

Japan Medical Association Journal



Special Feature: Home Care Services

Reviews

Historical Changes in Home Care Service and Its Future Challenges

Current Conditions and Issues for Home Care Support Clinics

Regional Collaboration in Home Care Services

Visiting Care by Family Physicians

The Present Situation and the Problem of Visiting Nursing: Team Care Management of Pressure Ulcers in the Elderly

Long-term Care Insurance Act and Home Care

Infection Prevention and Control at Home

Nutritional Management in Home Care: Including Eating Disorder and Dysphagia Assessments

Home Respiratory Management: From COPD to Neurological Diseases

Home Rehabilitation

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Efforts of Medical Associations to Support Home Medical Care Services: The Case of the Shizuoka Medical Association

Efforts of Medical Associations to Support Home Care Services: The Cases of Ichikawa City and Chiba Prefecture Medical Associations

From the Editor's Desk

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Historical Changes in Home Care Service and Its Future Challenges^{*1}

JMAJ 58(1·2): 1-5, 2015

Hisayuki MIURA¹

Introduction

The pressing changes to Japan's medical care delivery system as the population ages has been bringing attention to home care. As Japanese society ages, the elderly made up 23.1% of the population in 2010, the highest in the world, and this rate is expected to increase further. In these conditions, when we look at trends in the place of death in Japan, we find that the percentage of people who died at home was over 80% around 1950, while the percentage of hospital deaths was over 10%, but this trend has reversed since 1976, with 78.5% of deaths taking place in a hospital in 2011 and 12.5% at home.

The spread of medical technology previously only available in hospitals, such as artificial respirators, likely played a large part in this. This has resulted in a fact that very few people have the chance to experience a natural death in their own surroundings without using such an edgingcut device. At present, we rely on hospitals for end-of-life care and terminal care, but future estimates of terminal care locations suggests that even if the number of home deaths increases by about 1.5 times the current level, in 2030 about 470,000 people will not have a place for end-oflife care because of the limited capacity of the hospitals and nursing care facilities.

In a questionnaire asking respondents where they want to receive end-of-life care, about 60% said that they wanted to be treated at home for as long as possible, but many people also worried about burdening their families and about how sudden changes in their symptoms would be handled.

Indeed, in a patient survey carried out in October 2011, 110,700 people nationwide are expected to receive home care from either hospitals or clinics (visiting care or home visits by a doctor), but of these, 67,200 received visiting care, which is not very high. In order to deliver stable home care, a home care delivery system provided through inter-professional collaboration must be developed in collaboration with the hospitals that will be taking in emergency patients.

Historical Changes in Home Care Service (Table 1)

Home care was institutionalized under the medical fee system in 1981 when self-injection of insulin became eligible for health insurance coverage. Subsequently, in 1986, the year after the community health care plan started under the first revised Medical Service Law, the Health and Medical Service Act for the Aged was revised, and visits to bedridden elderly people became eligible for insurance coverage. In 1992, the second revised Medical Service Law designated homes as a place for medical care delivery. In the 1994 Health Insurance Act, home care was made eligible for medical insurance coverage.

Home care, previously called "home visits," was often employed as an emergency measure for patients who were bedridden due to a serious illness and patients whose condition had suddenly worsened, but in recent years, home care has been provided to patients who are in

^{*1} This article is a revised English version of a paper originally published in the Journal of the Japan Medical Association (Vol.142, No.7, 2013, pages 1511-1514).

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Year	Medical fee	Medical service law and long-term care insurance act	Related programs
1981	Establishment of guidance and management fees for home care (guidance and management of insulin self-injection at home made eligible for insurance coverage)		
1985		First revised Medical Service Law: community medical plans established	
1986	Concept of visiting care introduced		Revisions to Health and Medical Service Act for the Aged (health care facilities for the elderly set up)
1991			Revisions to Health and Medical Service Act for the Aged (visiting nurse stations for the elderly set up)
1992	Comprehensive home care for bed-ridden elderly covered under insurance	Second revised Medical Service Law: "Homes" designated as health service delivery point	
1994	Augmentation of assessment of end-of-life care at home (fees for medical management at home, end-of-life home care fees, terminal care made eligible for coverage)	Revised Health Insurance Act: Home care made eligible for insurance coverage; designated visiting nurse system set up	
1998	24-hour collaborative system for comprehen- sive home care for bed-ridden elderly added to coverage		
2000		Long-term Care Insurance Act goes into effect	
2004	Home care for seriously ill and terminal patients augmented		Program to promote visiting nurses
2006	Home care support clinics established	Fifth revised Medical Service Law: Aspects related to ensuring home care included in medical plans, revised Long-term Care Insurance Act	
2008	Home care support hospitals established		
2011			Home care collaborative base program
2012	Enhanced home care support clinics and hospitals established	Guidelines for development of home care system released	Home care collaborative base program

Table 1 Changes in systems and programs related to the promotion of home care

(Prepared by the author based on the Ministry of Health, Labour and Welfare: Fiscal 2012 materials 1. from briefing on home care collaborative base operations held on July 11, 2012.)

the convalescent stage after the completion of acute therapy as well as patients with chronic conditions requiring regular treatment.

Subsequently, when the medical fee program was revised in 1998, the 24-hour collaborative system for comprehensive home care for bedridden elderly was added to coverage. In 2006 and 2008, home care support clinics and home care support hospitals were established as systems eligible for insurance coverage.

Thirty years have passed since the national government took up home care as a policy issue. However, as we stated above, home care itself is still not being delivered to those who really need it. To address this, the Ministry of Health, Labour and Welfare initiated many operations nationwide in 2012, designating it the year in which home care and nursing would be stabilized.¹ The Ministry put 2.3 billion yen (ca. 20 million US\$) into the establishment of bases serving as home care support centers (home care collaboration bases) and 109 million yen (ca. one million US\$) on training home care physicians.

The 2012 medical fee revisions added 150 billion yen (ca. 1.3 billion US\$) to strengthen affiliations between medical care and nursing care and to augment home care. In the nursing fee revisions, resources were allocated with an emphasis on comprehensive community care, starting with the establishment of a new menu

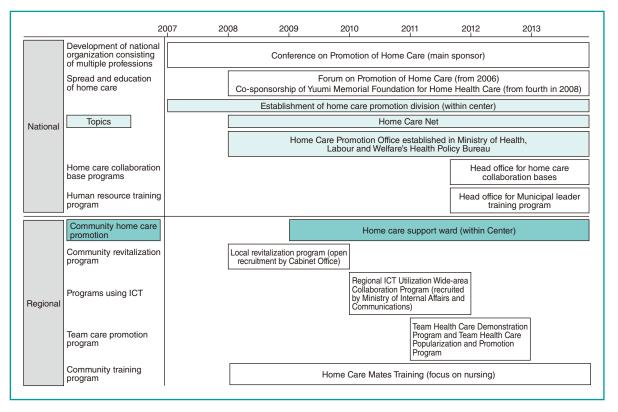


Fig. 1 Main home care-related programs run by National Center for Geriatrics and Gerontology

that included visiting nurses for 24-hour regular house rounds and on-demand visits.

When the medical plan was revised in 2012, home care was designated as a pillar alongside the "five diseases and five medical systems" for major challenges, with the establishment of the "Guidelines for Developing a Home Care System."

Initiatives to Promote Home Care at National Center for Geriatrics and Gerontology

Figure 1 shows the initiatives taken thus far by the National Center for Geriatrics and Gerontology to promote home care. The National Center invited members of groups, research organizations and academic societies related to home care in Japan to establish the Home Care Promotion Conference. Since 2007, conferences have been held to take opinions of stakeholders on policies to promote home care through end-oflife in Japan. One of the activities of the Home Care Promotion Conference was to form a working committee to review national studies on home care and policies on staff training. As part of this, in 2008 the Home Care Net was set up, and symposiums such as forums to promote home care were held in the respective regions. In the same year, the Home Care Promotion Office was established to actively promote home care as a national policy.

In these conditions, a model hospital ward intended to form seamless affiliations with home care physicians were set up in April 2009 (home care support hospital wards) and carried out specific activities aimed at revitalizing community home care services. It has been reported that with the active involvement of hospitals in home care support as a community base, the reversion rate from hospital to home and the rate of endof-life care at home increased, and that the involvement of hospitals in promoting home care is important.

Future Approach to Home Care

Expansion of home care collaboration bases programs

Home care collaboration bases programs were initiated throughout Japan, primarily in 2012, the year designated for stabilizing home care and nursing.

There were 10 programs nationwide in fiscal 2011, but 105 in fiscal 2012. In these programs, the institutions offering home care services were served as centers to build a support system for home care through inter-professional collaboration. And they carried out activities aimed at providing comprehensive and ongoing home care in communities in collaboration between medical care and nursing. The bases work to overcome obstacles at the municipal level, and ultimately must promote collaboration between governments, medical associations, home care support clinics and hospitals, visiting nurse stations and nursing organizations so that the program is deployed from single points to the greater population.

This operation is expected to contribute to the development of the comprehensive community care system currently promoted following revisions to the Nursing Insurance Act. Since fiscal 2013, it has been sustained as an official prefectural project with emergency grants for the revitalization of community health care, and more than 500 bases were set up nationwide. This is equivalent to almost one-third of the approximately 1,700 local municipal governments nationwide, thus bringing bases for home care close to most residents.

Contributions to the comprehensive community care system by medical and nursing collaborations

According to the Comprehensive Community Care Research Society (Fiscal 2008 Health Services and Health Promotion Services for the Elderly)² the definition of community care is "a community system which enables the appropriate delivery of services that support daily life in a variety of ways, including medical and nursing services, as well as welfare services, within their daily sphere to ensure safe, secure and healthy lives with the basic assumption being that homes should be provided based on needs." The comprehensive community care sphere is defined as, ideally an area that could be covered within 30 minutes—specifically, this would be equivalent to the boundaries for junior high-school district.

In providing comprehensive community care in the regions, the comprehensive community support center plays the leading role on the nursing side, but forming collaborations with physicians were difficult because of a sense of awkwardness about working with physicians. The health care collaboration bases are important as, within their activities, physicians approach the nursing side and build collaborations.

Conclusion

Comprehensive community care systems based on residences and lifestyle support services will continue to be promoted. This concept is called "Aging in Place,"³ which is the same concept as the program promoted overseas enabling the elderly to live in their customary community.

Japan will experience a super-aging society unprecedented in the world, and we will be judged for our success in creating communities that are gentle on the elderly and preserve interaction between the generations throughout Japan.

We believe that home care collaboration bases, together with comprehensive community support centers, will play an important role as bases to promote collaboration with community home care and nursing. In addition, training physicians and nurses who understand both hospital and home care, seamless collaboration between hospitals and home care facilities and collaboration between clinics and facilities, establishing information and communication technology (ICT) for use in inter-professional collaboration and intervention tailored to community's actual conditions to couple the actual work of comprehensive community care (social inclusion) to community development in anticipation of an ultra-aged society are necessary.

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Current Conditions and Issues for Home Care Support Clinics^{*1}

JMAJ 58(1·2): 6-9, 2015

Hideki OHTA1

Introduction

Spreading and promoting home care supporting patients through the end of their lives is an extremely urgent issue in Japan's super-aging society, where one in every three people is expected to be elderly in the near future. By 1992, the concept of visiting care, not just the traditional home visits, had emerged, with the patient's home as the medical care delivery point. Visiting care consists of regular visits based on a medical treatment plan tailored to the patient's illness, contrary to home visit at the patient and family request. It can be seen as a kind of ward round. A visiting nurse system for the elderly was established in 1992 under the Law on Health and Medical Services for the Elderly, and Visiting Nurse Stations began to be set up, so that this year became known as the birth of home care.

Two years later, in 1994, the revised medical fee system made 24-hour emergency home visits eligible for insurance coverage, and medical fees for home care, such as visiting care, were assessed as being more advantageous. However, home care was not actively promoted. In 2000, a nursing care insurance system that aims to have society fill the gaps in home nursing, which had previously depended on families, went into effect. This upheld the integrated delivery of medical care and nursing services as the basic concept behind the program, and further raised the importance of home care. However, home care did not earn civic rights as the national government expected. Accordingly, in 2006 home care support clinics came under the rubric of medical fees, with home care increasingly seen as beneficial. As a result, home care was no longer a burden for clinic management, and we even saw the emergence of home care specialist clinics without outpatient functions.

What Is a Home Care Support Clinic?

Home care support clinics are those clinics with acclaimed home care support functions available 24 hours a day until the patient dies, regardless of specialties such as internal medicine and surgery. The notification requirements (Table 1) must be met, and indicates the importance of collaboration. In addition, the visiting nurse station that is collaborating has incentives to make visits at the request of the support clinics. In 2012, enhanced home care support clinics were institutionalized (Table 2). If multiple support clinics that met the conditions strengthened their ties and provided 24-hour support through endof-life, additional medical fees would be eligible for coverage. In 2008, hospitals with functions similar to support clinics were positioned as home care support hospitals in the medical fee system.

Currently, society's expectations for home care, which form a crucial part of comprehensive community care system, are on the rise.

Current Conditions at Home Care Support Clinics (Figs. 1-3)

A study by the Ministry of Health, Labour and

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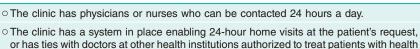
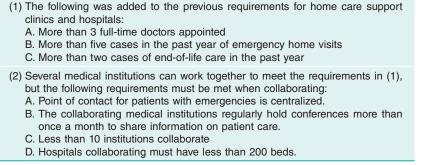


Table 1 Requirements for home care support clinics

- The clinic has a system enabling it to provide 24-hour visiting nurses based on the clinic
- physician's instructions at the request of the patient, or has ties with nurses at other health institutions authorized to treat patients with health insurance coverage or visiting nurse stations to ensure this.
- A system is in place ensuring that home care patients can be hospitalized in the event of an emergency at the clinic or at another health institutions authorized to treat patients with health insurance coverage with which it has an affiliation.
- The clinic has ties with nursing support experts (care managers), etc. in charge of coordinating medical services and nursing services.

(As of July 1, 2010.)





(Ministry of Health, Labour and Welfare: Quoted and altered from Fiscal 2012 materials 1. from briefing on home care collaborative base operations held on July 11, 2012.)

Welfare shows that 12,487 clinics have filed for approval as support clinics (as of July 1, 2010).

However, of these, 6,046 clinics did not actually provide palliative care to home patients, and instead general clinics are currently providing support through end-of-life. Moreover, the standards at which home care support clinics are equipped and maintained differ depending on the municipality. As such, support clinics face many issues to solve.

Future for Home Care Support Clinics

The history of home care as a third form of medical care, together with hospitalization and outpatient service, is brief, and Home Care Net was organized to work on spreading and promoting home care while resolving these issues at the same time.

