiguous of the three criteria for a long-term care system that works. For a program to achieve quality, it must meet its goals with an acceptable, or even better, an excellent standard of performance. Long-term care can be defined as health and social services given over a sustained period to people with functional difficulties. From the perspective of those receiving the care, the goal is to enable them to live their lives as meaningfully and productively as possible given the disabilities that created the need for long-term care in the first place. The help needed corresponds literally to the functional impairments—if the consumer needs help to get in and out of bed, to use the toilet, to bathe, to prepare meals, to take medicines, to purchase food and other necessities, then the corresponding services are transferring assistance, toileting assistance, bathing, cooking, administration of medicines, and shopping. If the long-term care consumer has severe memory and judgment problems because of Alzheimer's disease or some other kind of dementia, the services needed may include a particularly labor-intensive supervision for safety.

Ordinarily such services are provided by family members for each other, but if no capable family members are available (often the case, given an aging society and technologically complex service needs), then long-term care must be arranged to supplement or replace the family efforts. Studies in the United States suggest that consumers seek the following in long-term care providers: reliability and trustworthiness; technical competence; compassion and kindness; and a personality compatible with their own in those who provide regular personal care. If they need to move to a congregate residential setting, they seek a place that is home-like, where they will continue to exercise control over their lives, and which will not require them to move yet again if they get sicker. More basically, in making decisions about their long-term care, consumers are concerned about their dignity, comfort, continuity with the past, ability to sustain meaningful personal relationships with family members and others, and ability to contribute socially. If the long-term care consumer has dementia, family members seeking care on their behalf seek to maximize their relative's physical well-being, comfort, safety, and decency, and seek dignified, compassionate care.

How Long-Term Care Programs Fail

The ways in which long-term care programs fail to work in the United States include the following individual-level problems.

- Consumers and their families cannot find help. If they do find help, they cannot afford it. If they find a public program to help them, the amounts of help are insufficient. If they need housekeeping help, they can only get nursing help. If they need nursing help, they can only get housekeeping help. Personal care at occasional intervals throughout the day and night is particularly hard to arrange.
- The need for long-term care arises after a medical crisis. The consumer is in the hospital, family members are anxious, but advice is unavailable.
- Consumers are unnecessarily restricted. They may be unable to get help to function outside their homes because the help they can acquire is limited to services in their own homes. They may not even be able to control what their helpers do and how they behave while giving them care in their own homes. If they need extensive care and have low

incomes, they may be forced to relocate to nursing homes to get financial coverage for the services they need.
- The nursing home, which in the United States provides most of the publicly subsidized long-term care, is unattractive to consumers because of the disruption of familiar lifestyles and relationships, the loss of dignity and privacy associated with life in typical nursing homes, feelings of being abandoned and unprotected, and concern about the quality of care.

Systems also fail to work at the societal level. The problems include the following:

- The costs per case and overall are higher than public and private payers can afford.
- A mechanism is lacking to quickly identify those who need services and to equitably allocate services. There seems to be an unfair and haphazard aspect to allocation.
- There are concerns about the quality of the frontline workers who actually provide services. This has led to mandated training and layers of professional supervision, which has increased the cost but not alleviated the concerns.
- Fragmentation between health-oriented and socially oriented approaches has led to confusion, lack of service, or overpriced services. Some routine services (for example, administration of oral or other medications, managing catheters or ostomies) are interpreted to require close supervision of a nurse, making costs prohibitive at home. On the other hand, when people in a social program need advice of health professionals, it may not be easily acquired. Primary medical care for those getting long-term care is of variable and often poor quality.
- Personal care, the service most needed, is in shortest supply.
- All regulation and quality assurance seems directed at the overriding goal of consumer safety and minimizing consumer risks. Providers of service have become liability conscious above all. No mechanism has been developed to hold providers of care reasonably accountable without heavily restricting the way of life of the consumer.
- The most money is expended on the kinds of services—nursing homes—that consumers least value.
- Long-term care consumers are reluctant to accept services, and typically want fewer in-home services than professionals think are needed

for their safety. Although this helps balance budgets, it means that either the person did not need service at all (a case of poor assessment) or, more likely, that the services offered are not perceived as desirable, helpful, or trustworthy.

Systems That Work

In some parts of the United States, long-term care systems appear to work better than average. Public expenditures are better balanced between nursing homes and other in-home and out-of-home arrangements. Consumers and their families have better access to information with which to make choices. Consumers seem to have more control over planning their care. I conclude with a list of what seem to be the features that most characterize well-working systems. This is obviously a summary. The entire list of features "that work" does not apply to any one program.

- The long-term care program is driven by clearly articulated values, which may include dignity, choice, "normal" lifestyles, and independence for the consumer; respect for consumer preference; respect for the family structure, and so on.
- At a local level, a single, well-publicized point of access is available for consumers to learn about services that are available and their own eligibility, and to receive help with arranging the services. This implies a uniform assessment and case management process at the local level. This is a conceptual and organizational single access point, not a geographic place. For example, the case management system is available to people who are in the hospital.
- A repertoire of services is available in the community, but these services are *not* arrayed on a "continuum" where professionals can decide what service is "appropriate" on the basis of disability levels. Consumers and their families make choices about the services that work best for them. Flexible, innovative, and unorthodox arrangements can be made.
- Personal care is plentifully available. Consumers can choose whether to purchase that care from individually employed workers whom they largely train and direct (called the Independent Provider [IP] Model, in the United States) or from a home care agency. Whether an agency or an IP gives the service, a backup capability is available if the worker does not arrive.

- Under some circumstances, family members of the consumer may be selected as IPs, particularly if such family members withdraw from the labor force to give care.
- Safety is not the predominant value in the system, and there is no effort to attribute each death, fall, or worsened health status to somebody's negligence.
- Out-of-home possibilities are available for consumers who cannot live in their own homes and efficiently receive the full amount of care needed. These resemble private dwelling places—family homes and apartments—and the price of the housing is separated from the price of the services for reimbursement purposes. Therefore, consumers may pay for the costs of their housing from their pensions (public and/or private), whereas the long-term care services are viewed separately.

Some analysts believe that if consumers were merely to receive sufficient additional income to purchase long-term care services, the market would bring systems that work. Though an adequate income is part of the solution, it is insufficient. Many long-term care consumers are vulnerable, unable to make decisions because of cognitive impairment, or unable to execute decisions because of physical problems. Without some overriding planning at the community level and case management available at the individual level, long-term care systems are unlikely to work. If the system works well, long-term care consumers will be seen as and perceive themselves as simply living their lives rather than spending all their time as patients or clients of some long-term care program.

Further Reading

Kane RL, Kane RA (1987) Long-term care: principles, programs and policies. Springer, New York

Kane RA, Kane RL, Ladd RC (1998) The heart of long-term care. Oxford University Press, New York

The Development of Strategies for the Demented Elderly in the Tokyo Metropolitan Area

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Key words: Demented elderly—Care management—In-home services—Cooperative homes—Adult guardianship

The Prevalence and Status of Demented Elderly in Tokyo

The prevalence of dementia in the population 65 and over, which is said to be of the order of about 4%–5% in Japan, is derived from surveys conducted by local governments. Among these, the Tokyo Metropolitan Government has conducted a total of four surveys, one every 7 years since 1978. The method used has been referred to as the Tokyo Metropolitan Method. The population surveyed is that of 65 years old and over living in the community. About 10000 are randomly selected and are screened by an initial general survey, of which those suspected of being demented are seen by specialists in the secondary survey. These surveys have revealed the state of the demented elderly and have made longitudinal comparisons possible.

The most recent is the fourth survey, conducted in 1995, which showed that the prevalence of elderly demented was 4.21% (third survey in 1987, 4.0%; second survey in 1980, 4.6%; first survey in 1973, 4.5%). The prevalence increases with age so that for those 85 and over, the figure was 19.3% (1987, 21.2%; 1980, 33.4%; 1973, 35.7%). The ratio of dementia due to cerebrovascular disease was 30.1%, which was about the same as in the previous surveys. However, that due to Alzheimer's was 43.1%, which was much higher than the 23.4% in 1987 and the 12.6% in 1980, because there have been decreases those due to other and unknown causes. The use of day service, short stay, etc., was only in the range of 10%. Nearly 85% of the care providers were women, of whom about a third displayed symptoms of stress. Parenthetically, the incidence level of demented elderly in nursing homes was 54.3%.