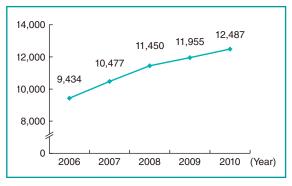


Fig. 1 Number of filings for status as home care support clinic (as of July 1, 2010)

An excerpt from the Association's charter reads as follows: A new form of medical care in which patients are treated at home through inter-professional cooperation is difficult to con-

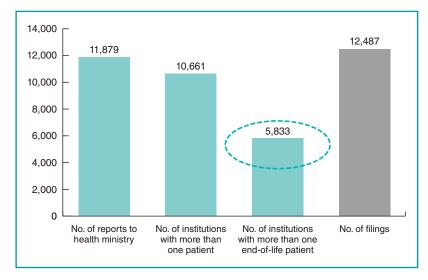


Fig. 2 Achievements of home care support clinics (as of July 1, 2010)

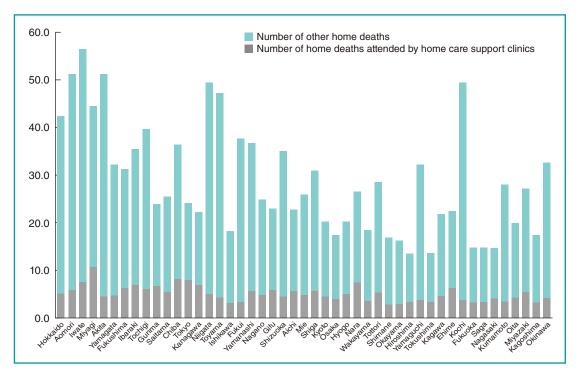


Fig. 3 Number of home deaths per home care support clinic (with more than one end-of-life patient at home) (as of July 1, 2010)

ceptualize with any specificity in the medical world. Moreover, medical academic societies, community physician societies and university medical departments would likely have difficulty supporting the activities of home care support clinics.

Accordingly, we have organized an association of home care support clinics on a national scale so that we can join together with the aim of enhancing the home care system while working diligently together to spread and develop home care in Japan.

Through our association, we hope to endeavor to meet the wishes of our fellow citizens who want to be treated with their families in the community they are accustomed to and end their days at home.

Any physician interested in home care can participate in the National Association of Home Care Support Clinics. An active dialogue is carried out on mailing list. Please refer to the web site for details (http://www.zaitakuiryo.or.jp/).

Conclusion

An ultra-aged society is also a society characterized by many deaths, and with 1,700,000 deaths annually anticipated, the number of citizens wanting intensive medical intervention is on the decline when disease treatment cannot be expected. While changes in the disease structure resulting from the aging society and progress in medicine mean that lives difficult to save with the previous standard of care can be rescued, secondary diseases such as paralysis and dementia as well as frailty mean that the elderly end their lives after a period in which they cannot survive without some kind of social support. We must face this reality. At present, the majority of physicians in private practice specialize in a specific internal organ or disease, but for many patients, all they want of their family physicians is to be able to end their lives in their own homes. With a major shift away from "health care for treatment" to "health care for support," a health care system relying on hospitals is changing to comprehensive community care. And high expectations are placed on home care support clinics. We are now in an era in which Japan's medical culture is changing as a matter of pride for private physicians.

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Regional Collaboration in Home Care Services^{*1}

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Naohiro TERADA¹

Introduction

In 2025, the elderly will account for over 30% of Japan's population, and we will truly become a super-aged society as the baby boom generation reaches age 75 and beyond. At the same time, the impact of the falling birth rate is widespread as it is not only a social security problem, but also lowers the nursing capacity of households and reduces the work force in medical and nursing settings. The decline in the generation who watches for elderly in broad sense may lead to a situation in which it is impossible to fully identify the growing number of elderly living alone, households consisting of two elderly people, the lifestyle of people with dementia and changes in their health. This could mean a quick end to a stable life in the community and homes they are accustomed to.

Comprehensive community care is based on the concept that the elderly's lifestyle and health can be preserved through affiliations and collaborations of a community's social resources. This is the broadest category in terms of interprofessional collaboration. Health care is one of the five pillars supporting comprehensive community care, and is expected to be closely involved with prevention, monitoring and daily support, and residences, primarily in collaboration with nurses. Of these, home care supports stable recuperation in an accustomed place, and makes it possible to provide ongoing medical services via a medical collaboration network if necessary in the event of a sudden deterioration or other events. In this sense, home care plays a central role in the collaborations involved in comprehensive community health care.

During my work primarily in home care in the area affected by the Great East Japan Earthquake, I have come to believe that looking at community collaboration from the perspective of reconstruction is meaningful. The earthquake made the health of many people vulnerable in a flash. Not only were lives lost, but also homes, economic foundations, and communities. Homes are the repository of the entire history of the people living in them, and are an important factor supporting their identity. Home care is based on the premise that a community has the ability to absorb and comfort people.

Securing the residences and establishing a system for monitoring and supporting daily life advocated in comprehensive community care essentially resurrects the lives, health and communities damaged by the earthquake in affected regions, and recreates the various ties that were broken. This is an overwhelming task, but there are also time constraints. This is because the loss of social factors determining health are already beginning to affect emotional and physical health, and if health and welfare concepts such as comprehensive community care are to take shape as real institutions, the speed at which infrastructure is restored becomes an issue.

In order to create communities that contribute to health with only limited time available, inter-professional collaboration that goes beyond the categories of home care affiliation and elderly care affiliations are essential. We believe that in examining the goals of reconstruction in the affected areas, we could get a better idea of the shape of care in society overall.

I will examine the current status of the development of community collaboration (inter-

^{*1} This article is a revised English version of a paper originally published in the Journal of the Japan Medical Association (Vol.142, No.7, 2013, pages 1518-1521).

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professional), issues and the outlook in terms of home care using examples of initiatives in the affected regions.

Role of Collaborations in Health Care

Definition of collaboration

Here we have defined collaboration as "cooperation of relevant professionals through a division of roles based on their expertise to resolve health issues facing a community and the people living in the community."

This defines a looser affiliation than the concept of a health care team, and keeps in mind affiliations with community groups and professionals that could contribute to health, such as collaborations with the activities of clubs for the elderly and urban planning divisions working on upgrading walking paths.

Collaborations with prevention as starting point

Prevention plays a major role in preserving health, both in terms of disease prevention and care prevention. Prevention consists of three stages, and is a concept based on a timeline. Thinking about the approach to a collaborative system in line with the prevention stages is based on the concept that the approach to collaboration changes as a person's health conditions change with time.

Collaboration by prevention stage

Collaborations are effective in any stage of primary, secondary and tertiary prevention. It is important to collaborate with flexibility allowing both the provider and approach change depending on the stage. We will consider what kind of role collaboration plays at each prevention stage and how they can contribute to health promotion.

Primary prevention is a method with the aim of promoting health and creating health so that people do not become sick or get into a situation requiring care. At this stage, the resident is encouraged to take the lead in his/her own care. For this reason, collaborations are focused on circle activities such as resident awareness activities and clubs for the elderly, improving health awareness such as employment in motivating jobs (jobs that give them the desire to live) and programs to build physical strength. Creating places in terms of the hardware of community development, for example community initiatives that motivate the elderly to get out of their homes, such as spaces for interaction and setting up walking paths, encourage prevention activities. The types of professions involved in the collaboration and the format that this collaboration takes are wide-ranging, and consist of long-term initiatives.

Secondary prevention focuses on the early detection and early treatment (response) of illness and decrease in vital function. Medical collaborations form the core of early detection and early treatment in disease prevention. In many cases, lifestyle diseases occur during one's working years, but affect one's vital functions after retirement. Given this, it is important to set up a system in which occupational doctors and business owners can mediate with the individual concerned and the collaboration links middle age and old age.

Broadly-defined "monitoring" forms the core of collaborations involved in the early detection and early response to a reduction in vital functions among the elderly. Mutual affiliations between community functions, such as volunteers, social workers and local government bodies, as well as government administration, nursing offices and physicians take the central roles. Mechanisms for information collaboration and information sharing also begin to play an important role at this stage.

Tertiary prevention focuses on managing basic illnesses and vital functions and preventing them from becoming serious. Affiliations in tertiary prevention are more separate, and the roles required of the respective professions are specialized. Collaborations when a patient is discharged and service manager conferences are part of this stage. Information collaborations and information sharing must be thorough and prompt.

As such, the provider and approach must be changed so that the collaboration responds seamless to the individual's health conditions. Ensuring that information collaboration is seamless between the stages, as well as the approach to information sharing, are major issues.

Examples of Building Collaborations in Kamaishi Medical Zone

There are several themes for building a colla-

boration, including forming a foundation for regional collaboration and team building on the actual site. In other words, the issue is the kind of collaborative foundation that should be built utilizing the key characteristics of a region, and how to make the collaborations involved in the individual cases effective. Let's take a look at the process for such endeavors in the Kamaishi medical zone.

Kamaishi medical zone

The Kamaishi medical zone is the secondary medical zone with a population of about 50,000 from Kamaishi City and Otsuchi-cho, located along the Sanriku Coast about 100 km southeast of Morioka City. Approximately 35% of the population is elderly, with about 150 doctors per 100,000 people, corresponding to about 67% of the national average. As in other areas affected by the Great East Japan Earthquake, the social infrastructure, as well as the medical and nursing environment, was shaken up significantly, and even now the social determinants that support health are in the process of being restored.

Requirements for building collaborations

Common objectives

In 2007, the Review Committee for a Kamaishi and Otsuchi Region Medical Collaboration System was formed. The initial objective of this committee was for all medical institutions, starting with acute hospitals, to meet together with dentists, pharmacologists, nursing offices and government offices to consider how home care collaboration could be developed. However, what emerged in the process of identifying issues was the managerial deterioration of acute hospitals. The dysfunctionality of the only acute hospital in the region and its withdrawal from the region indicates the collapse of the region's health care, making improving conditions at the acute hospital the imminent issue. I believe that reaching agreement that reducing the burden of and stabilizing the acute hospital would also stabilize the overall community and reaching consensus that this would be the best objective for the zone overall was a major turning point for the zone.

Clarification of community's division of roles

Specifically, to clarify the division of roles was an urgent issue. Roles were divided among the chronic hospitals, clinics, nursing offices and government offices in terms of what they could do to protect the acute hospital. The role of chronic hospitals was clarified as the hospital to which patients were transferred once their treatment in the acute hospital was over and as the hospital providing aftercare to home care patients, while the role of clinics was defined as the provider of home care, in addition to the management of the health conditions of outpatients. Government offices are primarily responsible for primary and secondary prevention, as well as educating residents about home care and spreading this knowledge. It was important to clarify the role of family physicians in home care, and identifying them as part of an organic collaboration aimed at achieving the community's overall objective.

Function of coordinating collaborations

The home care collaborative site project, which was initiated as the model program of the Ministry of Health, Labour and Welfare from fiscal 2011, is responsible for developing collaborations centered on health care. Broadly speaking, the project is responsible for the inter-professional collaboration in the medical arena carried out within the framework of the comprehensive community care system. Since there had not been any organization (division) dedicated to coordination in community collaboration thus far, individual communities had organized collaborations using their own methods. In fiscal 2012, Kamaishi City was selected as one of the 105 home care collaboration sites nationwide, and began activities as Team Kamaishi. The collaboration coordination function was essential to the community in building and maintaining a foundation for collaboration.

The objectives shared by the community overall, the clearly divided roles and the function of coordinating these were an essential element of collaboration development.

"Community development full of zest for life"

This was the title of the recommendation regarding community development that the Committee to Consider Comprehensive Community Care, established in November 2012 and consisting primarily of members of the Kamaishi Medical Association, submitted to the city mayor of Kamaishi in February 2013. This collaboration was put together, centered on the medical association, with the aim of reflecting the principles of comprehensive community care in the actual hardware in tandem with the construction of reconstructed public housing. The members were the Kamaishi Medical Association, the Institute of Gerontology, the University of Tokyo, Tokyo University Graduate School (Urban Engineering), Kamaishi Wide-Area Nursing Support specialist Liaison Committee, Kamaishi Social Welfare Committee, Suzuran Fureaino Kai (paid volunteers), Kamaishi Elders Club Association and the Kamaishi Silver Employee Center. This is a collaboration from the perspective of medicine, nursing, welfare, protection, health promotion, and work-in other words, a collaboration from the perspective of comprehensive community care and the perspective of urban engineering.

After about four months of work, the recommendations were completed and are currently being put into action. This case of collaboration confirmed again the effectiveness of forming a foundation for health that is not limited to collaboration between the care professions, but integrates knowledge from a wide range of professions.

Issues in Forming Collaborations

Below, we will take a closer look at two collaboration coordination activities currently carried out in regions throughout Japan to develop community collaboration.

Identifying solutions for issues in inter-professional collaboration

A wide range of methods is used to clarify the issues faced by the professions involved in home care and problems encountered in collaboration. They are often used in questionnaires, research groups and discussion committees targeting specific professions or multiple professions. A large number of views are compiled and then categorized to identify the issues. Simply identifying issues does not mean that the issue is explored further and resolved. The collaboration site must consider which approach should be used to resolve the issue.

Team Kamaishi attempted to categorize the identified issues based on the part of the collaboration flow that had created the issue. As a result, the team was able to divide the issues broadly into (1) issues within a profession, (2) issues between professions and (3) issues related to collaboration overall. Some examples of issues categorized as issues within a profession are a lack of an organization cutting across professions, a lack of human resources that can be involved with home care and the inability to obtain consensus within a profession and large discrepancies in enthusiasm.

The collaboration coordination site must delve thoroughly into the issues with each profession and deepen understanding, after which solutions can be considered in a collaboration between the site and one profession. This method makes it possible to listen to frank views, reach mutual understanding and, in particular, identify obstacles. This approach is a central task of the collaboration coordination site. Understanding of the respective profession's issues facilitates coordination between professions. Moreover, accumulating cases in which this process has been generalized can be effective when collaboration coordination sites are developed in identifying and evaluating community issues from a shared perspective and as material for advice for communities taking up the process subsequently.

Development of human resources employed in home care

Developing human resources for building community collaboration is an essential issue. This brings up the role of collaboration coordinator.

The collaboration coordinator is expected to play many roles. The main task is to identify information on the professions as noted above, educate and raise awareness among residents and professions involved in collaboration, planning inter-professional training sessions and lectures, and contributing to the development of information sharing systems. This position requires a broad perspective, knowledge and context. A role as a new specialist profession and an understanding of its importance are essential, and ongoing training tailored to the activities must be ensured.

Conclusion

In this paper, we have considered the need for community collaboration to respond to changes in individuals' health conditions while changing the provider and adjusting the approach from the starting point of preventative stages. We looked at the importance that roles in home care collaboration be divided within the shared goals for community collaboration, the importance of collaboration coordination sites and the possibility of collaboration between different professions in developing health infrastructure. We also demonstrated that techniques are needed in the process of identifying and resolving collaboration issues in building community collaboration, as well as the indispensability of training collaboration coordinators. Home care collaboration can play a major role within the framework of comprehensive community care while overcoming various issues.

Visiting Care by Family Physicians*

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Introduction

In recent years, the need for home care in this aging society has been stressed. However, the debate over this has not been resolved as this would require a system offering care 24 hours a day, 365 days a year since home care includes end-of-life care. Most of the clinics run by family physicians are managed by just one physician, making it extremely difficult to provide 24/7 care.

My clinic is an ordinary internal medicine clinic providing outpatient treatment in the morning and afternoon. I make home visits during the lunch hour and oversee about 40 in-home patients. I provide end-of-life care for about 15 patients a year. This article will outline a picture of how a single physician provides this kind of care.

Overview of My Clinic's Home Visits

My clinic serves the Ota ward in Tokyo. The clinic is run by myself and my father, but currently my father is not engaged in care to in-home patients. I visit patients in their homes from 1-3 pm a day in an area with a radius of about 2 km. I visit patients in their homes but also in group homes and private nursing homes. I travel primarily by bicycle, and mostly see 5-6 people in a day.

Most of my in-home patients are elderly people too weak to travel to my clinic or patients with cognitive impairment, but late-stage cancer patients account for about 10%. I visit these patients for about one month, with about 80% of cancer patients dying in their own homes. However, there are also end-of-life cases who do not have cancer but suffer from senility. In the past few years, about half of my end-of-life patients suffer from cancer and about half suffer from conditions not related to cancer.

I receive 5 or 6 requests a month for house calls. Many are not urgent, and I visit during my regular daytime visiting hours. I make home visits in the evening and on weekends about once or twice a month. Because I have received word of respiratory arrest, something that in most cases was anticipated. I make house calls about once a month on evenings and weekends due to unexpected fevers and other causes. At present, I make these home visits myself.

Steps Needed for a 24-hour System with One Physician

There are several key factors essential in my clinic's being able to provide home care with a single physician. I have discussed a few of these factors below.

Use of a visiting nurse

A visiting nurse is the most powerful partner in home care. With instruction from a physician, a visiting nurse can observe the patient's condition, adjust the patient's living conditions and provide medical care. A nurse can set up Intravenous drip when the patient is dehydrated, if so instructed, and can follow special instructions if the patient develops pressure ulcers.

During the period immediately after hospitalization when the patient is not yet stable, a visiting nurse can visit several days in a row and relieve any concerns over living at home. In addition, nurses can take the first call when there

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is an emergency summons from a patient. However, the family physician must accurately ascertain the patient's condition and give instructions as necessary to ensure that the visiting nurse can perform his/her functions well. If the physician does not fulfill this role and leaves it up to the visiting nurse, a trusting relationship with the visiting nurse cannot be developed and the quality of home care overall declines significantly.

The physician's first job is to prepare instructions. There are two kinds of instructions.

Visiting nurse instructions

When introducing visiting nurses, visiting nurse instructions are always prepared. With these instructions, visiting nurses can be introduced within the scope of long-term care insurance. The instruction period is optional for up to six months. In the case of end-of-life cases, conditions are not stable so visiting nurses are covered by medical insurance rather than long-term care insurance, but as with the attending physician's written opinion in the case of long-term care insurance, "terminal cancer" must be specified in the section for the name of the illness.

Special visiting nurse instructions

When conditions worsen during this process and the physician wants the visiting nurse to intervene further, special visiting nurse instructions are prepared. For example, when a patient catches pneumonia and the patient's condition needs to monitored daily and intravenous drip needs to be set up (if the visiting nurse uses intravenous drip three or more times a week, instructions for in-home patient visit IV is needed; the instructions are valid for one week), medical insurance would cover a visiting nurse for a limit of two weeks if such instructions are provided. In recent years, it has been pointed out that using this system so that a visiting nurse can intervene in a concentrated manner in the unstable period immediately after hospitalization is an effective method of stabilizing a patient.¹

These instructions can be issued up to twice a month for patients who also have severe pressure ulcers and patients who have bronchial catheters.

Clinic nurses participate in home care

Currently, my clinic has two full-time nurses, both of whom actively participate in home care services. I always visit patients at home with a nurse (changing every week) to share conditions and guidelines. The nurse plans the home care in consultation with myself, handles inquiries and questions from the family, communications with the visiting nurse and care manager, and coordinates new patients. Moreover, the nurse accompanies me even in the middle of the night to care for terminal patients, and provides "angel care (postmortem procedure)" in collaboration with the visiting nurses. These nurses are a key support bolstering this one-physician home care system.

Reduce concentrated medical intervention

Patients discharged from the hospital are often provided concentrated medical care in which they need continuous intravenous injections and high-calorie transfusions. However, there are surprisingly many examples in which these medical treatments can be reduced within the scope of home care. For example, a 1,000 mL/day continuous intravenous injection could be changed to a 500 mL/day subcutaneous transfusion.^{2,3} Insufficient hydration can be addressed by feeding the patient jellies and practicing swallowing. Even when various medicines are mixed into highcalorie fluids, there are many cases in which no difficulties will result from discontinuing mixed injections. In the past, I have seen cases in which simply reducing the amount of high-calorie fluids eases intractable swelling, as well as cases in which morphine can be administered orally. There are also a significant number of cases in which patients who repeatedly suffer from aspiration pneumonia at the hospital are able to take food and liquid by month when they return home. By reducing concentrated medical care in this way, the patient's burden, the family's burden and the physician's burden are all mitigated.

Respond while predicting patient's condition

Predicting symptoms is crucial in providing home care. Of course, it is very difficult to accurately predict sudden fevers. However, when a patient's condition gradually deteriorates, they are unable to move and they are unable to either eat or drink, it is easy to predict that the patient will die within a few days. This should be explained to the family once it is predicted, as well as the low likelihood of recovery, and if the family is anxious about having this last stage take place at home, the physician or nurse should increase his/her visits and reinforce support. I often begin visiting daily from that point. Since I can ascertain changes in the patient's condition on a daily basis, it is easier to predict the next change, and even if the patient experiences any uncomfortable symptoms, I can respond more smoothly.

Moreover, I visit in the evening as well as the afternoon when the patient's level of awareness is declining. By doing this, I am able to predict whether the patient will die that night. If I make a house call and the patient's vital signs are stable and I can confirm urinary output, there is a good chance that they will not die that night. In that case, I can also rest easily that night. If I determine that there is a good chance that they are stable the patient will die that night. If I determine that there is a good chance that the patient will die that night. If I determine that there is a good chance that the patient will die that night, I make sure I am on standby.

When this kind of intensive visiting care is organized, a nurse alone can address even respiratory arrest if I am providing outpatient service at the clinic. Once office visits have slowed down, I can visit the patient's home and confirm his or her death.

Support in decision-making

It is important to share what I predict from symptoms with the patient and his/her family. Thoroughly explaining where the patient will be treated going forward, whether the patient can remain in his/her current environment and the direction of treatment, based on these predictions, is crucial. Decisions should be made not only before home care is introduced, but several times during the process as well since decisions could change depending on the symptoms and the support that can be provided. Moreover, support is needed for the decision-making process itself. If the family decides on end-of-life care at home, they must be told that they can receive adequate support. When the family is struggling to make a decision, they should be supported in making a choice.

We must understand their fear that their own decision would mean that they are letting an important family member die without helping, and help them find the best course of action for that person.

Inter-professional collaboration and information sharing

I mentioned collaborations with visiting nurses, but the very essence of home health care is

supporting the patient's lifestyle. This means that collaborating and sharing information with various other professionals who also support the patients is essential. Cooperation with care managers, service providers at the visiting nurse support office, the pharmacist providing visit instructions, dentists and dental hygienists if there are problems with eating, speech therapists if the patient has problems swallowing, and physiotherapists and occupational therapists providing rehabilitation is essential.

We do not only collaborate, but communicate with each other and ascertain conditions so that we can utilize each other's expertise and support the patient and his/her family. I use cloud-based groupware to share information. In addition, if parents participate in groupware, close emotional support can be provided. Family living far away can occasionally participate and see how conditions change daily. This approach has almost eliminated the situation in which some family members intervene to undermine the treatment guidelines that have been used up until that point.

Ensure a collaborative system for backup hospitalization

End-of-life care cannot always be provided in the home. Some patients want to be hospitalized for their terminal care because they don't want to be a bother to their families. There have also been several cases in which unpredictable events occur that make it difficult to provide treatment at home, so that emergency transport becomes necessary. For this reason, hospitals able to provide backup are essential for home care.

The problem lies in ensuring that such hospitals are available in the region. The family physician must form a trusting relationship with the hospital and build a partnership that goes beyond that of acquaintances to a real friendship. By sharing information with this hospital, the "story" of the patient's home can often be passed on when he/she is hospitalized. Using the groupware I mentioned above, I share information with the nurse providing help with hospital discharge at the backup hospital and, if possible, the physician in charge or the physician from the medical liaison office. By this means, even if the patient dies a few days after discharge, the patient's "story" can be preserved without any refutation of his/her treatment at home. This kind of relationship cannot be built up in a single day. I repeatedly discussed ways of working with the hospital managers and regularly participate in hospital conferences so that we are able to understand each other's way of thinking and can build relationships of mutual trust. Simply sharing information will not help to build trusting relationships that go beyond the perspectives of a hospital and clinic.

Family physician attends patients until the end

Family physicians stand by patients and their families with their accessibility, comprehensiveness, cooperativeness, continuity and sense of responsibility. In this process, they build trusting relationships with the patient and family. If the patient has an incurable illness and wants to die at home, having the family physician take care of the patient until the end is ideal from the perspective of narrative-based medicine and the perspective of spiritual care. Watching over the patient during his/her last days—seeing how the patient lived, thought and behaved and then weakened—in the same community in which he spends his days is a matter of pride for the family physician.

Attending the terminal patient who wants to die at home is the key factor in ensuring that home care runs smoothly.

Closing Remarks

I have discussed the key factors in providing home care with a single family physician, but some of these aspects cannot be put into action immediately. Community medical systems have their own particular conditions, so this system should be implemented after the necessary time is spent to coordinate the program.

If terminal care for the elderly is provided primarily at hospitals, as it is now, hospitals will be overflowing with the elderly and the inpatient hospital system and emergency medical care system could collapse under the weight. For this reason, it is urgent that we encourage home care and terminal care at home. This is a crucial ordeal that we must overcome. Regional medical associations and municipal authorities will be the main actors in this initiative. We must build not only a home care system, but also a comprehensive community health care system. We are now in an era in which a system run by a single physician such as myself cannot take on the full burden. For the sake of the community, family physicians must cooperate and work together to reduce their responsibilities. The next generations will be called to revitalize the local community and this should probably start with the revitalization of our community of physicians.

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The Present Situation and the Problem of Visiting Nursing: Team Care Management of Pressure Ulcers in the Elderly^{*1}

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Introduction

Currently, over 70% patients visiting home nursing stations receive service under the national long-term care insurance policy. As many of them are elderly, we should consider prevention and management of their pressure ulcers in nursing. It is well known that a risk of developing pressure ulcers is related to not only local factors but also other factors such as systemic and environmental conditions. In home care, medical staff who are capable of providing professional care cannot manage a patient for a whole day unlike in hospital care. Home visiting nurses have to consciously share patients' information as much as possible with other members involved, and all those involved should understand the foundation of pressure ulcer management as the team approach.

Risk of Pressure Ulcers in Home Care

The total number of patients who visited at the Takashimadaira Home Nursing Station were 326 in the fiscal year (FY) 2012. 254 (77.9%) patients received service under their long-term care insurance policy, and 72 (22.1%) were covered under the Health Insurance Act or other plans. The age of the patients ranged from 1 month to 104 years old ($78.2 \pm$ years old); 86.2% were over 65 years old and 71.2% were over 75. The long-term care insurance coverage is divided into 7 categories according to a care level based

on the Long-term Care Need regimen. Among our patients in FY 2012, 59.3% of them were in the levels 3 to 5, which was in the "need care" category. Most patients (46.3%) had cardiovascular disease, with cerebrovascular disease accounting for 23.3%; the next highest was malignant neoplasm (24.5%) with 8.9% terminal cancer; followed by endocrine, nutritional and metabolic diseases (23.0%) with 19.0% diabetes; and ranked in fourth was musculoskeletal and connective tissue related disease (22.1%).

Many of them exhibited risk factors for pressure ulcers, such as changes in skin and metabolism as they aged, malnutrition from dysphagia or other disease, bedsore or pressure sore according to their reduced activity/mobility levels, and humectation and skincare problems by using adult diapers and also due to a lack of caregivers' capacity. We therefore believed that those people needed advanced nursing care for prevention and management of pressure ulcers. Because 23.0% of the patients lived alone and 26.1% of their caregivers were over 75 years old, about half of the patients had many problems in the home care they had been provided.

Tools for Pressure Ulcer Management

There are various tools relating to pressure ulcer management. However, we have to find a way to use tools for sharing information between medical and non-medical staff and evaluating the condition of pressure ulcers objectively.

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Braden scale¹

The Braden Scale (Japanese Society of Pressure Ulcers 2008) is useful for a group discussion (e.g., a staff meeting where different specialists and family members are present) because it helps verify the cause and factors involved in developing pressure ulcers in the context of the patient's condition. Non-medical caregivers such as family members, a care manager, long-term care staff (typically called "helpers" in Japan), and staff at short-stay centers can share the assessment of the patient, consider specific preventive or treatment methods within the role of each member, and then implement those methods.

There are 6 categories within the Braden Scale to evaluate: cognitive perception (range: 1 point for no perception to 4 points for no impairment); skin wetness (range: 1 point for always wet to 4 points for rarely wet); activity level (range: 1 point for bedridden to 4 points for being able to walk); mobility level (range: 1 point for complete immobility to 4 points for being able to move freely); nutritional status (range: 1 point for poor to 4 points for very good); and skin rubbing and sore (range: 1 point for having problems to 3 points for having no problem). In the home care environment, those with a Braden Scale score of 17 points or less are considered to be at high risk of developing a pressure ulcer.

DESIGN-R: Evaluation of healing²

The Japanese Society of Pressure Ulcers developed a tool in 2002 to evaluate the healing process of pressure ulcers. The tool's name, DESIGN, is an acronym of 6 pathologies, namely: Depth, Exudate, Size, Inflammation/Infection, Granulation tissue, and Necrotic tissue (Japanese Society of Pressure Ulcers 2009).

The letter P is added at the end (DESIGN-P) when an undermining pocket is present. DESIGN was revised in 2008 as DESIGN-R, with R standing for Rating, to determine the pressure ulcer severity using all categories except depth. DESIGN-R is incorporated as an objective indicator in the data sheet used by the Takashimadaira Home Nursing Station. DESIGN-R is effective for sharing information among medical staff or between hospital staff and home-care staff to provide collaborative care. The scale is widely known to physicians and home visiting

nurses, and the instruction sheet includes notes for visiting nurses.

Other evaluation methods

A classification based on the tones of the wound surface color (Fukui 2000)³ may be used as additional evaluation methods.

Sharing Knowledge and Standardizing Nursing Care

A home visiting nurse must visit a patient's home alone, make decisions alone, and nurse a patient alone. The care provided by home visiting nurses may vary among individuals because the care that each nurse provides is based on accumulated education and experience. For this reason, a case-study meeting, called the "pressure ulcers and wound conference," is conducted once a week at the Takashimadaira Home Nursing Station to standardize pressure ulcer management.

Purposes of the pressure ulcers and wound conference

- (1) All staff members should be able to practice the same care that follows the basics of pressure ulcer management.
- (2) All staff members should share the most current information about pressure ulcer management.
- (3) The goal is to provide standardized nursing care through pressure ulcer management training.

Rules of the conference

- (1) The conference should be short and effective, so it will not become a burden for members to participate.
- (2) Monitoring and follow-up evaluation are made possible by using a data sheet attaching photographs of pressure ulcers and notes. When taking a photograph, its purpose must be first explained to the patient and family members, and their consent must be given beforehand.
- (3) Issues such as factors that are distracting the healing process or the effectiveness of the current treatment must be reviewed based on standardized management of pressure ulcers.