Activities and Measures Implemented by the Deliberative Committee on Demented Elderly Issues of the Tokyo Metropolitan Government

The Metropolitan Government has set up committees of specialists and investigative committees to look into various options and to use the results of these studies to gain a clearer idea of what measures should be taken to aid the demented elderly.

1. Most of the members of the first special research committee had participated in planning and implementing the special survey of 1973. They summarized the results and looked into some possible measures suggested by those results, but they were unable to come up with good answers. One reason is that the prevailing attitude during that era, in the Ministry of Welfare as well as elsewhere, was that the demented elderly should be treated as if they were mentally ill, and so the committee was unable to devise any measures other than expanding the number of hospitals for elderly mental patients. For this reason, demented people who exhibited problem behavior were left in their own homes, which placed a huge burden on their families.
2. Accordingly, the First Investigative Committee on Measures for the Demented Elderly was set up in 1980, taking the results of the second special survey as the starting point for its attempts to improve the situation. For the most part, this investigation took a social welfare approach, filling in the gaps in the overall policies toward older people who needed care and also suggesting specific policies for the demented elderly. Most notably, the committee proposed the construction of model institutions specifically for the demented elderly and experiments with caring for them in homes for the aged. The committee had found that the practice of placing demented people in mental hospitals was strongly opposed by the elderly people themselves and by their families. Furthermore, the committee found that the therapies and treatments offered in mental hospitals were not suitable for these patients.

Taken as a whole, the report put forth the possibility of caring for demented people with problem behavior in homes for the aged. At the same time, the report asked whether these patients should be relegated to specialized facilities or special wards or whether they should be cared for together with the general population of the homes for the aged. In other words, the argument was over whether the demented elderly should received segregated care or should be mainstreamed. Spurred by this committee's suggestions and the social welfare offices' efforts, the various insurance and medical care authorities began showing an interest in researching treatment of the demented elderly apart from the mentally ill. The Ministry of Welfare also began an investigation of policies toward the demented elderly in 1982. During this period, studies were focused mainly on having the demented elderly enter homes for the aged. That same era saw increased use of short-term stay facilities by the demented elderly, an idea that the Committee had mentioned, and training programs were set up for nursing home employees who dealt with demented patients. In addition, extensive and varied efforts were seen on the local and regional level, and information gleaned from the experiences of foreign countries was also brought into the picture.

3. As these trends continued and more and more information became available, the Tokyo Metropolitan Government set up the Second Investigative Committee in 1987, charging it to look into and report on overall policies toward the demented elderly. This Committee looked mainly at policies in which public health, medical, and social welfare facilities would work cooperatively. Thus it not only suggested adding specially trained personnel to promote more effective institutional care but also emphasized enhancing in-home care. To that end, it urged the use of home helpers and short-stay facilities, proposed the establishment of adult day care programs, and pointed out the need for a comprehensive system linking the public health, medical, and social welfare sectors in everything from offering advice to providing actual care. The Committee also promoted the establishment of what we might think of as a "social guardian" system, dedicated to protecting the assets of the demented elderly and managing their finances. (Based on this suggestion, the "STEP" advocacy center was established to defend the rights of people who are mentally retarded or suffer from dementia.)

New Trends in the Measures for the Demented Elderly

The Third Investigative Committee on General Measures for the Demented Elderly then took a new tack as it looked forward to the twenty-first century. Its report was particularly notable in its call for preventive measures. This first set of suggestions included measures for primary prevention of cerebrovascular dementia and atrophy; secondary prevention in the form of early detection and early treatment, including checkups, therapy, and care; and tertiary prevention, which consisted of halting mental deterioration and providing a stable way of life.

The second set of suggestions had to do with overall public health, medical, and social welfare measures for care management. Here the focus was on keeping the patient's needs and desires in view while conducting consultations, examinations, and evaluations and modifying services accordingly. The third set was concerned with having the public health and social welfare sectors provide carefully thought out in-home and institutional services, with emphasis on the cooperative homes that would be established in the future. Moreover, since care in the community requires the participation and cooperation of local residents, the report also urged the establishment of oversight networks, an SOS patrol system, and a system of peer counselors.

New Issues in the Measures for the Demented Elderly

The fourth set of recommendations proposed expanding "STEP," which previously concentrated on financial maintenance and management, into a system that provides overall support for everyday life. Also included was a proposal for a complaint processing system for people who are dissatisfied or have grievances about the services provided by local governments or about the treatment of the elderly. In addition, the Committee proposed the introduction of an ombudsman system to handle complaints of human rights violations, such as inappropriate services or abuse.

The fifth set of recommendations proposed a new type of institution, one not seen much elsewhere in the world, combining social welfare and medical facilities for senior citizens. The main function of these combined institutions would be comprehensive care for the demented elderly, including consultations, medical checkups, therapy, nursing, and caregiving. The Committee suggested that these and other efforts should be informed by the research into aging carried out at the Tokyo Metropolitan Institute of Gerontology.

Thus since 1980, the Tokyo Metropolitan Government has set up three study groups focused on the demented elderly and has looked into a number of special measures for handling the problems of aging. It now has an extensive menu of options for cognitively impaired older people. These days, the main emphasis is on respecting the human rights of the demented elderly, maintaining their independence as much as possible, and treating them as full members of the local community. Service providers are supposed to concentrate on employing scientifically valid means of maintaining each patient's quality of life through care in the local community.

We face the pressing question not only of how to provide services and institutions close to home, but also how to publicize information on the quality and nature of these services. It is difficult for the demented elderly to select services on their own, and we need third-party individuals and organizations to act as advocates for older people who cannot protect their own rights, including the right to privacy. With recent reports of abuse and other violations of human rights, we need oversight mechanisms for preventing these problems and rescuing elderly victims from undesirable situations. At this juncture, the national government appears to be moving toward setting up the legal basis for an adult guardianship system. This and other trends bear watching by everyone concerned with the care of the demented elderly.

Further Reading

Miura F (1992) A study of policy on social welfare—welfare policy and welfare reform in Japan (Shakai fukushi seisaku kenkyu-Fukushi seisaku to fukushi kaikaku). National Council of Social Welfare, Japan

Miura F, Karasawa A (eds) (1994) Caring for dementia (Chihoushou o kaigosuru). Asahi, Shinbunsha

Achieving Quality in Institutional and Home-Based Long-Term Care

YASUO TAKAGI

Key words: Care management—Quality of long-term care—Financing problems of long-term care

The scale of elder care in Japan began to increase exponentially with the legislation of free medical treatment for the elderly in January 1973. At the same time, a disproportionate emphasis came to be placed on medical treatment, as opposed to health maintenance and social services, giving rise to such social problems as the proliferation of low-quality geriatric hospitals and overmedication and overtesting of elderly patients. For this reason, the government legislated the Health Care Act for the Elderly in 1983 with the aim of ensuring appropriate care for the elderly and stable funding for such services. However, the legislation failed to come to terms with the issue of long-term care for the bedridden, those afflicted with Alzheimer's, and other elderly patients in need of extended nursing care. Recently, the government decided to address the problem by establishing a system of national long-term care insurance to go into effect in the year 2000.

During each of these phases in the evolution of elder care, attention was focused on establishing cooperation and coordination among health, medical, and welfare services. Yet because of the speed at which Japanese society is aging and the obstacles to sufficient funding, Japan failed at each point to establish an adequate comprehensive system of elder care embracing home-based and institutional care. I would like to examine what sort of solutions the planned system of care insurance holds in store and consider some of the issues they raise in terms of ensuring the quality of institutional and home-based long-term care.

The fundamental problem with long-term care in Japan is the inadequacy of social services available for either home-based or institutional care of elderly patients requiring extended nursing. The question of how to provide both the necessary support for families caring for their elderly in the home and the necessary institutional facilities for terminal care is a major issue facing this nation. According to 1995 statistics, of the 18.28 million people over 65 in this country, a full 4.9% were undergoing nursing at home, while only 1.2% were in residence at special nursing homes, and only 0.5% were in convalescent centers known as health care facilities for the elderly. Meanwhile, the percentage undergoing long-term hospitalization, meaning 6 months or more in a hospital or clinic, was 1.6%, roughly the percentage of those using nursing homes and health care facilities. Another 2.3% were hospitalized for periods of less than 6 months. When the last two figures are added together, it becomes apparent that the bulk of institutional care for the elderly is handled by hospitals and clinics, that is, medical facilities.