Issues debated in the conference

- (1) Identify disease status and general condition of the patient. Verify any issues that may be related to pressure ulcers, such as cognitive perception, nutritional status, activity and mobility levels, joint contracture or pathologic protruding of bones, tremors or involuntary movements, edema, impairment in blood flow or peripheral circulation, cancerinduced pain, and difficulty breathing.
- (2) Verify the site and shape of each pressure ulcer as well as the direction of the pocket, if present. Explore possible cause for developing a bedsore or pressure sore. Identify the direction of the pocket by imagining the patient's head as at the 12 o'clock position and feet at the 6 o'clock position. Examine possible influencing factors, such as raising the head or feet, body position changes, patterns of moving around or the movement to transfer to a wheelchair, body position when lying in a bed or seated in a wheelchair, and care methods. The effect of shoes or socks should also be considered for a pressure ulcer on the foot.
- (3) Observe the color of each pressure ulcer. Check for the presence of infection or inflammation, necrotic tissue and accompanying stiffness, presence of epithelialization, and the nature of granulation tissue (i.e., benign or malignant). Family members or long-term care service staff may observe the wound, since medical staff are not always available. Therefore, the terms used in expression should be easy to understand for non-medical people (e.g., "color of beef" for benign granulation). When the granulation color changes (e.g., to the color of chicken or pork, or when a part of a granulation suddenly turns black ["decubitus in decubitus"]), medical staff and family members should preferably discuss the possible causes together.
- (4) Monitor the skin that surrounds the wound. Check for possible fungal infection, such as eumycetes or candidal infection due to prolonged use of a diaper; sagging of the skin; recurrence of pressure ulcers; and the presence of skin rash due to taping, incontinence, or diarrhea. Other factors to examine include possible consequences of skin care methods; incontinence management methods including the use of adult diapers, caregivers' skill

level, and care methods; and the validity of services.

- (5) Recheck the physician's instructions. Changing a topical medicine or dressing material frequently according to the condition of the wound, which is possible in hospital care, is often difficult in the home-care environment. Therefore, moisture balance of the patient's skin needs to be controlled through adaptive measures, such as applying the prescribed topical medicine according to its basic characteristics and using gauzes and film dressings in combination (Furuta 2006). The outcome of the conference discussion may need to be shared with the attending physician from time to time, and in many cases this leads to changes in the instructions to appropriate dressing materials or topical medicine. It is also important to assess how family members are practicing the instructed treatment every dav.
- (6) Consider consulting other specialists. Many physicians involved in visiting care are internists. Therefore, the attending physician may need to consult other specialists (e.g., a dermatologist, plastic surgeon, or surgeon). A home visiting nurse may serve as a mediator in such cases.
- (7) Review the frequency of visiting nursing. Visiting nursing must be provided once a day when a patient has severe pressure ulcers or is undergoing postsurgical debridement. The frequency may be changed as a patient's condition improves; for example, a once-weekly visiting nursing may be appropriate, depending on the condition of pressure ulcers or care environment.
- (8) Share information, including that of nutritional management, and have means for multidisciplinary collaboration. Medical staff are not always the ones providing treatment or care in the home. Different roles that home visiting nurses, family members, caregivers, or other care providers fulfill should be discussed at a conference meeting.

Outcome of the patients in FY 2012

Thirty three patients were the subject of the FY 2012 conference meeting of the Takashimadaira Home Nursing Station. Of those, 26 had pressure ulcers; 7 pressure ulcers were in Stage I, according to the National Pressure Ulcer Advisory Panel (NPUAP) classification; 6 were in Stage II; 5 were in Stage III; and 8 were in Stage IV. The 13 patients with pressure ulcers in NPUAP Stages III and IV had been either discharged from the hospital with these ulcers or been introduced to our home nursing station due to these ulcers from their care managers. The 13 patients with pressure ulcers in Stages I and II completely healed in about 1 month, except for those whose service was terminated due to hospitalization or other reasons. Of the 13 patients with Stage III or IV pressure ulcers, 5 either passed away or were hospitalized, 4 are still receiving care, and 4 completely healed in 77-203 days.

Conclusion

The necessity of visiting nursing will only increase in order to support both medical care and long-term care, and high-quality nursing will be in demand as well. More than 1,700 nurses in Japan are certified as the skincare and excretion care nurse, which requires a special training in pressure ulcer management. However, as matters now stand, less than 1% of them work at home nursing stations. Therefore, each home nursing station must have an original care program and make an effort to improve the quality of the nursing care service it provides.

We believe that we were able to achieve good results in our station by our special efforts,

including holding the conference about the pressure ulcers and wound once a week. Family members and long-term care service staff have also started practicing evidence-based care and applying their own initiative to prevent and heal pressure ulcers. Because the conference has been producing excellent results, our nurses have been able to gain more knowledge and skill, and it also made easy for other support members including family members to join and cooperate in our efforts. We recently had an opportunity to address residents of adjacent university hospitals and visiting care physicians in the neighborhood and invited them to participate in our conference. Our approach of caring patients with pressure ulcers as a team is expected to spread to other communities.

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Long-term Care Insurance Act and Home Care*

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Introduction

In 2006, the Ministry of Health, Labour and Welfare implemented healthcare system reforms, steering healthcare in Japan away from medical institution-centered healthcare to "communitycentered healthcare." The aim of this move is to build and strengthen cooperation within each community regarding healthcare and long-term nursing care. Behind this is recognition of the current situation whereby it is difficult for medicine alone to resolve problems stemming from regressive changes due to aging that are difficult to resolve solely through medical care. That the healthcare model has changed from a medical model to a lifestyle model¹ can be said to be a natural progression as the individuality-seeking generation enters old age. Furthermore, a society conscious of "living true to oneself," which is represented by the postwar baby-boomer generation, holds high expectations for home care, including care giving.

The author is an 11th-generation physician in private practice in Ichinoseki City, Iwate Prefecture. I grew up watching my grandfather and mother making house calls by carriage and bicycle. For me, visiting patients' homes was an integral part of healthcare, and I recall that this is the lifestyle that physicians lead decades ago. Today I am the head of a small clinic (with beds), and for 10 or so years—since the time I was teaching at a university—I have been providing visiting care. Each year I visit between 80 and 100 patients receiving medical care at home, and it is recognized that the ratio of patients receiving home care is increasing yearon-year. In March 2013 I formed a team with 5 other physicians, members of our local medical association, to create an enhanced home care support clinic. This team comprises physicians specializing in urinology, dermatology, and various fields of internal medicine as well as a physician from an emergency hospital. While utilizing their individual specialist skills, these physicians coordinate with nearby medical institutions to provide home care.

Reform of the Long-term Care Insurance System

Aimed at socializing nursing care and reducing the burden of nursing care on patients' family members, the Long-term Care Insurance Act was established in 2000, despite various problems. Since then, the number of nursing care service users has increased (**Table 1**), with numbers reaching more than 4.4 million in 2012 (an increase of approx. 2.4 times the initial number), and the system has become established as a system for supporting elderly living.

The purpose of the reforms implemented beginning in April 2012 was promoted as being to aim to create a society in which people can, as far as possible, live independently and with peace of mind in their familiar living environment within their community, shifting the focus from facility-centered healthcare. In particular, these reforms include strengthening of meticulous home care support through regular visits and services provided on an as-needed basis available 24-hours-a-day; performance of medical procedures, such as suctioning phlegm, and promotion of care prevention; and various living support and advocacy measures in response to

^{*1} This article is a revised English version of a paper originally published in the Journal of the Japan Medical Association (Vol.142, No.7, 2013, pages 1529-1531).

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No. of insured persons	21.65 million	23.98 million	28.95 million		
• The number of insured persons aged 65 years or older increased by approx. 7.3 million (34%) in 10 years.					
(2) Trends in the number of people certified as requiring long-term care (support)					
	End of April 2000	End of April 2003	End of April 2010		
No. of certified persons	2.18 million	3.48 million	4.87 million		
•The number of people certified as requiring long-term care increased by approx. 2.69 million (123%) in 10 years.					
(3) Number of applications for certification as requiring long-term care (support)					
	FY 2000	FY 2003	FY 2008		
No. of applications	2 69 million	5.47 million	5 million		

Table 1 Status of implementation of the long-term care insurance system

End of April 2000

01.05 million

(1) Trends in the number of insured persons aged 65 years or older

	FY 2000	FY 2003	FY 2008
No. of applications	2.69 million	5.47 million	5 million
The number of explications for	artification on requiring long to	man age in area and by an area	

. The number of applications for certification as requiring long-term care increased by approx. 2.31 million (86%) in 9 years. Note: The number of applications for 2008 is lower than for 2003 because in 2004, the validity period for renewing certification as

requiring long-term care was extended to a maximum of 2 years.

(Source: Health and Welfare Bureau for the Elderly, Ministry of Health, Labour and Welfare.)

End of April 2003

the increase in the number of elderly people living alone and incidence of dementia. Demand is increasing for the seamless provision of services, whether in medical institutions or at home.

NI (1)

However, with the increase in elderly people aged 75 or over, there are various issues that need to be addressed going forward, such as care for patients requiring a high level of nursing care, living support for aged households and elderly people with dementia, and securing nursing care human resources, whose turnover rate is said to be higher than that for other professions. The problem of nursing care workers leaving their jobs to care for their own family members has also been reported, and behind this is the trend towards nuclear families, the high percentage of unmarried people amongst second-generation baby boomers (born 1971-1974), and other changes in household composition. In future, there will be a need for thorough support for middle- and older-aged people forced to leave their jobs to care for an elderly relative.

In 2001, the WHO expanded the previous International Classification of Impairments, Disabilities and Handicaps (ICIDH) to create the International Classification of Functioning, Disability and Health (ICF).² Based on these classifications, there are voices calling for a change in focus regarding phrases such as "partial assistance" that appear in current long-term care insurance certification evaluations to residual

function support-type care, demanding more effective utilization of societal resources by maintaining and strengthening nursing car recipients' skills.3

End of April 2010

00.05 million

Super-aged Society and Dementia

According to the "Population Projections for Japan (January 2012)" issued by the National Institute of Population and Social Security Research, attention in focusing on the "2025 Problem"-when members of the baby-boomer generation reach age 75 or older as the aging of society progresses-and it is anticipated that aging of society in the three major metropolitan areas will become even more marked in the future. Furthermore, in regions where the population is declining, the population aged 75 and above is slightly increasing, while the population aged 65 to 75 is remaining constant or decreasing, presenting a different situation than that in major cities.

It is estimated that 15% of people aged 65 or older have dementia-more than 4.62 million dementia patients as of 2012.4 In particular, a large percentage of these dementia patients have Alzheimer's dementia, and in addition to "elder-to-elder nursing care," "dementia patientto-dementia patient nursing care" has been indicated as an issue for the aging society.

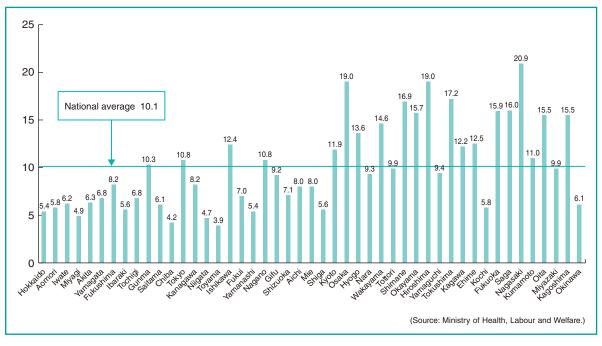


Fig. 1 Number of home care support clinics per 100,000 population by prefecture

Current Situation Regarding Long-term Care Insurance and Home Care

The Ministry of Health, Labour and Welfare has formulated policies to reduce the number of hospital beds occupied by elderly patients by 70,000 by the year 2025, with the patients released from hospitals being cared for mainly at home or in pay nursing homes or housing designed for elderly people by some 470,000 caregivers. The Special Feature (1) "Home Care" in Issue 139 of the Journal of the Japan Medical Association (published in June 2010)⁵ was subtitled "Home Care in Spare Time: Into the Community from Afternoon," but are there no regional characteristics to afternoon medical care systems?

As of 2010, there are more than 12,487 home care support clinics nationwide (13% of all clinics), an average of 10.1 per 100,000 population. The largest number is in Nagasaki Prefecture, where there are 20.9 home care support clinics per 100,000 population, and the smallest number is in Toyama Prefecture, where there are 3.9 home care support clinics per 100,000 population. The total number of home care support

clinics in the Hokkaido and Tohoku regions is below the average, showing a trend towards higher numbers in western Japan and lower numbers in eastern Japan (**Fig. 1**).

Analysis of the current situation regarding home care conducted by the Japan Medical Association Research Institute found that the content of services provided by facilities that are not registered as home care support clinics compares favorably with facilities that are registered as home care support clinics, and that maintaining motivation is important for their facilities to continue providing home care going forward. The institute's report also points out the need for strengthening logistical support with clinics with beds and hospitals supporting home care in order to construct a system.

Recently I participated in a workshop on home care and heard a wide range of opinions. "Why is visiting care necessary in addition to house calls?" was a question from physicians who, rather than going "into the community from afternoon" are "also very busy in the afternoon." In contrast, many physicians who provide visiting care sought coordination between medical associations and physicians, saying that "Multiple physicians are necessary to provide house calls in response to emergency situations."

Even greater leadership in the local community overall is being required of family physicians. The benefit of home care is that it can be adapted to individual lifestyles and family situations, and various aspects of people's lifestyles can be seen in home care that cannot be seen in a physician's examination room. For families, accepting visits by healthcare professionals is a major decision. What is most important, I believe, is relationship between family members and healthcare professionals involved in home care where "each can see the other's face."

Conclusion

Since the implementation of reforms to the Long-term Care Insurance Act beginning in April 2012, attention has been drawn to problems such as the increase in the number of people requiring a high level of nursing care and with dementia, as well as the decline in the ability of families to provide nursing care.

In addition, there is an increasing demand for the provision of seamless healthcare service by professionals in different areas of healthcare, such as the shift in emphasis from healing healthcare to a living support model under the healthcare system reforms indicated in 2006 and construction of comprehensive community health care systems under the simultaneous reforms of healthcare and nursing care implemented in 2012. In particular, in order to maintain the motivation of medical institutions that have not registered as home care support clinics, there is a need for medical institutions providing logistical support and home care support clinics to work together and support each other's activities. Going forward, as a major turning point changing community medicine from lines to surfaces, enhanced home care support clinics established in or after 2012 will be required to further strengthen coordination using living support for the aging society as a pivoting point.

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Infection Prevention and Control at Home*

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Introduction

Infections have always been a problem for health workers. As for infection prevention and control in welfare facilities and medical facilities including hospitals and clinics, such institutions prepare infection control manuals and endeavor to adequately implement control measures as specified in them. However, infection control at home presents a different set of challenges. The situation may well be that many people are at a loss as to how to take infection control measures because the environment and situations vary from one home to another. Given the importance of this issue, the present article focuses on infection prevention and control at home, with the ultimate goal of allowing all physicians to provide home care with assurance.

Basics of Infection Management at Home

Similar to the situation in medical or welfare facilities, the first priority of infection management at home is the implementation of standard precautions. Among these practices, "hand hygiene" and "use of personal protective equipment" play the central roles.

Hand hygiene (hand washing)

Hand washing is regarded as the most important measure among the various protective measures applied against infection. It is necessary to implement this practice without fail to protect both patients and care providers. In the home care practice setting, it is recommended that the hands be washed after examining a patient in their home whenever possible. In this case, the hands should be washed with running water for at least 15 seconds, rather than with pooled water in a wash bowl, a common practice for doctors providing visiting care in past times, as seen in TV programs, etc. The use of liquid soap is desirable, because it is likely that various bacterial organisms will be growing in the soap plate or in the soap itself at home. After washing, the hands should be wiped completely dry with a paper towel, which is then discarded hygienically. Finally, the doctor should keep the hands dry when traveling to the home of the next patient.

However, if there are no obvious contaminants (blood, body fluid, secretions, excretions, etc.) on the hands, a quick-drying rubbing alcohol preparation can be used instead. In actuality, when a doctor sees patients serially within an institution such as a group home or a nursing home, this method is recommended because it is difficult to wash the hands with running water before seeing each patient. Hand cleaning employing this procedure is feasible when it is difficult to access tap water at the patient's home because the sink is not nearby, because there is a shortage of time, or because various other circumstances are present. The bottles of rubbing alcohol preparations are portable and can be placed at any site; therefore, this procedure can be practiced more easily than hand washing which is not always convenient. In practice, a small, portable bottle of antiseptic may be suspended from the waist, put in a pocket, or prepared in the visiting vehicle.

"Hand-rubbing with an antiseptic in the absence of contamination" is strongly recommended by the 2002 update of the Guideline for

*1 This article is a revised English version of a paper originally published in the Journal of the Japan Medical Association (Vol.142, No.7, 2013, pages 1532-1534).

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Hand Hygiene by the US Centers for Disease Control and Prevention (CDC). The reasons for this recommendation are explained as follows: alcohol causes a more prominent decrease in bacterial counts, and is effective in a shorter period of time than the use of soap and running water when there is no macroscopic contamination of the fingers. It is also noted that alcohol preparations containing skin protective components are less likely to cause the hands to become rough and dry.

Wearing gloves

Gloves should be worn when contact with the patient's blood, body fluid, secretions, or excretions is inevitable or presumable, for instance in the case of blood sampling, oral care, or wound treatment. From a different perspective, however, the doctor should also wear gloves when there is a wound on his or her own hand. Hand washing should always be conducted after removing the gloves.

Wearing a mask and apron

Masks and aprons are not always necessary. In fact, the occasions for wearing such equipment are not particularly common. However, the care provider should wear a mask when the face is likely to come into contact with the patient's blood, body fluid, secretions, or excretions, and should wear an apron when the body is likely to come into contact with these biological materials.

Infection Specifics

Influenza

Influenza is a prevalent disease virtually every winter. Home-bound patients often become infected with influenza when they go out to use ambulatory services such as day services or day care, or with their families.

Elderly people infected with influenza are apt to be dehydrated because of high fever, and are characteristically prone to developing pneumonia as a complication. Even if they remain free of pneumonia, it is not rare for general condition to worsen rapidly and become life-threatening in patients who have had a disease of the lung or heart before being infected with the influenza virus. In fact, many elderly people die every winter because of influenza or pneumonia associated with influenza. If influenza spreads in welfare institutions where numerous elderly people reside, there is a high risk of severe or lifethreatening illness. Therefore, influenza is a very important infection for which aggressive preventive measures should be in place.

For prevention of influenza, vaccination is significant and effective. Once vaccination has been conducted, disease onset might be inhibited even when the vaccinated person is infected, or worsening of the disease and the occurrence of complications may be prevented even after the onset of this disease. Therefore, vaccination prior to the beginning of the influenza season is currently considered to be one of the most effective methods of preventing influenza outbreaks among home-bound patients and residents of institutions. As mentioned previously, infection with influenza in home-bound patients often occurs when they go out in order to use ambulatory services or with their families. Therefore, it is necessary to encourage others, who may carry such infections, i.e., health workers, nursing care providers, and family members, to receive the vaccine every year. In welfare facilities, epidemics within the institution can be prevented by recommending vaccination for institution staff members.

However, unfortunately, the efficacy rate of vaccination is not 100%. Therefore, the rapid diagnosis kit should be used promptly when influenza infection is clinically suspected, and anti-influenza drug therapy should be promptly initiated whenever the test result is positive.

Tuberculosis

The incidence of tuberculosis remains high in Japan as compared to other major industrialized countries. In particular, increased disease onset in people of advanced age has recently been attracting considerable attention. It is said that secondary tuberculosis is now occurring in patients over age 70 years who were previously infected when tuberculosis was more prevalent in Japan. Tuberculosis may manifest in elderly people who have decreased immunity even if they were immunized due to previous infection with the tuberculosis organism. Tuberculosis is clearly an infection that requires particular attention in the practice of home care that involves many elderly patients.

Clinical diagnosis of tuberculosis is difficult. Diagnosing tuberculosis by general examination, while providing home care, is especially challenging. Tuberculosis should first be suspected in patients who have symptoms such as prolonged coughing (particularly that persisting for more than 2 weeks), sputum, and fever. Doctors practicing in the age when tuberculosis was prevalent probably had extensive experience, but modernday doctors seldom see patients with tuberculosis. It should again be underscored that initially suspecting tuberculosis infection is the most important step in diagnosing this disease. For home-care patients in whom it is difficult to perform chest radiography, conducting sputum examination aggressively is recommended.

If active tuberculosis is identified by sputum examination, etc., the major task that home-care doctors must carry out is to promptly refer the patient to an appropriate medical facility for hospitalization. Chest radiography and the tuberculin test should be performed on the patient's family members, residents of the same facility, and medical and nursing care providers who had contact with the patient. These steps should be carried out in consultation with the local health department.

Methicillin-resistant Staphylococcus aureus (MRSA)

Carrier tests for MRSA were strictly conducted in home-care patients or residents of institutions until a decade ago. Restrictions and limitations were set for receiving various services by persons in whom MRSA was detected. This situation was derived from the misunderstanding that MRSA infection might manifest in healthy elderly carriers, although this disease manifests in people with weak defenses such as postoperative inpatients who have undergone major surgery. Basically, MRSA carriers who live at home or in an institution usually reach the ends of their lives without disease onset. Currently, MRSA carriers are not subject to isolation or bacterial eradication, but basic procedures including hand washing are still necessary.

Scabies

The major symptom of scabies is itching. However, many elderly people also complain of itching from other causes. Scabies is often mistaken for eczema, if the skin is not observed closely. Basically, it is very important to examine the skin meticulously on a routine basis. In actual clinical practice, prolonged use of steroids for intractable eczema without careful consideration should be avoided. Instead, it is desirable to refer the patient to a dermatologist in an early stage (transmitting images to the specialist by email via the Internet is a recent, efficient method) to facilitate early diagnosis and early treatment. For this purpose, care should be regularly coordinated with dermatologists in the local medical association.

Viral gastroenteritis

Viral gastroenteritis is a type of gastroenteritis that often becomes widespread in welfare institutions and similar facilities in winter. Most cases are caused by norovirus or rotavirus. To prevent epidemics in institutions, those institution residents in whom infection is suspected should be dealt with in a private room if possible, with strict adherence to procedures for washing hands and wearing gloves, in accordance with standard precautions. If the floor is contaminated with vomitus or bodily excretions, 0.1% sodium hypochlorite should be used for disinfection. If viral gastroenteritis is prevalent in the community and if one or more family members have become infected, it is important that visits to the institution by the family are suspended, to the maximum extent possible, until the outbreak has fully subsided.

Blood-mediated infections

Prevention of needle-stick accidents, among other inadvertent events, is important for preventing blood-mediated infections including hepatitis B and hepatitis C. Basically, the most important procedures involve absolute avoidance of recapping the needle tip and also discarding needles appropriately.

Conclusion

Although some devices are necessary in individual homes, infection control and prevention measures in home care are basically similar to those in medical and welfare facilities; it is the standard precautions that truly matter the most. Because people who are involved in home care of patients are not restricted to healthcare providers, it is important for a variety of workers to strictly adhere to the established standard precautions.

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Nutritional Management in Home Care: Including Eating Disorder and Dysphagia Assessments^{*1}

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Ichiro FUJISHIMA¹

Assessment of Malnutrition in the Elderly

Malnutrition is a condition that generally develops when one's intake of protein and calories is chronically lower than the consumption. There are many nutritional assessment methods such as the Subjective Global Assessment (SGA) and the Mini Nutritional Assessment[®] (MNA[®]), which are discussed in another text book.¹ In this article we mainly focus on the challenges of nutritional assessment in home care.

The first step of nutritional assessment is to obtain the accurate amount of food intake. The patient him/herself or the family members may claim that the patient has eaten enough; however, the amount of food the patient has actually ingested is often questionable. In some situations, elderly patients may frequently spill or drop food, or family members may think that the elderly require only a small meal portion. The caloric intake and nutrition of an elderly patient may become imbalanced. The entire family may also have a habit of consuming an unbalanced diet. All of these diet issues must be approached with caution. It is important to conduct interviews to specifically ask questions regarding the type and quantity of food consumed by the patient and maintain records of all meals consumed. Although it may be difficult in a home care environment, it is recommended to weigh (in grams) food intake portions on a scale for more accurate records.

A simple method of nutritional assessment is regular monitoring of body weight. Understand-

ably, regular blood tests should be conducted to evaluate albumin or total protein, blood urea nitrogen, creatinine, and electrolyte levels as well as anemic conditions. Physicians should also remember that malnutrition may be a hidden cause of pressure ulcers, repeated fever, aggravation of dementia, muscle weakness, or reduced activity levels. Physicians should also recognize that electrolyte abnormalities among the elderly can be caused by the excessive use of laxatives due to constipation, diarrhea, extremely low-salt diet, excessive intake of vegetable juices or nutritional supplements, or administration of herbal medicines or over-the-counter drugs. Furthermore, malnutrition can be caused by a reduced food intake due to dysphagia (described in detail below), which should be considered for nutritional assessment.

Assessment and Tests for Dysphagia²

The common symptoms of dysphagia patients are described in **Table 1**. The two main methods for assessing dysphagia are screening and detailed examinations; evaluations using questionnaires (**Table 2**) and clinical observations are more reasonable and easier for general physicians and nurses. Patients who eat regular meals or softened vegetables are asked to mark their answers on a questionnaire. Patients are considered as being "problematic" or having "no major problem" if they answer A or B, respectively, to any of the questions. The main points to observe during eating are summarized in **Table 3**. Please note that these are only examples

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Table 1 Main symptoms for suspecting and diagnosing dysphagia

Choking: When and what kinds of food the patient chokes?

Cough: Does the patient cough more frequently during and/or after a meal or at nighttime?

Sputum (its character and amount): Does the sputum contain food residue, or is there an increase in the amount of sputum after the patient starts to eat?

Sensation of residual food or abnormal sensation (in pharynx): Does the patient experience an abnormal sensation (e.g., residual food) in the pharynx or other areas?

Sense of swallowing difficulty: Does the patient feel a different swallowing difficulty sensation with different food items?

Voice: Does the patient's voice change after a meal (i.e., hoarse voice)?

Loss of appetite: Dysphagia can cause choking or breathing difficulty, causing the patient to become hesitant in eating. Change in diet: Does the patient select foods that are easy to swallow?

Longer mealtime: The patient continues chewing for an extended period without swallowing the food or takes extra time to swallow.

Changes in eating pattern: The patient eats while looking up, switches between soups and other dishes in an alternating fashion, or drops food from his/her mouth.

Fatigue during meals: Does the patient experience hypoxemia associated with eating?

Oral care problems: The patient may have extensive dental plaque or residual foods; bad breath may be associated with the oral stage of swallowing (during which a bolus moves from the oral cavity to the pharynx).

Table 2 Contents of dysphagia screening questionnaire

Name		Age	M / F
Date of Birth (Year/	Month/Day)	/	/
Height	cm	Weight	kq

The following questions are related to how you swallow food (i.e., swallowing food from the mouth until it reaches the stomach). All questions are related to important symptoms. Please read each question carefully and mark your answer as A, B, or C. Please answer these questions based on your experiences during the last 2 or 3 years.

	1. Severe symptoms	2. Mild symptoms	3. No symptoms
1. Have you ever been diagnosed as having pneumonia?	Many times	Once	No
2. Do you feel you are becoming thin?	Obviously	Slightly	No
3. Do you ever have difficulty when you swallow?	Many times	Sometimes	No
4. Do you ever choke during a meal?	Many times	Sometimes	No
5. Do you ever choke when swallowing liquids?	Many times	Sometimes	No
6. Do you ever have difficulty with coughing up phlegm during or after a meal?	Many times	Sometimes	No
7. Do you ever have the feeling that food is getting stuck in your throat?	Many times	Sometimes	No
8. Does it take you longer to eat a meal than before?	Obviously	Slightly	No
9. Do you feel that it is getting difficult to eat solid foods?	Obviously	Slightly	No
10. Do you ever drop food from your mouth?	Many times	Sometimes	No
11. Do you ever have the feeling that food is remaining in your mouth?	Many times	Sometimes	No
12. Do you ever have the feeling of food or liquid going up into your throat from your stomach?	Many times	Sometimes	No
13. Do you ever have the feeling that food is getting stuck in your esophagus?	Many times	Sometimes	No
14. Do you ever have difficulty sleeping because of coughing during the night?	Many times	Sometimes	No
15. Do you feel that you are getting hoarse?	Obviously	Slightly	No

(Kawashima K et al. Dysphagia Screening Questionnaire.)

Objective/symptom	Points to observe	Potential primary conditions and disabilities
Food recognition	The patient is dazed or has restless eyes.	Impaired cognitive perception of food and distraction
Use of devices for eating	Food drops before reaching the mouth.	Paralysis, ataxia, apraxia, and agnosia
Meal contents	The patient avoids certain items.	Oral and/or pharyngeal stage problems, taste disorder, reduced saliva secretion, and oral disease
Dropping from the mouth	Food is dropped out of mouth.	Problems in taking and holding food into the mouth and paralysis in lips/cheeks
Mastication	Vertical movements of the lower jaw only; no rotational movements Inability to chew hard foods	Problem in the masseter muscle Caries, incompatible denture, periodontal disease, etc.
Before initiation of the swallowing reflex	Continued chewing without swallowing for a long time or takes effort to swallow Swallowing with neck extension	Problems in the oral and/or pharyngeal stage Problem in transporting food
Choking	Certain items (e.g., soups) cause choking. Choking occurs early during the meal. Choking occurs later during the meal.	Aspiration and pharyngeal residues Aspiration and carelessness Aspiration, pharyngeal residues, fatigue, muscle weakness, and gastroesophageal reflux
Cough	Coughs occur mainly during and/or after a meal.	Aspiration, pharyngeal residues, and gastroesophageal reflux
Voice	The voice changes during or after a meal.	Aspiration and pharyngeal residues
Mealtime	Each meal takes 30-45 minutes (or longer).	Cognitive stage disorder, problems in bringing food into the mouth, or transporting food from the mouth
Appetite	Appetite is lost during a meal.	Cognitive stage disorder, aspiration, pharyngeal residues, and reduced physical strength
Fatigue	Vitality is lost or feels tired during a meal.	Aspiration, pharyngeal residues, and reduced physical strength

 Table 3 Points to observe when the patient is eating

of observations; it is fundamental to carefully listen to the patients and family members and observe the clinical setting. The 2 options of precise examination for dysphagia are videofluoroscopic and video-endoscopic evaluation of swallowing. Both tests are usually conducted at hospitals. However, video-endoscopic evaluations can also be conducted at home using a portable fiberscope, which has become popular among physicians.