Elder care today is scattered among distinct health, medical, and welfare facilities. The institution of long-term care insurance will increase the number of appropriate facilities for elderly individuals in need of nursing. At the same time, it will boost social support services for elderly individuals and their families to enable more people to continuing living independently at home even after they come to require nursing care.

Three things are necessary to ensure quality in home-based and institutional services under the new care insurance system. First, we must draw up good care plans based on systematic and objective assessments to ensure that institutional care and home-based care are provided in an appropriate manner. The new LTC insurance system will cover not only institutional care but also, for those living at home, visiting nurses, visiting and live-out physical therapists, and periodic visits by doctors to monitor and guide home-based care, as well as "home helpers," home bathing services, adult day care, and respite care. It will be necessary to ensure that all these services meet the needs of the elderly individuals they serve from the standpoint of their physical capabilities, general health, and level of family support. To this end, the various professionals involved in home care—nurses, public health nurses, doctors, social workers, home helpers, and so forth—will have to conduct an objective and comprehensive on-site assessment to determine the type and level of services required in each case. It will then be necessary to draw up a care plan on the basis of this assessment, taking into account immediate requirements as well as the potential for further deterioration in physical capacity, so as to ensure quality care. Japanese researchers are studying MDS and RAPs in institutional care and MDS-HC and CAPs in home-based care, and the results of this research should be applied to the new LTC insurance system.

Second, we must grapple with the problem of ensuring that reimbursements accurately reflect the costs of elder-care services, which the medical and welfare communities cooperate to provide. To maintain quality, it is important to establish a fair and accurate fee schedule for services provided by various specialists. If reimbursement of costs for services provided to elderly individuals in need of a high level of care is too low, then the providers of institutional and home care will naturally be reluctant to accept such individuals. The insurance system must reimburse in such a way as to realistically cover the costs for each of the services involved, taking into account the salaries for the various professionals involved, as well as such common expenses as meals and fuel. As this fee schedule will be used by the providers of institutional and home care as a key tool in managing the costs of administration, services, and personnel, a fair and reasonable schedule will be essential for ensuring the quality of these services.

Third, the new system must respect the position of the users, or consumers—that is to say, the elderly individuals receiving care and their families. Beginning with the assessment phase, care managers must listen attentively to the views of the individual and the family regarding his or her care needs and judiciously incorporate the views of the users/consumers when drawing up a care plan. Because publicly supported care for the elderly in Japan has generally been regarded as a matter of institutionalizing individuals for their own "protection" or taking "measures" to correct an untenable situation, the users/consumers have had little awareness of their own rights. Moreover, in this country, where the concept of care management is largely unknown, there are concerns that services will be rendered on the basis of what benefits the provider instead of what benefits the recipient. For this reason, the system should require periodic reassessments and reviews of the care plan to determine changes in the recipient's needs and in the services required. It is also important to institute a system for evaluating the quality of services, including an independent agency to evaluate the providers of institutional and home-based care.

Further Reading

Takagi Y (1993) Adoption of inclusive fees in geriatric hospitals and changes in cost and manpower (Roujin byouin ni okeru kaigoryoku kyouka to hiyou, manpawaa no henka). Kikan Shakai Hosho Kenkyu (Social Security Studies Quarterly) 28(4)

Takagi Y (1996) Increases in medical costs resulting from an aging population and issues in health care policy (Koreika ni yoru iryohi zoka to iryo seisaku no kadai). In: Iryou Hoshou to Iryou hi (Health security and medical costs). Tokyo, University of Tokyo Press

The Role of Housing in Long-Term Care for Old People

AGNETA MODIG THAM

Key words: Housing for elderly people—Design—Finance of housing

"Good housing conditions at costs affordable to all citizens" is one commonly formulated main aim of most countries' housing policies. For old people this general aim is of special significance. It means that we, until we are really ill or severely handicapped, have the right to live in our own home and that this home should be accessible and equipped at standards that allow us to live there even when we become older and weaker.

The role of housing policy in LTC is first of all to provide enough housing (a number of dwellings that fit the real needs of the population). Second, housing policy should support that these dwellings are designed and equipped at standards that make it possible for older and weaker persons to continue living in their dwellings so long as they themselves wish. Third, housing policy can by different economic means ensure that the costs of housing will be appropriate to what the elderly can afford.

In Sweden, these fundamental aims of housing policy have guided the outlay of various housing policy means during the last decades. A combination of economic/financial means with physical planning and building regulations has been used. The result of which now is that an overwhelming majority, 92%, of the elderly (more than 65 years of age) are living in their own, private homes. Most of these households do live independently and manage perfectly well all by themselves. In some cases home help service is given by the municipal social service to assist the aged person with cleaning, cooking, shopping, washing, and personal hygiene. Medical treatment at various levels can also be given to the elderly in their homes. The role of housing policy has here been to ensure that the dwellings generally are constructed and equipped in such a way that they allow for both the accessibility and treatment of weaker, aged, handicapped, and, for example, wheelchair-bound persons.

With growing weakness or illness, the need for more specialized and around-the-clock service grows. This requires a supply of special types of housing for elderly people. As the needs can vary quite a lot between different individuals, it is important that the housing policy stimulates a supply of different types of housing for the elderly. In 1994, altogether about 135 000 people in Sweden were living in various forms of special houses for old-aged people; this included 20% of all Swedish residents aged 80 and over. There is a range of growing care and service given in the various types of special housing, from the so-called service houses and old age homes to nursing homes and group dwellings up to home nursing and hospital care.

When coming to these kinds of special housing, the role of housing policy is twofold, and in both aspects the municipalities play an important role together with the State. The first aspect is that according to the Swedish law every municipality is responsible for the provision of housing adapted to the needs of the inhabitants. They are especially required to look for the needs of aged and disabled people. This means that the municipalities must do special investigations, and have adequate plans and planning for housing provision for the weaker elderly. So the municipalities collect facts and knowledge, do close follow-ups, and continually revise the plans to reflect actual changes.

The second aspect of the housing policy concerns the financing of the construction of dwellings for the elderly. It might be easy to tell how much elderly housing is needed, but that is of little use if no one can pay for it. There are general housing subsidies given by the state to facilitate these investments, like all other housing investments. There have also been targeted subsidies, varying from one time to another, aiming at enlarging the supply of some special type of housing for the elderly. For example, in the late 1980s there was a shortage of the new form of so-called group dwellings. The Swedish state then decided that the municipalities during a 5-year period could get an extra subsidy for every new group dwelling that they constructed. Likewise, special subsidies are given to facilitate the adaption of ordinary dwellings to special needs. Additionally, means-tested housing allowances are also given to individual households to support the demand/consumption of housing.

To summarize, my main conclusion is that for the great majority of aged persons who want to and are able—with some help—to live in their own homes, the housing policy is a central issue to solve their LTC. For the smaller part of the elderly, who need adapted or specially designed dwellings, the housing policy is working together with social policy to fulfill the needs of decent housing together with decent social services and medical treatment.

Balancing Institutional and Home and Community-Based Care

JOSHUA M. WIENER

Key words: Nursing homes—Home care—Balancing care—Cost control—Financing

One of the most important policy issues in designing a long-term care system is the balance between institutional and home and community-based care. Decisions about financing and coverage will greatly impact what services are provided and where. In considering this policy issue, at least three questions should be considered. First, what do we mean by "institutional" and "home and community-based care"? Second, what should be the share of public funding that goes to institutional services and to noninstitutional care? Third, what are some of the financing barriers to expanding home and community-based care?

Although the answer to the first question would seem obvious, one of the most notable recent policy developments in the United States has been the expansion of less rigid and institutional residential settings. These facilities, known by a wide range of names including assisted living facilities, adult foster care, and community-based residential facilities, potentially offer more homelike settings with greater personal autonomy and lower costs than nursing homes, while capitalizing on the economies of scale that are inherent in institutional settings. In the United States, the state of Oregon has been the most aggressive in promoting this strategy. Thus, the bright line between institutions and home and community-based services that has characterized long-term care policy in most countries is becoming dimmer, raising questions of how to deliver needed services to disabled people regardless of their residential setting.

The second question, which has dominated policy debates in long-term care, is the allocation of resources between the two broad types of services. There is little doubt that the vast bulk of public long-term care expenditures in almost all countries is for institutional rather than noninstitutional services. For example, in the United States, only 10% of long-term care expenditures for the elderly through the Medicaid program, the federal state health care program for the low-income population that is the main source of financing for long-term care, are for home and community-based services. While there is a policy consensus across countries that more should be spent on home care relative to institutional care, there is no agreement on what the appropriate balance should be.

The emphasis on home and community-based services derives from two factors. First, in many countries, most disabled elderly live in the community and receive only unpaid, informal care from family and friends, often imposing a great burden on these caregivers. Home care is a way to provide services to the disabled population in the setting where they want to be; few elderly want to enter nursing homes.

Second, the most persistent dream of long-term care is that the expansion of home care and other nonmedical residential long-term care services would reduce overall long-term care expenditures. The fundamental hope has been that lower-cost home care would replace more expensive nursing home care. However, within the United States, there is a substantial research literature suggesting that expanding home care is more likely to increase rather than decrease total long-term care costs.

Older people's aversion to nursing homes explains this increase. Given a choice between nursing home care and no formal services, many elderly people will choose nothing. But when the choice is expanded to include home care, many will choose home care. Thus, the costs associated with large increases in home care use more than offset relatively small reductions in nursing home utilization.

Observers outside of the United States tend to be wary of generalizing from the American research literature. Some believe that home care can be more cost-effective if services are better targeted to persons who would otherwise be institutionalized and if proper levels of services are provided. In addition, some countries (and states in America) have a conscious policy of halting or constraining the growth of institutional services, in essence forcing a substitution of home care for institutional care. In the United Kingdom, fixed budgets to cover both institutional and non-institutional care appear to have reduced modestly the use of residential facilities. In addition, within the United States, the apparent success of Oregon in substantially reducing nursing home use through the aggressive expansion of home care and nonmedical residential services has led some to argue that their experience could be duplicated elsewhere.

Despite a general policy commitment to home and community-based services, many barriers remain. To the extent that resources are limited, public programs are likely to allocate resources first to persons with the most severe disabilities and who lack family supports. If governments make such an allocation decision, which is a rational one, then funds will be used primarily to support nursing home care and only secondarily home- and community-based services.

From a financing perspective, the other major barrier is the fear that utilization of home care will increase uncontrollably if offered as an open-ended entitlement. As noted previously, most disabled individuals who qualify for long-term care do not receive any paid care. And, while the reluctance of the elderly to enter nursing homes limits use even when coverage is available, the same cannot be inferred for home care. The inherent desirability of less medically oriented services, such as housekeeping, meal preparation, shopping, and chore services, means their use is likely to increase much more substantially if offered on a wide-scale basis. Moreover, disabled individuals and their caregivers are likely to have great control over utilization, since social, rather than strictly medical, considerations are often the key determinants of long-term care use.

In conclusion, probably no other policy issue in the design of a long-term care system is more fundamental than determining the proper balance between public spending for institutional care and home and community-based services. Complicating this debate are new developments in service delivery that blur the traditional distinctions between institutions and home and community-based care. There is a broad policy consensus that countries should spend more on home care than they are now, but there is no agreement about what the appropriate mix should be. Limited resources and fear of exploding costs have also constrained the provision of noninstitutional care.

Further Reading

Wiener JM, Hanley RJ (1992) Caring for the disabled elderly: there's no place like home. In: Shortell SM, Reinhardt UE (eds) Improving health policy and management: nine critical research issues for the 1990s. Health Administration Press, Ann Arbor, MI, pp 75–110

Weissert WC, Henrick SC (1994) Lessons learned from research on effects of community-based long-term care. J Am Geriatr Soc 42:348–353

Kane RA, Kane RL, Illston LH, Nyman JA, Finch MD (1991) Adult foster care for the elderly in Oregon: a mainstream alternative to nursing homes. Am J Public Health 81:113–1120

Summary of the Discussion for Session 4

1. The Scandinavian Focus on Housing and Care in the Community

The Scandinavian experience indicates that a focus on housing policy with a universalistic base—all citizens are entitled to housing according to their individual needs—can take care of many problems of care for the elderly as well. Along with designing or reconstructing the housing itself to be appropriate for frail older people, the key is getting the right amount of services.

To shift policy from institutions to housing-based services requires targeted policy. In Denmark, LTC policy was given to the Housing and the Social Affairs Ministries, with the Ministry of Health excluded. In the early 1980s further construction of nursing homes was halted, and financial incentives were offered to municipalities to build special housing for the elderly as well as to develop in-home services. At first younger people felt threatened by not having nursing homes available for their parents, but they have gotten used to it.

It is widely believed that investment in community-based services can save money by helping to prevent or postpone institutionalization. Or at least, that will be the case if maintaining the dignity and quality of life of frail older people and their caregivers is an important national goal, and people are therefore seen as entitled to a relatively high level of services. If the only policy goal is cost-cutting by preventing institutionalization, then additional community-based services will probably cost more than they save.

According to Scandinavian participants, individual choice is paramount: the principle is that "anyone should be able to live at home as long as he or she wishes." Participants from other countries mostly thought it should be "as long as is practical."

Of course, even Scandinavia does not have an unlimited supply of special housing or services; indeed, the constraints imposed recently may have been felt more keenly there than for example in the UK (where people are used to cutbacks). Because demand exceeds supply, the preferences of individuals must be discussed with local officials, and some prioritization and queuing is required. The substantial variation of old age provisions among local governments within Sweden indicates that they have a lot of discretion over their own programs, and individuals must fit into these frameworks.

Scandinavia is something of a special case, with small, rather homogenous populations (although less so than Japan) and a strong commitment to equality. Scandinavian nations have been willing to spend between 2% and 3% of GDP on long-term care, double or more than elsewhere. One Japanese participant was led to say that although participants had agreed there is no "ideal system" for long-term care, Sweden and Denmark were pretty close to one (and Japan was still far away). Among policies for the elderly in Japan, targeted housing is particularly far behind and needs much more emphasis. As well as the Scandinavian example, the British program of offering subsidies to local nonprofit organizations to build senior housing is worth a look.

In Japan, because of changes in the family, the proportion of long-term care provided in institutions rather than at home has been increasing, at least until quite recently, when formal community-based services have become much more available. Japan does still have a lot of relatively heavy-care people at home and light-care people in institutions. In most countries the balance of LTC policy has been changing in the direction of more community-based care, away from institutions. One result now quite apparent in the Netherlands is that those who remain in nursing homes or other institutions are increasingly frail (including many dementia cases), with low turnover, and the task of providing care for them gets harder and harder.

2. Fairness in Deciding on Services

The social insurance model of LTC, in Germany and Japan, decides on eligibility for benefits strictly on the basis of physical and mental condition, without taking into account the individual's income or even the family situation and whether informal care is available or not. The choice of services is left to the consumer. This is a major change in pattern for Japan.

The social insurance model is one type of fairness, but it can be argued that the British or Scandinavian model, in which the individual negotiates for services with a local official, can be more fair in terms of outcomes; e.g., the person with no informal care available is given more services than the one who has family available, so that about the same level of well-being is achieved. Also, the official may have a better idea of which services to choose. Such a policy, and for that matter means-testing as well, can be more efficient in the sense of not "wasting" scarce resources on those who need them less. In designing programs, it is a value judgment of how to balance these notions of fairness, and to balance equality versus efficiency.

3. Care Managers

The role of "care manager," a hot topic in Japan, varies a lot from country to country. For one thing, the care manager may "work for" the client, a service provider, or the government. Whoever the formal employer may be, the job usually involves balancing conflicting interests among clients, providers, and society as a whole. At a minimum (the "travel agent" model), the care manager must be able to provide accurate information about available services and offer advice about the appropriate "package" for the individual client. A good care manager will also monitor changes in the client's situation, and will check on the quality of delivered services. Moreover, by gathering and systematizing information on underfulfilled needs among individuals, the care manager may even help to stimulate the development of new services.