Dysphagia Management

The procedures that can be performed immediately to address minor dysphagia problems are shown in **Table 4**. Patients with a moderate or severe degree of dysphagia are generally treated in well-equipped hospitals.

Practical Factors Involved in Providing Swallowing Rehabilitation at Home

Providing swallowing rehabilitation at the patient's home involves his/her family, a service provider under the national long-term care insurance, medical institutions, and other various professions. Collaborations among all these members are essential,³ and it is important to approach rehabilitation from the idea of community-based teamwork, i.e., community dysphagia management teams. Each dysphagia management team may consist of different members and roles, such as meal preparation including an easy-to-swallow diet⁴ and staff who can provide swallowing rehabilitation, manpower to assist eating, and risk management. The requirements in a team can vary greatly among communities and institutions;

Table 4 Rehabilitation procedures on the scene

- 1. Ask the patient to focus on the act of swallowing
- 2. Ask the patient to hold his/her breath while swallowing (i.e., the patient must firmly hold his/her breath when swallowing)
- 3. Chin down (i.e., the patient should look down when swallowing)
- 4. Neck rotation (i.e., the patient should look down at his/her right or left when swallowing)
- 5. Change to a thickened liquid (toromi) or jelly diet
- 6. Drinking and eating in a reclining posture

therefore, the collection and organization of information regarding the capacity of each team is required. When collaborating, it is important that the team shares common treatment policies and goals, knowledge about the underlying disease (e.g., state of the disorder, prognosis, risks, and future approaches), and provide education to family members. Furthermore, the team should discuss and share information regarding the type of oral care provided, content of the meals, and methods applied to assist with eating. It is strongly recommended to use documents and pictures to specifically verify the care that the patient was provided.

Dysphagia Management Methods by the Degree of Severity

The key in educating and instructing patients with preliminary or a mild degree of dysphagia is detecting its signs, providing instructions early, and devising inexpensive and effortless methods. Patient instructions should include: (1) explanations about normal swallowing and dysphagia, (2) oral care, (3) swallowing exercises (the Fujishima Style swallowing exercise set),³ (4) conscious focus on swallowing, (5) not lying down right after a meal, and (6) 10 rules to maintain eating ability for years.³ Patients with a moderate or severe degree of dysphagia should ideally be diagnosed and treated at well-equipped hospitals.

However, the patient may need to be placed under home care if: (1) the patient's dementia will likely progress by staying at a hospital, (2) the patient is receiving end-of-life care, (3) the patient and/or family members are refusing to be admitted, or (4) home care is the only option because nearby hospitals cannot accept inpatients. Home care, on the other hand, may provide better outcomes because of several unique advantages, such as: (1) lack of pressure to vacate an inpatient bed, which will enable the patient to fully commit to rehabilitation; (2) familiarity of environment that allows the patient to demonstrate his/her best efforts; and (3) opportunity for care providers to become familiar with the patient's background, allowing them to provide attentive and personalized responses for each individual patient.

Key Points in Managing and Maintaining Eating Function

The key points in managing and maintaining eating function are to correctly understand the underlying diseases and disorders, and prevent pneumonia, dehydration, and malnutrition by applying knowledge and techniques regarding swallowing rehabilitation. The daily nutritional goals should be a calorie intake of 20-25 kcal/kg, fluid intake of $\geq 30 \text{ mL/kg}$, and protein intake of 60-70 g. Malnutrition and dehydration can exacerbate dysphagia, which in turn can worsen malnutrition, leading to a vicious cycle. Introducing fluid therapy, supplementary meals/snacks, and/ or nutritional supplements⁵ should be considered while patients are still in an early stage of dysphagia. There may be cases in which tube feeding should also be considered as an option.6

It is crucial that family members and the staff involved establish a close relationship so that they can report to and consult each other when a change is noticed and discuss any concerning issues that may arise.

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Home Respiratory Management: From COPD to Neurological Diseases^{*1}

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Significance of Respiratory Management

Difficulty breathing leads directly to a lifethreatening condition, representing a serious issue in clinical practice. Respiratory failure is defined as a functional disorder of the respiratory system showing an arterial oxygen tension (PaO₂) of 60 Torr or less in the absence of oxygen administration. Physical findings of respiratory failure include tachypnea, tachycardia, engorgement and edema of the jugular vein, and cyanosis. Emaciation, depression of the clavicular fossa due to hypertrophied accessory respiratory muscles, shoulder breathing, and pursed-lip breathing may also be observed as characteristic findings. If the patient lapses into CO₂ narcosis, headache or disturbed consciousness ranging from subtle personality changes to confusion or coma may occur. Respiratory management is aimed at reversal of the pathological systemic and mental states derived from respiratory failure, toward restoration of an acceptable physiological condition.

Respiratory Management and Its Current Status in Japan

Home respiratory management includes home oxygen therapy (HOT) and home mechanical ventilation (HMV). HOT comprises inhalation of oxygen at home by patients with advanced chronic respiratory failure due to cyanotic congenital heart disease or various other causes, those with pulmonary hypertension, or those with chronic heart failure (Table 1).

HMV is defined as mechanical ventilation at home in patients who are in a stable disease state and who depend on continuous long-term mechanical ventilation. Patients on HMV are mainly those who have neuromuscular diseases, chronic obstructive pulmonary disease (COPD), or sequelae of pulmonary tuberculosis. HMV uses a positive pressure ventilator by which air is delivered to the airway via positive pressure or a negative/positive pressure external ventilator with a cuirass respirator.¹

Positive pressure ventilation is widely used in Japan; this procedure is divided into invasive mechanical ventilation that involves tracheostomy, i.e., tracheostomy intermittent positive pressure ventilation (TPPV), and noninvasive mechanical ventilation, i.e., positive pressure ventilation (NPPV) by which ventilation is implemented through a mask covering the nose and mouth or the entire face. According to a questionnaire survey by the Japanese Respiratory Society, patients with neuromuscular disease account for 72% of all those on TPPV, whereas patients on NPPV had COPD (26%), sequelae of pulmonary tuberculosis (23%), neuromuscular disease (18%), sleep apnea syndrome (14%), and so on.² Continuous positive airway pressure (CPAP) at home is used for patients with sleep apnea syndrome (Table 1). The major advantage of TPPV is that a patent airway can reliably be maintained, but the implementation rate of this method is only about 5% because of its invasiveness.

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	НОТ	NPPV	TPPV	СРАР
Chronic Obstructive Pulmonary Disease (COPD)	\bigcirc	O	0	
Sequelae of pulmonary tuberculosis	\bigcirc	\bigcirc	\bigcirc	
Lung cancer	\bigcirc			
Pulmonary fibrosis/interstitial pneumonia*	\bigcirc	\bigcirc	\bigcirc	
Kyphoscoliosis		\bigcirc	\bigcirc	
Neuromuscular disease**	\bigcirc	\bigcirc	\bigcirc	
Congenital heart disease	\bigcirc			
Diffuse panbronchiolitis	\bigcirc	\bigcirc	\bigcirc	
Angiogenic pulmonary hypertension	\bigcirc	\bigcirc	\bigcirc	
Cheyne-Stokes breathing due to chronic heart failure	\bigcirc			
Pulmonary thromboembolism	\bigcirc			
Alveolar hypoventilation syndrome		\bigcirc	\bigcirc	
Sleep apnea syndrome		O	0	O

Table 1 Methods of respiratory management and indications

 \odot Recommended, \bigcirc Indicated

* Interstitial pneumonia: idiopathic pulmonary fibrosis, pneumoconiosis, sarcoidosis, farmer's disease, etc. ** Neuromuscular disease: muscular dystrophy, myasthenia gravis, ALS, spinal progressive muscular atrophy, Parkinson's disease/related diseases, multiple system atrophy, sequelae of poliomyelitis, sequelae of cerebrovascular disorder, Werdnig-Hoffmann disease, phrenic nerve paralysis, etc.

Indications and Practical Aspects of HOT

HOT is indicated for patients with a PaO_2 of 55 Torr or less and those with a PaO_2 of 60 Torr or less who have marked hypoxemia during sleep or exercise. Among the beneficial effects of HOT, it was reported to alleviate subjective symptoms, reduce the burden on the cardiorespiratory system, and lead to mental stability, resulting in improved quality of life (QOL), reported as "enabling the patient to go out" or "decreasing hospitalizations."²

Indications for and Practical Aspects of NPPV

The introduction of HMV is planned when control of respiratory failure is assumed to have become difficult. Because NPPV is noninvasive, it is common for NPPV to be introduced first. Timing of the introduction of NPPV is as follows: when the patients have subjective symptoms such as morning headache, sleeplessness, and fatigue, when signs of cor pulmonale or dyspnea on exertion occur, or when day-and-night hypoventilation symptoms or hypercapnia occur. If compensation as evidenced by labored respiration is present, it is necessary to avoid exhaustion of respiratory muscles by early introduction of NPPV even in patients whose laboratory values are within the normal ranges.

Bilevel PAP is a method of assisting ventilation in concert with the patient's breathing employing two pressures, i.e., an inspiratory positive airway pressure (IPAP) of 8-20 cmH₂O and an expiratory positive airway pressure (EPAP) of 0-4 cmH₂O. Nose, nose-mouth, and face masks are available. For smooth introduction of this method, use of the mask should be restricted, i.e. kept within a short period of time, and then gradually prolonged in the early introductory phase, until the mask becomes usable during the night. The general initial settings are as follows: spontaneous/timed (S/T) mode, IPAP 6-8 cmH₂O, EPAP 4 cmH₂O, respiratory rate 12/min, and maximum percent inspiratory time (%IPAPmax) 30-40%. This procedure is worth conducting even in patients with progressive disease who will require respiratory management with TPPV in the future, because QOL is improved by relieving respiratory discomfort albeit temporarily and because the patient is given additional time to mentally prepare for starting TPPV.

Indications for and Practical Aspects of TPPV

Neuromuscular disease is the most frequent reason for patients being on TPPV. In recent years, downsized turbine-type mechanical ventilators have become dominant, allowing patients to go out or travel using portable batteries if their conditions are stable. Although the mean survival time is about 6 years in patients with amyotrophic lateral sclerosis (ALS) using TPPV, some may survive for more than 10 years. Therefore, approaches to achieving better palliative care and improvements in QOL are extremely important.³

Positive end-expiratory pressure (PEEP) and fraction of inspiratory oxygen (F_1O_2) are important elements in condition setting for mechanical ventilation. The level of PEEP must be set so as to prevent pulmonary collapse, while minimizing oxygen administration. In condition setting for acute lung injury, a tidal volume of 6 mL/kg and a peak airway pressure of less than 30 cmH_2O are recommended.

Synchronized intermittent mandatory ventilation (SIMV) is a method of providing mandatory ventilation intermittently in synchronization with spontaneous breathing. In addition to a pressure support level of $10 \text{ cmH}_2\text{O}$ and a PEEP of 4-10 cmH₂O, mechanical ventilation management should be performed by SIMV with pressure controlled ventilation (PCV) at 15-18 cmH₂O, a ventilation rate of 10 breaths/min, and an inspiratory time of 1.5 s.

The frequency of regular exchange of the tracheal cannula is usually about once a week. However, in cases with marked expectoration likely to cause airway obstruction, the cannula should be exchanged on additional occasions, and the frequency of regular exchange should be reconsidered. Because the use of disposable circuits has become more common recently, the ventilator circuit is usually exchanged once a month. It is desirable to use minimum cuff pressure of the tracheal cannula to avoid air leakage during inspiration, the risk of aspiration during body motion, ischemic injury to the lining membrane of the trachea, and so on. The instruction should be to set a target pressure that gives "the same hardness as the ear lobe," preferably not more than $30 \,\mathrm{cmH_2O}$.

To treat intratracheal granulation or granulation at the tracheal orifice, adrenocortical steroids should be used in an early stage, and external antibiotics should be applied if there is accompanying bleeding. Consultation with an otorhinolaryngology specialist is recommended for cases showing marked granulation because endoscopic observation and surgical treatment are required. When pneumothorax, pneumomediastinum, or subcutaneous emphysema has occurred, proper insertion of the cannula into the trachea should be confirmed, and the conditions of the ventilator be adjusted to properly maintain the airway pressure at 20 cmH₂O or less. Stress including communicative disorders due to prolonged respiratory management may cause gastrointestinal ulceration, and administration of antiulcer drugs such as proton pump inhibitors should thus be considered.

When the alarm of the ventilator is frequently activated, the patient's respiratory status should be confirmed first, and the ventilator and accessories should then be examined for defects. The setting of the ventilator should, in fact, be double-checked. If there are no abnormalities, the alarm level should be adjusted. However, prudence is required in altering the alarm level because this may lead to overlooking problems in the patient or the device.

Double-lumen cannulas and speech cannulas have recently become available, and are now conducive to home TPPV management. The use of intra-cannula continuous quantitative suction devices and cough assist devices decreases the risk of aspiration and respiratory infection in patients on HMV. In view of the importance of securing batteries as recognized through the experience of the Great East Japan Earthquake Disaster, the favorable appraisal that external batteries are now covered by health insurance has been obtained.

Items Necessary for Home Respiratory Management

At the time of introducing home respiratory management, various actions such as administering drug therapy, instructions on the use of devices, respiratory rehabilitation, diet/nutrition therapy, and infection prevention measures are taken to the maximum extent feasible, necessitating adequate preparation and training of the patient and family. Home medical care aims to reduce the need for hospitalization by stabilizing the disease state while paying attention to the aims and requests of the patient, and to support the patient in leading an adequately satisfying life by providing a good environment for treatment at home, to achieve the goal of QOL improvement for the patient and family.

Respiratory rehabilitation involves modification of the breathing pattern and flexibility training. In whole-body endurance and muscle strength training, specific and easily understandable instructions should be given to facilitate incorporation of an exercise habit into the patient's lifestyle. When the disease has progressed, programs designed for protectively and palliatively maintaining physical strength and reducing the burden of nursing care should be implemented, without causing undue strain on the patient. To enhance the effect of rehabilitation training and to suppress weight loss that progresses along with decreasing respiratory function, combined use of nutrition therapy is important. Beginning with oral care and diet therapy, artificial feeding management should be considered.4 Needless to say, influenza and pneumococcal vaccinations are important in the infection prevention strategy.

It is important to take advantage of regional health resources and formulate plans for the coordination of primary care doctors and homevisit nursing care stations via the regional medical network. According to a questionnaire survey conducted by the Japanese Respiratory Society, institutions that provide doctors' visits to patients receiving home TPPV account for 52%, prescription of home-visit nursing care 92%, and use of helpers or public health nurses 74%.² Prompt establishment of a home management system that includes the home-visit medical care system, rehabilitation training at home, home-visit nursing care, and telemedicine (remote medical care), based on the active use of social resources such as the Law for the Welfare of the Physically Disabled Persons (physical disability certificate) and long-term care insurance, is desirable to reduce the burdens on both patients and their family members.