The nature of service provision, by many small single-function providers or by large and integrated "one-stop shopping" providers, must structure how care management should work. To the extent that service provision is fragmented, it is important that the care manager be oriented toward serving the client's interests, toward active "networking," and toward quality control. If most services come from a large, integrated provider, the care manager will almost inevitably work there (since the provider would not tolerate interference from an "outsider"), and should emphasize coordination. An external mechanism to monitor quality would probably be needed in this situation, particularly if there is no real competition between integrated providers.

Although the "independence" of care managers is an ideal, there are doubts whether it can be practical. The Dutch tried to move some care management functions from providers to "independent experts" but had difficulty in finding any. Japan will need some 40 000 care managers rather quickly and there seems no alternative to having them be employed by providers (although when carrying out eligibility assessments and writing care plans, they will be working as temporary officials of the local government, with the concomitant legal responsibility).

A worrisome possibility is that care managers who work for a provider will be serving its interests, as by preferentially recommending its kinds of services. Some participants hoped that professional norms or ethics would develop to encourage a client orientation and an arms-length relationship to providers (even when care managers are employees). Also, it is possible that the procedure for reassessing client eligibility can serve as some check on care manager performance—the independent committee that decides on eligibility and level could become something of a watchdog, particularly when the client's condition seems to have deteriorated.

In any case, it is important that clients have some choice among care managers, including access to information about who is available, and also have the ability to fire one they do not like. It is also important to avoid the situation not uncommon in the United States in which the care management function uses up half or more of the resources available for services, or care managers try to coordinate services that do not exist. Some participants expressed concern about the adequacy of the new Japanese system for care managers. It has very loose requirements about previous experience, will pick people on the basis of a multiple-choice exam, and will offer only 6 days of training for both assessment of eligibility and writing care plans.

It is important to clarify the goals of care managers, and of the various programs and of long-term care policy in general. Only if these are specified concretely can we get some sense of how well they are being accomplished.

4. Service Development

A variety of specific services important in long-term care were suggested, again drawing heavily on the Scandinavian experience. Home help, including personal care and household work, is often the key. For many people even a fairly small amount of these services is enough to keep their independence. When people know they will later have access to extensive services (as a "right"), they are likely to be happy to get by with little help while they can.

A recent emphasis in Scandinavia is group rather than individual activities, including small group homes for demented people as well as using day care for social interaction as well as long-term care. Mobilizing volunteer assistance skillfully for "softer" aspects of care can be very effective. Volunteers have been a big topic in Japan, perhaps with insufficient attention to what they can do best (generally not heavy care, which should be done by paid people). Excellent volunteer programs require good training and, usually, professional staff for coordination.

In Germany, the detailed fee schedule for LTCI mainly reimburses for hands-on care, and softer care such as shopping with the client or just talking seems to have suffered. In the new Japanese LTCI system, it seems at least possible that local grassroots organizations would be able to provide care giving services with hired staff, and use some of the fees for professional management of volunteers to supplement those services for the same clients. Particularly when based on genuine neighborhood ties, such an organization could have a real competitive edge among service providers.

In Japan, a major current deficiency is that there are very few professional social workers, and no real posts for most of those who do have the right training. There is also not much coordination between medical and social personnel, although awareness of the "team approach" is growing.

Good programs will need effective quality control, including modern information systems, and systematic measures of objective and subjective outcomes for patients.

Letter From Tokyo Public Long-Term Care Insurance in Japan

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A public long-term care (LTC) insurance program is likely to be introduced to Japan in the year 2000. A consensus on the need for more LTC resources in the rapidly aging society and dissatisfaction with the current system are some of the factors that have contributed to its introduction. Half the costs will be paid by premiums that will be levied on all those older than 40 years, and half will be covered by general taxation. The insurer will be the municipalities with a pooling mechanism at the national level to balance the differences in their demographic structure. The benefits will include institutional care, respite care, day care, home help, visiting nurses, and loan of devices. Eligibility status will be classified into 6 levels that will be determined by assessment of functional and cognitive status. However, there are few mechanisms to limit benefits and contain costs. Problems also exist in the design of the eligibility classification and in the assessment instrument. The proposed LTC insurance system highlights the need for defining what should be included in a "basic package" of LTC as an entitlement for every citizen, for an organizational mechanism and an assessment instrument to deliver services efficiently and equitably, and for physicians to work outside the traditional medical model. To what degree the Japanese public in general, and physicians in particular, is willing to deal with these issues is a challenge for the 21st century.

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The author has been commissioned by the Japan Medical Association Research Institute to develop an alternate method of assessment and classification for the long-term care insurance program.

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Since the publication of this article, the public long-term care legislation has passed the Diet on December 9, 1997, so that it will be implemented as planned from April, 2000.

The need for access to long-term care (LTC) in an aging society is self-evident.[1] However, few countries have been successful in developing a model LTC system. Why should this be so? The first reason may arise from a lack of active support from the general public, which, in turn, could be ascribed to the psychological reaction of denial. When faced with unpleasant realities, such as the debilitating conditions requiring LTC, a common response is a denial that such conditions exist.[2] The second reason is fiscal concerns by the government. There is concern that if LTC becomes an entitlement, costs will escalate because of an explosion in service demand. The third reason lies with the medical profession. Physicians do not necessarily oppose LTC but, given limited resources, would generally prefer that resources be invested in acute care. Long-term care has not been an attractive field for physicians because dramatic improvements seldom occur and because of the concern that physician autonomy would be encroached by nurses and social workers.[3]

These fundamental problems have not been solved in Japan. Yet, the very fact that a public LTC insurance act has passed the Lower House in May 1997 and is also likely to pass the Upper House (which reconvened in September 1997) is an indication that the country has managed, at least initially, to overcome these hurdles. When this legislation is enacted, Japan will be the third country to establish public LTC insurance after the Netherlands (which has gradually expanded LTC coverage under a catastrophic insurance program first introduced in 1967[4]) and Germany (which started with home care in 1995 and extended to institutional care in 1996).[5] Thus, Japan would be embarking on largely uncharted territory and should therefore provide lessons for other countries.

Background

Universal coverage was achieved in 1961. Two thirds of the population is insured through the employment of the household head and one third through the municipalities where they reside. Although there are minor differences in premium rates and benefits, payments to all physicians and health care institutions are determined by a uniform fee schedule set by the central government. Tight control on the fees has kept health care costs at a relatively low level; its ratio to the gross domestic product was 7.3% in 1993. Health care is provided predominantly by the private sector with most of the hospitals being freestanding and physician owned. However, the large medical centers tend to be in the public sector or attached to universities because they are able to receive subsidies to offset the deficit arising from their low fees. Two thirds of the physicians are employed by hospitals and one third are in office-based private practice with no hospital privileges. Patients, regardless of their plan, have unrestricted access to virtually all physicians without an initial referral.[6]

Because of an increase in longevity and a decrease in birth rates, the proportion of the population aged 65 years and older doubled from 6% in 1960 to 12% in 1990, and it will double again to 25% by the year 2020.[7] Both the speed and scale of this increase are unprecedented. These dramatic demographic changes will require a major restructuring of the health and social service sectors.

Caring for the elderly is already perceived as being a major social problem. Japanese society's traditional norms place the responsibility of caring for the elderly on the daughter-in-law. Despite significant increases in the proportion of those living alone or with a spouse, the majority of the elderly still live with their children.[8] Within the household, there is still considerable pressure for the daughters-in-law and spouses to take on virtually all the burden of caring. In addition, because of the advances in medicine, those with debilitating conditions are now able to survive for quite long periods, so that the caring burden may be for a prolonged time. (A major survey conducted by the welfare department of the Tokyo metropolitan government shows that, of those who are bedridden, half have been in that state for more than 3 years.[9]) With increased longevity, many of the daughters-in-law are now in their 60s, some of them requiring care themselves. At the same time, an increasing share of those who are younger are now working outside their homes, while the housing situation has not improved to an extent that would ensure adequate living space for the elderly.

Japan's formal social support system has remained inadequate, and, moreover, largely targeted to those with low income and lacking in family support. To obtain home-help services or to be admitted to a nursing home, one must apply to the municipal welfare office and undergo a means test. There are few privately funded services, partly because of cost and partly because of the social pressure for the family to provide care. As a consequence, those who are caring for family members are frequently placed in desperate situations that have been well publicized by the media. The public's sympathy with their plight has been instrumental in generating support for a new system of financing LTC and in overcoming the denial for the need of LTC. According to a general opinion survey conducted by the government in 1995, 82% were in favor of its introduction.[10]

The hurdle of fiscal containment has at least initially been successfully crossed because the government had already committed itself to dramatically increase funding for LTC. This decision was made in 1989 to sweeten the effect of introducing an unpopular consumption tax and win the support of women voters.[11] The government's Gold Plan (Ten Year Strategy on Health and Welfare for the Aged) set goals to increase nursing home beds, home care services, and sheltered housing. These goals were revised upward in the 1994 New Gold Plan and increased funding has been made available in the form of grants and subsidies despite the difficult fiscal situation. In total, more than 9 trillion yen (US$80 billion) will be invested during the 10-year period that started in 1989.[12]

The LTC insurance system has also been presented to the public as a way of lowering health care costs so that the net effect of its introduction would not be so costly. As a result of making health care "free" to the elderly in 1973 (before 1973 they had to pay a 50% co-payment), LTC, especially institutional care, came to be provided through health insurance. In the face of an absolute shortage of formal home care services or nursing homes, the most readily available option to the overburdened families became hospital inpatient care. (Three quarters of the population 65 years and older who are institutionalized are in hospitals.) In turn, the hospitals, especially the physician-owned, small to medium ones, have welcomed elderly patients to fill their beds (many were emptied when patients turned to the large medical centers for their acute care).[13] As a result, nearly half the hospital inpatients at a time are older than 65 years, and approximately one third of these have been hospitalized for more than 1 year.[14] Some hospitals are therefore de facto nursing homes, while others provide both acute care and LTC. In absolute terms, the number of the elderly 65 years and older who are hospitalized at one time has grown 10-fold from 1963 to 1993.[14,15]

However, neither hospitals nor the reimbursement system was designed for the purpose of providing LTC. In the 1970s and 1980s, there were accusations of overmedicating, excessive use of laboratory services, inadequate staffing, and ill treatment of elderly inpatients.[16] The government responded in 1981 by gradually restricting the billing of drip infusions and laboratory tests, and in 1990 the government offered hospitals an option to be paid at a per diem rate inclusive of drugs and diagnostic test fees if they had a high ratio of elderly patients. In addition, a new type of intermediate health care facility, health facility for the elderly (HFE), was established in 1986 for the purpose of facilitating the discharge of hospital patients to the community.

Such efforts have so far had limited effects. Although the absolute number of nursing homes and HFE beds have expanded under the Gold Plan, there is still heavy demand so that the waiting time for admission to the nursing homes, which are the only facilities designated to provide extended care, runs into several years in the metropolitan areas. The percentage of the population aged 65 years and older that is institutionalized is 6% (a slightly higher share than in the United States).[13] The HFEs have not been successful in their original objective, in that nearly half their residents stay more than 6 months.[17] A common problem to all LTC facilities is that, with the exception of the hospitals still paid by fee-for-service, reimbursement is set at a flat rate. This is probably the main reason Japan's LTC facilities appear to have the largest ratio of patients requiring minimal care in the world.[18] In the face of these difficulties, the government hopes to reform the LTC system by formally unifying the financing and management of LTC facilities (now divided between health and social services) under the new LTC insurance program and by expanding home care.

Despite the fact that one of the goals for introducing the LTC insurance lies in containing health care costs, the medical profession and the Japan Medical Association in particular has declared support of the public LTC insurance.[19] One reason was that as long as LTC remained an integral part of the health care insurance system, it would be difficult to increase resources for acute care, and transferring LTC to the new insurance system could result in a windfall of released funds. Another reason was that the per capita number of physicians is projected to double, from 179 per 100 000 in 1990 to 360 per 100 000 in 2025,[20] while the number of hospital beds will remain capped by legislation. Thus, the expansion of LTC could provide a new and much needed additional field for physicians, especially if they take a leading role. With these facts in mind, the Japan Medical Association has successfully lobbied to explicitly include the statement that medical care, along with social services, will be provided in the proposed legislation for the public LTC insurance and has since been actively promoting the need for physicians to become involved in LTC.

The Public LTC Insurance Program

The description given below is as the proposed act currently stands in September 1997.[21] Many of the details remain to be decided, but the essential framework is not likely to change.

Funding and Insurers

Half of the funding of the public LTC insurance system will come from mandatory premium contributions and half from general taxation (of which the central government will pay half and the remaining half will be equally split between the prefectures and municipalities). Premiums will be paid by everyone older than 40 years: including payroll deductions for the employed (with the employer expected to contribute half), health insurance premiums for the self-employed, and deductions from pensions for the pensioners. The monthly payment will initially be 2500 yen (US$20) with a 10% co-payment at the point of service provision. Both would be subject to deductions or waivers for those with very low income.

The insurers will be the municipalities (cities, towns, and villages). The municipalities became the insurers because they are the carriers of the health insurance programs for the self-employed and pensioners, and they are responsible for the provision of social services. Because there are wide differences in their age range, there will be a pooling mechanism at the national level to allocate resources equitably. (Premiums from those in the age range of 40 to 64 years will be pooled and distributed to each municipality to equalize its burden.) In addition, the prefectures will provide financial and logistic support should the municipalities run into difficulties.

Benefits and Eligibility

The benefits will be institutional care (including respite care) in geriatric hospitals and units of general hospitals designed for the elderly, HFEs, nursing homes, and group homes for those with dementia. It will also include home-help services, most visiting nurse services, day care, loan of devices (such as wheel-chairs), and financial assistance for improving the home (such as making it accessible to wheelchairs). Physicians' services will generally be included in the inclusive payment made for institutional care (note that physicians are either directors or employed by hospitals and HFEs). In home care, a monthly medical management fee will be paid to the attending physician, which would cover the cost of 1 home visit. However, ambulatory care in physicians' offices and hospitals, physicians' extra home visits, as well as acute care in general will continue to be covered by the current health insurance system. Payment to institutions will be regulated by a fee schedule, similar in design and concept to the one that has been long been used in health insurance.

All residents of Japan aged 40 years and older who have paid and are paying the LTC premiums would be potentially eligible. However, the eligibility status would differ according to age. Those aged 65 years and older will be automatically eligible, but those between 40 and 64 years old would only be eligible if their condition is a result of an "age-related disease." Exactly which diseases fit these criteria has not yet been determined, but it is likely to be limited to Alzheimer disease and cerebrovascular stroke.

The assessment for the eligibility status can take place either in the community or in institutional care settings. Prior hospitalization would not be a condition for being assessed but patients will be expected to continue to require LTC for at least 6 months hence. Reassessment will be periodically made every 3 to 6 months after commencing LTC. The on-site assessment will be performed using a 71-item form that measures activities of daily living (ie, functional status such as eating, toileting, dressing, and so on), cognitive status, and sensory status (visual and verbal), but not the degree of medical supervision. Note that the extent of informal care available is not taken into consideration in determining the eligibility status. This means that the provision of formal services will become an entitlement irrespective of how much family support the patient may have. In this respect, Japan has adopted the standards set by the Scandinavian countries, which place the ultimate responsibility of caring on the state, rather than the family, as a reaction to the existing overdependence on informal support.

The assessment forms will be processed by computers that will automatically, though tentatively, classify individuals into 6 levels. These 6 levels were derived from statistical analysis using care time, obtained from time studies, as the independent variable.[22] Based on this computer-generated classification, the municipal committee, made up of professionals (including physicians, nurses, social workers, dentists, pharmacists, and others), will decide if this initial classification is appropriate after obtaining further information from the qualitative part of the assessment and the opinion form from the attending physician. The 6 levels will determine the maximum amount that would be paid by the public LTC insurance. For example, if the eligibility level is determined to be class 2, then that individual would be able to obtain benefits up to approximately US$1000 per month, while for the most severe level, class 6, it could be as much as $4000. However, there will be no direct cash benefits to family members so the money can only be used for purchasing LTC services.