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Home Rehabilitation*

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Introduction

There has been a general tendency to shorten the duration of hospitalization, and the focus when restarting home care is placed on disease control and management. Consequently, the support for home care patients (hereafter referred to as the subjects) in terms of assisting their everyday life has become insufficient. Home rehabilitation is one of the supportive tools that allow the continuation of care in a familiar living environment. The aim of home rehabilitation is to resume the subject's "activity," improve the quality of life (QOL), reduce the burden on caregivers, and prevent the manifestation of new disabilities by assisting with what the subject desires to do.

How to Proceed with Home Rehabilitation

Rehabilitation is a medical technology regimen to manage "disabilities." The WHO (2001) defines the term *disability* as all that make one's life difficult to live, stating that very comprehensive approach should be adopted to examine and resolve all issues caused by such difficulties including the limitation in activity and social restriction as well as private and environmental problems (Ueda 2005).¹ All knowledge and skill that can improve the subject's QOL is rehabilitation, and rehabilitation is applicable to all cases of home care.

It is important to send someone and prepare something active in the subject's environment to be incorporated in the subject's "activity" as soon as any change in his/her living functions is found out. A subject who is recently discharged from a hospital or other health institution after an acute illness requires greater caution since the subject is facing a major change in environment. In the case of the elderly, uncomplicated reasons could reduce their living function, for example, simple events such as almost falling over or staying in bed for a few days.

In home rehabilitation, the key to maintain their living function lies in the ability to take a "sitting position." The posture and the duration of the sitting position should be evaluated. A subject may be able to take advantage of outpatient services if he/she can safely stay in a sitting position in a chair with a back support, e.g., a wheelchair, for more than 30 minutes. Staying in a sitting position can stimulate a subject's mental activity and reduce the burden on his/her caregivers.

There are 2 types of community services. One involves home-visit rehabilitation by the rehabilitation specialists that is offered as a personalized therapy, and the other involves daycare rehabilitation that is offered as a group therapy. Those interested in using home-visit rehabilitaion are advised to consult a Care Manager. The service is available under the national longterm care insurance. However, a Care Manager may need to evaluate the services that the subject is already receiving due to the restriction in the fee schedule under the national health insurance policy. Once the issue of the fee restriction is resolved, a standard Patient Referral Document will serve as the source of information for prescribing rehabilitation. Information regarding medical risks is essential to prescribing rehabilitation. Nevertheless, the document can

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be comprehensive in nature such that it incorporates the goals set for the subject that have been discussed and agreed among the subject/ caregivers and other experts in home care and rehabilitation including a Care Manager.

What Can Be Achieved

Case of a cancer patient

Case: An 83-year-old male, who suffered cerebral infarction that caused right hemiplegia after right lung cancer surgery and developed prostate cancer with thoracic and lumbar vertebral metastases.

History: The subject's lower lobe of the lung was resected 3 years ago during the right lung cancer surgery, but a part of the lesion remained. As for his activity of daily living (ADL), he spent his life independently and walked with a cane, and he was receiving treatment on an outpatient basis by visiting a hospital alone. On March 8, he suddenly started to slur, and right hemiplegia appeared. He was diagnosed with cerebral infarction and hospitalized. The metastatic bone lesions were later confirmed, and a biopsy revealed that his prostate cancer had metastasized to the thoracic and lumbar vertebrae. He was discharged from the hospital and returned home on April 24 since he could not be transferred to a specialized rehabilitation hospital because of his cancer.

On April 30, his family called the author's office with a request for home rehabilitation for hemiplegia. The grip strength (right/left) was 18.9/16.0 kg. He required help to move to an upright position. His Long-term Care Need was identified as level 3. He lived with his wife and a daughter's family, in a family with a total of 6 members. He regularly used diapers and required his daughter's assistance for defecation. His appetite increased after being discharged from the hospital, and the irregular schedule of his defecation made the excretion care difficult. Transferring to/from a wheelchair required 2 or more nurses when he was an inpatient. In-hospital evaluation for bathing was not conduced because he did not take a bath during a hospitalization. As for future care, no home nursing plan had been made, and there was no specific physician involved for house calls yet. He only had an appointment with an urologist in May. When the author examined him, his blood pressure was

recorded at 135/62 mmHg and his pulse was 102 beats per minute. The subject reported no symptoms in particular.

"I want to go outside," he said. It was deemed necessary to prepare the environment in which the subject can safely assume the wheelchair position, so we started regular visits twice a week. Upon identifying contraindicative movements due to bone metastasis with the original hospital, a method to safely transfer the subject to a wheelchair was investigated, and the training was carried out to practice waking up and improve sitting tolerance. Some medication management methods were also proposed to control the regularity of the excretion schedule. On May 14, he received his first bathing service, which marked the end of our intervention for improving his everyday life at the moment, so we referred the subject to a home nursing station (where physical therapists were on duty).

Discussion: This is a case of an elderly with cancer who developed cerebral infarction, as well as another cancer with bone metastasis that were found during his hospitalization. Although he was not ready to be discharged from the hospital, we valued his desire to go out and were able to successfully and timely intervene mainly by setting up an environment that can reduce the burden of caregivers. When medical problems are expected to occur, a home rehabilitation may intervene only during the introductory part of home care. The author often requests a home nursing station to provide follow-up visits after that.

Case of a dementia patient

Case: An 82-year-old man who suffers from dementia with post-falling syndrome.

History: The subject has been suffering from dementia for 2 years, and his range of activities has been gradually reduced. He fell from a bicycle in February and has been falling repeatedly since. On March 16, he suddenly became unable to move and received an MRI and other tests at a nearby hospital for possible brain damage, but none was found. Both knee joints began to show extension angle limitations, and he had to start crawling to move around indoors. He applied for the long-term care insurance service in April, and was identified as having level 2 for the Longterm Care Need. In October, home rehabilitation was requested because it became too difficult for caregivers to assist in his bathing. Daycare service was not an option since the patient strongly opposed to this and strongly verbalized his desire to go home. His daughter and her husband used to live with him but have moved out because he started to frequently exhibit ill-mannered attitudes (e.g., hurling abuse). The wife was now acting as the caregiver for all his needs.

The grip strength (right/left) was 6/16 kg (note: he was right-handed). He appeared to be at the level 4 in the manual muscle test. As for the basic movements, he was capable of independently waking up and rolling over, but required assistance to stand up and hold an upright position due to his limitation in the extension angle in his knee joints. His short-term memory was markedly reduced, and he could not control his emotions. The author also occasionally observed that he would raise his voice at his wife during the examinations. He particularly showed strong interest in meals, frequently commenting "It's almost a meal time" or "Is it ready?" He apparently spent almost all of his time sitting in front of the television when he was not eating. His wife's fatigue was evident, so a regular home visit once a week was started in order to reduce her burden.

The author suggested lying on his stomach to address the knee joint extension angle limitation, and he immediately did so without any resistance. He could maintain his focus for over 40 minutes when playing Shogi [Japanese chess], which had been his hobby. Then, we tried going for a walk. We had been informed that it would be difficult to go outdoors unless his wife was accompanying him; however, we managed to take him to a park. He spent some time there, apparently enjoying watching children who were playing. He started to yell once the children were gone, saying that he wanted to go back now. He became unstable around 12:00 and 17:00 unless his wife was with him since he was concerned about his meals, so rehabilitation and training were scheduled during other hours. The training in the prone position continued. After 2 months, he voluntarily started to say "Let's go to a park, everyone." We started to bring him to a small-scale multi-functional facility on a trial basis since he could now go out with 3 nurses without his wife. After several months, although he could still only eat at home, the wife's burden was dramatically reduced since he could use the

said facility 3 times a week between the hours of 13:00 and 17:00, and home rehabilitation visits were terminated in May of the following year.

Discussion: Functional training specialists intervened to change the rhythm in the subject's everyday life while monitoring his conditions and responses. This was a case where the use of a day care facility reduced the burden of caregivers in stages. Day care facilities have a significant role to play in providing continued home care, just as home rehabilitation does.

Case of a disuse syndrome patient

Case: An 81-year-old male who had post-ileus disuse syndrome and right hemiplegia due to previously suffered cerebral hemorrhage and the right hip and femoral neck fracture post-operation. History: The subject suffered right hip osteoarthritis 50 years ago, cerebral hemorrhage with right hemiplegia and the right femoral neck fracture 22 years ago, and a repeated right femoral neck fracture 10 years ago. Because of repeated injuries, there was a 10-cm difference in length between his right and left limbs. He was able to walk indoors up to a certain degree by wearing an ankle foot orthosis with plantar flexion support and the extension for leg length discrepancy, using a quad cane. His wife had suffered polio and had a physical disability certificate (the level 1, which is most severe in Japan), so the best she could do was to take care of herself. He had an appetite loss from January but recovered naturally, so he had been under observation. In July, however, he could no longer walk, and he was hospitalized in August 30. Detailed examinations revealed no significant finding, and he was discharged on September 11. At home, he could no longer use the restroom alone. He started to soil the rooms, so his wife asked for home rehabilitation. She hoped that he would become capable of using the restroom safety and cleanly again.

During home visits, he had no problem in communication and was cooperative. He had his bed set at the lowest setting, and he would lie in his bed at an angle. He was capable of waking up on his own and could sit upright. As for meals, he would slide down from the bed and ingest only liquid diet using his left hand without any assistance; he was not having any solid food at all. He used adult diapers and a urinal. When something had gone wrong, he would request periodical or on-call home care visits.

As a first step, we became involved in his excretion and eating. He had a concern about the risk of increasing her burden of care. However, the more he tried, the more he failed in using a toilet, which apparently added to her stress. There seemed to be some emotional friction between the couple. We introduced a wheelchair, changed where he would eat a meal, and made modifications for easier use the toilet. After his movements to/from a wheelchair became stable and his wheelchair tolerance in a sitting position improved, walking training was introduced at his request. The brace that he had been using for over 10 years had a fitting problem, so we explored social resources, reproduced the leg brace, and provided walking training. As his living function started to show signs of improvement, the marital relationship also improved. He vomited after 6 months and was hospitalized. He was diagnosed with gallstone and gastric ulcer and is currently receiving treatment.

Discussion: This case concerns the subject who has a long medical history whose living functions would decrease from indirect factors such as the loss of appetite. After his hospitalization in late summer, his recovery was believed to be difficult since his condition further deteriorated. However, his functional recovery was confirmed after approximately 6 months of home rehabilitation therapists as the third party resulted in a positive mental effect, and the subject's conditions as well as the marital relationship improved.

Conclusion

The situations of people needing home care are highly variable. In case of the elderly, underlying geriatric syndrome and other factors further complicate the overall picture, making the understanding of their disabilities more complex. Our only available approach when a person has an illness that is difficult to treat is to eliminate multiple disabilities. All of the comprehensive efforts toward this goal are considered as rehabilitation. In home rehabilitation, the subject's residual abilities and potential capacities should be assessed, and this assessment will serve as the basis for re-establishing his/her activities. In particular, maintaining a sitting position is a key issue. For home care patients, it is important not only to find each subjects' stimuli and introduce them into the daily life and increase the number of times in training but also to watch affectionately and attend with sympathy. Those kind of approach would relieve a subject's sense of anxiety and provides motivation and a peace of mind. Home care staff who are not specialized in rehabilitation will more frequently encounter the subject, and they should remain attentive to the subject with the mind of rehabilitation.

A family physician, on the other hand, is in a position to prescribe professional rehabilitation service offered by rehabilitation specialists. Family physicians are expected to play an extended role as a practitioner of general medicine, as well as a coordinator for the long-term care service (Hotta & Liu 2010).²

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Death, Dignity, and the Significance of Home Hospice Care^{*1}

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Introduction

The human being have the ability to meet their end, as well as to provide end-of-life care for others, and it is the role of home hospice care to support persons in these situations. Those are the author's beliefs acquired during 20 years of home hospice care.

In the decades since the end of World War II, it has been constantly pointed out that Japanese people have a tendency to avoid facing death (e.g., to attend a dying person). However, the disasters, crimes, and accidents that have taken the lives of many, such as the case of *Aum Shinrikyo* (a Japanese cult that committed a sarin attack on Tokyo Metropolitan area in 1995), the Great Hanshin-Awaji Earthquake, also in 1995, and the 2011 Great East Japan Earthquake and the subsequent nuclear accident of Fukushima, have demonstrated the inevitable reality that a human life consists not only of living but also of dying and death.

Major changes in the world of medicine also have occurred during these years. Demographic changes, such as the aging of Japanese society; low birth rates; an increase in nuclear families; and structural changes in disease from acute illness and infectious diseases to chronic illness and lifestyle-related diseases, have greatly influenced the life and death of each person. Macrosocioeconomic changes, such as the disparities among countries induced by globalization and expanding inequality inside the country, are affecting people's lifestyles, too.

We could say that "a society in which people

have a free choice" is a truly affluent society. A person makes various choices when he or she encounters different life events, such as choosing a school, a place to work, or a place to live. Perhaps not only the width of available options, but also the profoundness in one's decision, is one of the indicators of an affluent society.

In Japan, the vast majority of the people die in hospital; about 90% of cancer patients reportedly die there. This figure, unusually high compared to other developed countries, indicates that in Japan, people cannot choose the place where they will meet their end of lives. Although Japan may appear rich superficially and economically, we cannot really say that Japan is truly an affluent society.

End-of-life Care

Let us think about what is perhaps life's major event—its end. The end of life, i.e., death, is the final event in a person's life. However, one cannot be aware of it, just as one cannot be aware of one's birth. The fact that the one passing away is not aware of the moment of his or her death may create some meaning for the people who are providing deathbed care, and for those who are involved in the person's life.

Taku Shinmura (2001) discusses the "culture of end-of-life care" in Chapter 1 of his work, *Era* of *At-home Death*. He points out that the awareness of death has become diluted in modern times, and he states that this dilution brings certain kind of poverty in life because longer average life expectancies and the busy daily life

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push the memory of the deceased away. This tendency seems to be enhanced by the general beliefs that the death is the end of everything. He further wrote that pondering about death condenses life, and that the reinstatement of the right to die is necessary in that sense.¹

Let us examine the end of life from the viewpoint of a medical practitioner. Currently, a physician verifies a death by announcing, "He/she has passed away," and reports the death to the authorities. In Japan, this practice began after the promulgation of the 1874 law codifying the practice of medicine and public health. People's reliance on medical care and physicians, as well as the subsequent development of medicine primarily based on the Western model, led physicians to play increasingly greater roles in end-of-life care.

At the same time, as medicine advanced, the belief that a physician should never lose hope as long as a patient is alive and should make every effort to extend his/her life, has become increasingly stronger. As a result, it became more common for people to accept medical care until their last breath and to die in hospital. People came to increasingly believe that dying at home is ominous and that it is an evidence that family members failed to provide proper care for the deceased. This has resulted in the current situation that approximately 80% of Japanese die in hospital.

However, doubts about death in hospital grew among people. Could it be that seeking to preserve life until the end and clinging to my life is actually making me lose my humanity as well as my human dignity? Maybe to be hooked up with many tubes and surrounded by various machines is no way to meet my end as a human being.

Dignity

What is human dignity? It is not something special; it is said to be an essential element that every person inherently possesses as they grow as a human being. However, this description lacks specificity. What does "human dignity" actually mean?