Care Management

Care management, ie, deciding how to best use the money to purchase an appropriate package of services, will usually be performed by care managers. Care managers will provide advice to patients in planning their care, and all plans must be approved by the patients or their families. In addition, patients have an option of purchasing services on their own initiative. Patients can also ask for alternate care plans that include additional services, which can be purchased wholly out-of-pocket if they feel that the care plans remaining within the financial limits set by their entitlement level are inadequate.

To train as many care managers in as short a time as possible, and to lower the entry barrier, anyone who has had a minimum of 5 years of experience in LTC would be eligible to sit for a relatively simple multiple choice examination to be held in each prefecture. Those who are successful will undergo 6 days of training divided into 2 parts with a month interval in between, after which they will be given a certificate.

Potential Problems in Implementation

Different constituents have pursued different objectives in embracing public LTC insurance. While the general public is in favor of the idea, this support might rapidly decline if the costs were to escalate or if the benefits were seen as inadequate. The government hopes that at least part of the increased costs would by offset by decreases in health care costs. Physicians hope to expand their role in the new and rapidly growing field of LTC. Trying to steer a middle ground within this minefield of conflicting interests will be extremely difficult.

The greatest problem is that, to break from the budget-constrained, means-tested approach that has characterized social services and to generate public support for the new system, the government may have gone too far in the opposite direction. For example, one of the much publicized new services that would become available is the 24-hour visiting home-help service, in which home helpers will come to the patients' homes every 4 or 6 hours to change diapers. This would in itself be very expensive to provide but additional costs would also arise because visiting nurse services and home-help services would also have to be provided. The most concerning part is that the government has not yet disclosed how many of those requiring LTC will be placed in each of the 6 categories, which is crucial for validating their cost estimates. Apart from lacking the necessary data of doing so, the government is wary of making the eligibility classification seem like a quota system because they believe it would negate the rationale of displacing the present form of social service provision that is strictly controlled by the budget.

As the new system is currently designed, the eligibility decisions will be made on the basis of individual need without taking into account the fiscal limitations of the municipal LTC insurance fund. The difficulty is that the concept of "need" in LTC tends to be subjective because the wishes of the patient and his or her family are the most important factor in deciding what kind of services should be provided. This situation is quite different from acute care, where the decision is primarily based on the physician's professional judgment. Thus, unless there are explicit mechanisms to objectively limit eligibility, there is a high risk of cost escalation that would have to be resolved by raising premiums and taxes. It is surprising that none of the major actors in the policy arena has raised this crucial issue. Attention has been focused on how the cost burden will be divided (ie, the share of central government to that of the local government, the share of the employers to that of the employees, and so on). Having reached a consensus on the need for a public LTC insurance program, top-level leaders and interest groups appear to be prepared to leave the more important decisions concerning how to limit benefits to the bureaucrats.

The above problem has been exacerbated by the following methodological flaws in the proposed system. The first defect lies in the eligibility classification. As has been mentioned, each level has been defined statistically by the patient characteristics that best differentiated the care time that had been provided. However, each level thus defined does not constitute a meaningful and distinct clinical entity. The only rationale for classifying an individual to a specific level is how he or she was assessed in the 71-item form. Thus, even if municipal committees wanted to provide meaningful input, they would find it difficult to explain why they had to change the eligibility level. In particular, the fact that the degree of medical need is not taken into account in either the 71-item form or in the 6 levels makes it difficult to reflect the opinion of the attending physician. Moreover, the results of the reliability testing for the 71-item form have not yet been disclosed so the objectivity of the assessment remains even more questionable.

The second defect is inadequate attention to maintaining the integrity and objectivity of the assessment process. Under the current plan, the assessment for eligibility status will most likely be delegated to the LTC clinicians themselves. The arguments for doing so were because the municipal authorities lack a trained cadre of public health nurses and social workers, and because they wanted to avoid duplicating the present bureaucratic procedure for obtaining social services. It was also believed that the frontline clinicians would know most about the patient's needs. Moreover, in addition to performing the eligibility assessment, the LTC clinicians would also be responsible for care management. That is, they would be in a position to advise individuals as to how to best spend their entitlement. Although the patient may refuse the care plan drawn by the care manager, since he or she is likely to have limited knowledge of the resources available in the community, most are likely to accept what is offered. Thus, the problem is 2-fold. First, both the LTC clinician and the patient are given incentives to have the patient placed in the highest eligibility level possible. Second, the clinician will develop care plans that result in most of the entitlement money being used to purchase services from that clinician's institution.

The third defect is that patients essentially will be allowed to choose between institutional care and home care, and among the different types of facilities that provide institutional care. Although patients' eligibility level itself will remain the same, to account for the differences in costs among the various care sites, additional amounts of money will be made available if the patient chooses institutional care instead of home care and also if a hospital were to be chosen instead of a HFE or nursing home. The institution may refuse to admit the patient if the amount set by the entitlement level is not high enough to cover his or her costs, which would be a serious problem if there were no alternatives in the community. However, the main problem is that, for the patient, there will be no economic disincentives to choosing the most expensive form of care within the same eligibility category, apart from the 10% copayment.

In addition, other operational issues need to be resolved. One is where to draw the line between the existing health insurance system and the new LTC insurance. The criteria for determining when a patient's condition worsens to the extent that he or she requires acute care under health insurance need to be made explicit. Unless some rules are set, institutions who are in the position to provide both may try to maximize revenue by weighing the advantages of the 2 insurance systems and transferring the patient accordingly. Another is the limitation of eligibility to those with age-related diseases for the 40- to 64-year-old age group. This was a result of a political compromise to keep costs down, but exactly how these diseases are to be defined remains to be decided; no matter how they will be decided, there will always be justifiable grievances from those having diseases not included in the category, since they will be denied benefits even though they have been paying the premiums.

However, despite these major problems, we must realize that ad hoc measures and compromises are inevitable to pass a bill with such an enormous impact. From a perspective of rational policymaking, the course taken by Japan could be severely criticized for paying insufficient attention to the cost implications. However, sophisticated estimates and endless debate based on assumptions that have little substantive grounds in the real world may be equally counterproductive. Moreover, introducing new legislation depends on timing. If the government were to have waited until the completion of the Gold Plan so that the infrastructure for delivering LTC would be more adequate, the opportunity may not have occurred. Thus, although it may seem haphazard, the route followed by Japan could well be the most realistic way for introducing public LTC insurance.

There are some grounds for being cautiously optimistic about the future. While policymaking in Japan in general tends to be ad hoc and lacking in logic or consistency, policymakers are noted for their skill in making adjustments and improvising as events unfold.[23,24] Some of the defects in the present design, such as in the assessment instrument for determining eligibility status, could be remedied by the time the LTC insurance program is implemented. In the short run, payment according to the eligibility level in institutional settings should prevent the admission of light care cases and alleviate the worst defects of the present flat-rate reimbursement. In the long run, one can envision that service delivery would become concentrated to a few competing LTC institutions that will provide the full comprehensive range of services as they build networks or amalgamate. With respect to the problem of determining whether a given medical condition should be covered by the present health insurance or by the new LTC insurance, the Japan Medical Association is proposing that the health insurance system for the elderly eventually be merged with the LTC insurance.[25] Finally, and most importantly, the passing of this legislation would lead to an influx of more resources for LTC that should greatly improve some of the major defects in the present system.

Conclusions

The introduction of the public LTC insurance in Japan raises several general issues that need to be considered globally. The first is that LTC offers a unique opportunity for defining what should be included in the "basic package" as an entitlement for every citizen. While the present Japanese proposal may be too generous, this legislation should force people to think seriously about this issue. For, unlike acute care, where withholding treatment may be a life-or-death issue, in many respects, LTC in Japan is similar to ordinary life, in which it is acceptable that income largely determines one's degree of comfort. Moreover, in the professional aspects of care, such as preventing pressure ulcers, evaluating the quality of LTC would be easier than in acute care because the high-risk groups can be more readily defined by functional status, and the interventions available to improve outcome tend to be less complex.[26] Thus, the conditions for consumers to choose and for market competition to work are more favorable in LTC. For precisely the same reason, the level of LTC that society is willing to provide as an entitlement to its citizens will be a decision that will have to be squarely faced.

The second issue is, having determined the "basic package," how to ensure that this is made available to those who need LTC in an efficient and equitable way. This requires 2 elements. One is an organizational mechanism that balances the available funding to the needs of individuals, which should not be as rigid as a quota system driven only by fiscal considerations, yet not so flexible as to rapidly overspend the budgeted ceiling. The process would also have to be monitored to see that the system is performing as planned. Such care management objectives have been successfully implemented in the various demonstration projects in the United States and the United Kingdom.[27] Whether it can be done at a national level remains to be seen, but similar rigorous procedures must be implemented if the public LTC insurance is to be made sustainable in Japan.

The other requirement is an objective and valid instrument for assessing each individual's eligibility status. Each level should have clinical validity and be defined by assessment items that have been tested for reliability and include the degree of medical need. These are the objectives of an alternate method of assessing and classifying the eligibility level that I have been commissioned by the Japan Medical Association to develop. The assessment will be based on items from the Minimum Data Set—Home Care[28,29] (MDS-HC), developed by Inter*RAI*, an international consortium of researchers and clinicians whose members are the designers of the original MDS being used in virtually every nursing home in the United States and those who have translated and validated the instrument in each of the member 15 countries. The goal of MDS-HC is to provide a useful patient assessment system that will inform and guide comprehensive care planning in the current home care environment around the world. Testing of the MDS-HC in Japan and other countries has shown that reliability scores are as good as for the MDS, despite the more difficult conditions in the community, and its objective to serve as an aid to care planning has also been validated. The reliability of the items and the inclusion of medical aspects would be major advantages over the current assessment form, while the fact that the full assessment can be used for care planning purposes would not only make the process more efficient, but also serve a pedagogic purpose for improving the quality of care.

The third issue is the need for physicians in an aging society to be more prepared to work outside the traditional medical model. For many elderly, especially those older than 75 years, the possibility of achieving a complete cure is low, but the potential for improving the quality of life remains high. At the same time, care of the dying patient will become an increasingly important responsibility of the physician. In Japan, those aged 75 and older made up one sixth of the total number of deaths in 1950, half in 1993, and is projected to be two thirds in 2010.[30] Such demographic changes clearly indicate that the curative role of physicians will be limited. As the Japan Medical Association has stressed, physicians can and should make a major contribution to LTC. Focusing on LTC would lead to more commitment to primary care, another area in which much has been advocated but little has been accomplished,[31] as both emphasize continuity of care, a holistic attitude toward patients, and a team approach.

To what degree the public in general, and physicians in particular, is willing to deal with these issues is a challenge for the 21st century.

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References

1. Organisation of Economic Co-operation and Development (OECD). The policy context. In: OECD. *Caring for Frail Elderly People: Policies in Evolution: Social Policy Studies No. 9.* Paris, France: OECD; 1996:13–31.
2. Ikegami N. Best medical practice: the case of Japan. *Int J Health Plann Manage.* 1989;4:181–195.
3. Clark DW, Williams TF, eds. *Teaching of Chronic Illness and Aging.* Bethesda, Md: Government Printing Office; 1973. DHEW publication (NIH) 875–876.
4. Kerkstra A. Home care in the Netherlands. In: Hutten JBF, Kerkstra A, eds. *Home Care in Europe.* Aldershot, Hampshire: Ashgate Publishing Ltd; 1996:219–244.
5. Alber J. The debate about long-term care reform in Germany. In: Organisation of Economic Co-operation and Development (OECD). *Caring for Frail Elderly People: Policies in Evolution: Social Policy Studies No. 9.* Paris, France: OECD; 1996:261–278.
6. Ikegami N, Campbell JC. Medical care in Japan. *N Engl J Med.* 1995;333:1295–1299.
7. Ishikawa A. Population. In: Miura F, ed. *Illustrated White Paper for the Elderly, 1996* [in Japanese]. Tokyo, Japan: Zenkoku Shakai-fukushi Kyogikai; 1996:32.
8. Okuyama M. Family. In: Miura F, ed. *Illustrated White Paper for the Elderly, 1996* [in Japanese]. Tokyo, Japan: Zenkoku Shakai-fukushi Kyogikai; 1996:48.
9. Tokyo Metropolitan Government Welfare Dept. *Survey of the Lives of the Elderly, FY 1990* [in Japanese]. Tokyo, Japan: Tokyo Metropolitan Government Welfare Dept; 1991:115.
10. Prime Minister's Office. *Opinion Survey of People's Attitude Towards LTC Insurance* [in Japanese]. Tokyo, Japan: Prime Minister's Office; 1995.
11. Campbell JC. *How Policies Change: The Japanese Government and the Aging Society.* Princeton. NJ: Princeton University Press; 1992:245–247.
12. Japan Ministry of Health and Welfare. *Trends in the Nation's Welfare* [in Japanese]. Tokyo, Japan: Kousei Tokei Kyokai; 1996:198–200.
13. Ikegami N, Fries BE, Takagi Y, et al. Applying Rug-III in Japanese long-term care facilities. *Gerontologist.* 1994;34:628–639.
14. Japan Ministry of Health and Welfare. *1993 Patient Survey* [in Japanese]. Tokyo, Japan: Kousei Tokei Kyokai; 1995.
15. Japan Ministry of Health and Welfare. *1963 Patient Survey* [in Japanese]. Tokyo, Japan: Kousei Tokei Kyokai; 1965.
16. Ohkuma K. *Geriatric Hospitals* [in Japanese]. Tokyo, Japan: Asahi Shinbunsha; 1988.
17. Japan Ministry of Health and Welfare. *1995 Report on the State of Health Facilities for the Elderly* [in Japanese]. Tokyo, Japan: Kousei Tokei Kyokai; 1997.
18. Ikegami N, Morris JN, Fries BE. Low-care cases in long-term care settings: variation among nations. *Age Ageing.* In press.
19. Interview with Dr Tsuboi, President, Japan Medical Association. *Nichi (JMA) News.* January 20, 1997:1.
20. Japan Ministry of Health and Welfare. *Points for LTC Insurance* [in Japanese]. 2nd ed. Tokyo, Japan: Ministry of Health and Welfare; 1996.
21. Kaihara N. *Estimation of the New Demand for Physicians, FY 1992: Report of the Health Science Grants Study* [in Japanese]. Tokyo, Japan: Ministry of Health & Welfare; 1992.
22. Japan Ministry of Health and Welfare. *Points for Determining Eligibility Criteria and Care Plans.* Distributed at the 36th meeting of the Health and Social Services Council for the Elderly; March 28, 1996; Tokyo, Japan.
23. Campbell JC. Bureaucracy and democracy in Japan. In: Ishida T, Kraus ES, eds. *Democracy in Japan.* Pittsburgh, Pa: University of Pittsburgh Press; 1989:113–137.
24. Campbell JC, Ikegami N. *The Art of Balancing in Health Policy: Maintaining Japan's Low Cost, Egalitarian System.* New York, NY: Cambridge University Press. In press.

25. Japan Medical Association. *Reform of the Health Insurance System for the 21st Century* [in Japanese]. Tokyo, Japan: Japan Medical Association; 1997.
26. Ikegami N. Functional assessment and its place in health care. *N Engl J Med.* 1995; 332:598–599.
27. Challis D, Davies B, Traske K. Immediate concerns and long-term care perspectives. In: Challis D, Davies B, Traske K, eds. *New Agendas and Challenges in Community Care of the Elderly: Lessons From the UK and Overseas.* Aldershot, Hampshire: Ashgate Publishing Ltd; 1994:303–316.
28. Ikegami N, Fries BE, Igarashi C, et al. Long-term care payment: assessment and care planning in home care [in Japanese]. *Byoin Kanri.* 1996;33:343–352.
29. Morris JN, Fries BE, Steel K, Ikegami N, et al. Comprehensive clinical assessment in community setting: applicability of the MDS-HC. *J Am Geriatr Soc.* 1997;45:1017–1024.
30. Japan Ministry of Health and Welfare. *1995 White Paper on Health and Welfare* [in Japanese]. Tokyo, Japan: Gyousei; 1995:19.
31. Block SD, Clark-Chiarelli N, Peters AS, et al. Academia's chilly climate for primary care. *JAMA.* 1996;276:677–682.

Biographical Sketches of Participants

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