Allow me to introduce the case of Girl S. She was a 10-month-old child who was brought into this world with a congenital disease caused by a genetic abnormality. The mother was informed of the baby's diagnosis during pregnancy, but her decision to carry the baby to term was firm. She received genetic counseling and other support and prepared for the delivery and child rearing. The baby spent her first 8 months in hospital. When the baby's pulmonary hypertension progressed and her chance of recovery faded, she was brought home as it was considered her last chance to spend any time there. Surprisingly, her stay in home was filled with tranquility, but the baby developed pneumonia after about 2 weeks and was re-hospitalized. Despite every effort in treatment, her condition further deteriorated, and her parents were told that she had a day or two left to live.

The parents decided to care for her on her deathbed at home, and requested home care for the last time. On the day of discharge, they were told that their child might not live to see another day, but the baby spent a week at home. She was surrounded by such apparatuses as an oxygen concentrator, an oxygen cylinder, and an aspirator, but she was able to live at home with her parents and older brother (age 4). Physicians and nurses from the hospital visited her. She was also bathed, which she liked very much, with the help of a visiting nurse and my hospital's nurse. Although she was never able to express her own will, her parents spoke on her behalf during home care.

"What if her life was shortened because we took her home?" The mother still asks this question, even now. This question troubles her, because she seriously considered how Girl S's life should be and she made decisions on S's behalf. She suffers from anguish because she actively tried to protect S's dignity as a human being. It is said that dignity is an essential element that every person inherently possesses as a human being. Nevertheless, maybe one's dignity is something that is realized through relationships and the efforts of parents, other family members, schools, communities, and other players in one's life, just as education and other involvement in life shapes a human being. The case of Girl S demonstrated to us what I have believed: that dignity cannot be maintained without such continuous involvement and efforts of family members and health professionals.

Home Hospice: Supporting the End-of-life and Dignity

The following are the factors that the author

	Comprehensive palliative care	Selective palliative care
Disease/stage	All (cancer, intractable neurological disease, dementia, child with severe disability, organ failure, etc.)	Terminally ill patients with cancer or AIDS
Persons in charge (team)	Medical team, life support team, and others	An integrated team of physician(s) and nurses
Relationships within the team	Equal (i.e., no hierarchy)	A physician or skilled nurse provides guidance (i.e., vertical hierarchy)
Approach	Narrative approach	Evidence-based medicine (EBM)
Relationship with welfare workers or long-term care insurance service workers	Strong, and constantly in contact	Weak, and occasionally in contact
Prospect (mental horizon)	Community and diversity	Each team is independent from one another
Involvement with a primary care physician	Closely involved	Not very involved

Table 1 Comprehensive palliative care and selective palliative care

believes constitute the "requirements for good death," based on his experience in home hospice care:

- (1) One's way of life;
- (2) One's relationship with family members (and others);
- (3) The dying person receives optimal care; and
- (4) Death is peaceful.

Fortunately, a patient who requests home care and a family that accepts such a decision already meet the conditions 1 and 2 mentioned above, meaning that the patient has lived a full life and that the family accepts his or her way of life. Many of these people have much to teach us in that sense. Our support plays a significant role in the conditions 3 and 4, but the involvement of the family (i.e., as caregivers) also is important.

Patient K, a 70-year-old male, suffered from pancreatic cancer and cervical spondylosis with paralysis of both lower limbs as a complication. He had been repeatedly admitted for chemotherapy for his cancer, but the paralysis of his lower limbs gradually progressed, to the point that he needed to use a lift for bathing at home. He became completely bedridden and barely able to ingest food when his condition further deteriorated, but he chose to stay at home. Our home hospice team (physicians and nurses from my clinic; visiting nurses from a home nursing station; a care manager; helpers; and visiting rehabilitation specialists, among others) supported his wife and son, who were providing care. Although K could not walk on his own, he was able to spend his remaining time at home and meet the end of his life there as he wished because we were successful in controlling abdominal pain and in providing home care support. So, in a sense, we supported the family by providing end-of-life care and the patient by helping him to live—and meet his end—with dignity.

As was seen in case Girl S, home hospice is not always limited to cancer patients; in fact, it can be for any kind of disease. Palliative care for cancer is one of the most urgent needs, given that of the 1.2 million annual total deaths in Japan, 30% are due to cancer. However, it is also time to expand the target of palliative care to other diseases by adapting its history and the experience that we have accumulated (**Table 1**). In the USA and Europe, palliative care for cancer patients already has been expanded; palliative care for patients with intractable neurological disease, the elderly, or dementia patients, as well as children's hospice care, have become the current leading discussion topics.

The social critic Kei Yonezawa (2009) considers that the human life has two phases; the time for "life" and the time for "death," and that life is a round-trip consisting of going and returning.² Medicine and its practice have traditionally focused on the "living" part, but Yonezawa proposes medical practice that supports the "death" side as well as supporting life until its end. His argument extends beyond medicine and its practice to encompass a view of how society, as well as people's values and behavior, should change (Yamazaki et al. 2012).³

For us physicians and other medical workers,

it is the nature of our work to become involved in someone's death as well as life. We therefore need to take a step beyond our areas of expertise and master humility, so that we can provide end-of-life care not only as professionals but also as human beings.

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Current Situations and Problems of Home Care for Children^{*1}

JMAJ 58(1·2): 48-52, 2015

Yoshiyuki TANAKA1

Introduction

Recent progress in neonatal care has enabled us to save the lives of children with very severe diseases. However, at the same time, these advancements have resulted in an increase in the numbers of children requiring lifelong medical care. Children receiving such medical care grow and develop like other children, and it is therefore desirable for them to live in local communities. The history of home care for children in Japan is short. The current situations of home medical care remain as yet unclear, and numerous problems have been recognized. However, this issue has gradually been elucidated as a relevant monograph was recently published.1 Under these circumstances, this report examines the current situations and problems of home care for children in Osaka Prefecture, focusing particularly on the issue of medical fee, an important factor for local pediatricians in general practice who are providing home care.

Background

In 2006, a pregnant woman died in Nara Prefecture. This death was reported by media under headlines such as "emergency acceptance of a pregnant woman rejected by 19 hospitals." After this case, various measures were taken with the aim of resolving difficult acceptance of mothers and neonates by hospitals, under the presumption that prolonged hospitalization of neonates in the neonatal intensive care unit (NICU) was the major underlying cause.²⁻⁴ As a result, in major 5 hospitals in Osaka, the rate of discharge within 2 years after NICU admission increased from 63% in fiscal 2008 to 94% in fiscal 2010.³ Along with this increase, the number of children receiving advanced medical care at home also increased. According to the data from healthcare centers in Osaka, the number of children on a mechanical ventilator at home has increased 5.4-fold over the past 7 years (**Table 1**).

Many of the children in home care programs receive multiple types of medical care,4 necessitating coordination with social resources in the patient's local community after discharge. Available data from Osaka Prefecture show that there was a certain extent of coordination with public health nurses and home-visit nursing care stations which serve as cooperating bodies, but other aspects of coordination were very poor, suggesting weakness as regards the social basis for supporting home care of children. The involvement of clinics (family physicians) accounted for only 18.8% (Table 2). Home-visit nursing care stations, which provide relatively strong coordination, desire the participation of visiting pediatricians (Fig. 1).⁵ Given the current situation, i.e. many infants about 1 year after birth who need advanced medical care at home return to the local community, the participation of local pediatricians in home care is a pressing issue.

Problems Surfaced from a Questionnaire Survey

The Osaka Pediatric Association conducted a

*1 This article is a revised English version of a paper originally published in the Journal of the Japan Medical Association (Vol.142, No.7, 2013, pages 1547-1550).

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Fiscal year	Actual No. of patients	Gross No. of patients	Self-intra- peritoneal perfusion at home	Total parenteral nutrition at home	Tube feeding at home		Self- urethral	Home-	Home	Home	Trache-		
					Nasal feeding	Gastros- tomy	catheter- ization	care stoma	oxygen therapy	mechanical ventilation	otomy alone	Suction	Others
2004	220	362	2	11	78	45	14	11	68	17	41	75	0
2005	290	509	7	7	109	54	29	7	96	26	47	126	1
2006	331	574	6	9	114	73	27	12	106	28	66	127	6
2007	363	682	7	8	130	96	22	9	118	52	60	164	16
2008	413	768	7	8	149	100	26	11	150	58	67	178	14
2009	450	853	8	13	146	118	24	10	154	74	77	204	25
2010	519	1,015	7	12	173	134	31	11	201	82	100	246	18
2011	577	1,153	8	14	183	165	32	15	221	92	116	284	23

Table 1 Changes in the number of children supported by advanced home medical care

The actual number and gross number of patients increased 2.6-fold and 3.2-fold, respectively, from 2004 to 2011.

In regard to the content of medical care, home mechanical ventilation, suction, and gastric fistula increased 5.4-fold, 3.8-fold, and 3.7-fold, respectively, from 2004 to 2011.

[Cited from the survey of the actual situation of children with advanced home medical care under the jurisdiction of Osaka Prefecture public health centers (excluding government ordinance cities and core cities.)]

•		
Home-visit nursing care station	19	59.4%
Public health nurse	25	78.2%
Hospital	3	9.4%
Clinic	6	18.8%
Out-of-hospital pharmacy	12	37.5%
Nursing-care helper	2	6.3%
Public office	3	9.4%
Child consultation center	2	6.3%
School	2	6.3%
Others	1	3.1%

Table 2 Coordinating organizations for care after discharge

(n = 32)

(Cited from the 2009 report of Osaka Prefecture support project for facilitating discharge of children with prolonged hospitalization.)

questionnaire survey on its 673 members in 2011 to ascertain the current situations of and problems involved in home care for children.⁶ The response rate was 18%, suggesting minimal interest of the members in home care. It was found that 98% of responders advocated home care, answering that "home care should be promoted," but only 28% would "positively accept home medical care." To the question as to what is important in hospital-clinic collaboration, 94% of responders cited "emergency response." More than 70% cited "preventive vaccination" and "response to febrile children" as home care services they could provide. The cited problems in

the implementation of home care include "being pressed for time," "specialized measures," "medical fee claims," and "respite care." At present, 75% of the members who had not provided home medical care gave the response "not requested or no inquiries."

Problems Involved in Medical Fee Claims: Development of a Guide to Claim Medical Fees for Pediatric Home Care Services⁷

The medical fee schedule for home care services is complicated, a factor which was cited as a problem in the aforementioned questionnaire, and charging for home care services is also difficult in the fields of both internal medicine and pediatrics. In this connection, the Osaka Pediatric Association issued a "guide to claim medical fees for pediatric home care services" that gives a detailed description of claimable points, using simulated cases, aiming at clinics. The points for medical fees are presented below, according to the presence/absence of various notifications, taking a case example, and the problems that have become apparent are further discussed below. The point designations are valid as of April 2012. The numbers in brackets denote claimable medical services.

Case

A boy, 1 year and 3 months age, had required mechanical ventilator control starting immediately after birth because of severe asphyxia.

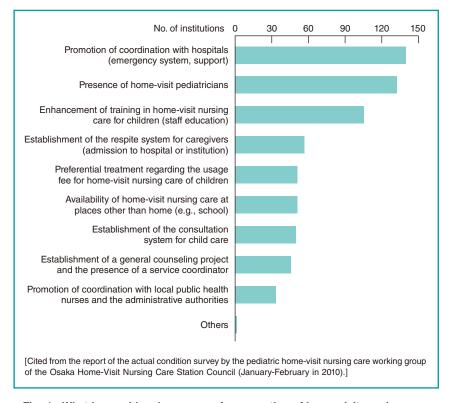


Fig. 1 What is considered necessary for promotion of home-visit nursing care for children?

Weaning from the mechanical ventilator was not possible, and his condition was diagnosed as congenital central hypoventilation syndrome. Tracheotomy was performed on the patient 1.5 months after birth. Thereafter, transition to home medical care was attempted under all-day oxygenation, use of a mechanical ventilator at the onset of sleep, and nasal tube feeding.

Process to home medical care

1.5 months before discharge: The hospital approached a clinic about medical management at home.

1 month before discharge: First pre-discharge conference [1] was held.

1 week before discharge: Second pre-discharge conference [1] was held. A physician or nurse from the clinic participated in these pre-discharge conferences.

Course after discharge

On the day after discharge, a doctor from the clinic visited the patient's home as scheduled [2]. Thereafter, visits were made every Wednesday [2]. A written directive for home-visit nursing

care was issued [3]. Home-visit nursing care was implemented every weekday. A non-regular doctor's visit to the patient's home was made 2 weeks after discharge to evaluate bloody stool [4]. Bacteriological examination of the feces was carried out [5]. Antibiotic and antiflatuent drugs were prescribed, and a pharmacy was directed to deliver the drugs based on the instruction of the doctor on the use of drugs [6]. Home-visit care was also provided two days later [2]. An extra conference was held with the visiting nurse because there was persistent abdominal distension accompanied by vomiting [7].

During this month, a non-regular visit and 5 regular visits were made by the doctor [0].

In the case of a clinic issuing outside prescriptions and accepted as an institution claimable for home-care general management fees but not as claimable for pediatric outpatient care fees

Claimable points before discharge are: [1] Collaborative guidance at discharge 1 (600 points + special management guidance addition, 200 points) $\times 2 = 1,600$ points

Claimable points after discharge are:

[2] Regular home-visit care: Home-visit care (830 points + infant care addition, 400 points) $\times 5 = 6,150$ points

For actual individual medical actions:

[3] Written direction for home-visit nursing care: Direction for home-visit nursing care, 300 points [4] Home visit by a doctor for bloody stool: Follow-up consultation, 69 points + infant care addition, 52 points + doctor's visit, 720 points = 879 points

[5] Examination: Fecal bacterial culture and identification, 160 points +3 or more types of general bacterial drug sensitivity testing, 280 points + microbiological test results judgment, 150 points = 590 points

[6] Providing information to a pharmacy and directing the pharmacy to instruct the patient's caregivers on use of the prescribed drugs: Provision of treatment information (I), 250 points

[7] Conference for the home-care patient in emergency situations, etc., 200 points

Basic points are as follows:

[0] Home-care general management, 2,200 points (claimable when at least 2 home visits per month are made) + early transition to home care addition (claimable until 3 months after discharge), 100 points + severe patient addition, 1,000 points (this case example is eligible) = 3,300 points

Consequently, the claimed medical fee totals 13,269 points for the month before discharge and the month of discharge.

In the case of a clinic issuing outside prescriptions and accepted as an institution claimable for pediatric outpatient care fees (In this case, fee for home-care instruction and management is claimed by the hospital) (fee for instruction and management of home-care pediatric patients is usually claimed by hospitals)

[0] Home-care general management: Not claimable, 0 points

[1] Collaborative guidance at discharge is the same as above, 1,600 points

[2] Regular home visits are regarded simply as follow-up consultations. Follow-up consultation, $380 \text{ points} \times 5 = 1,900 \text{ points}$

[3] Fee for written direction for home-visit nursing care is included, 0 points

Table 3 Role sharing between clinics and hospitals

Clinic

- Vaccination and child care counseling (including those within the clinic and on the phone)
- General practice for common cold, etc.
- Nutritional management
- Assessment of severity
- Hospital
- Treatment and follow-up of the primary disease
- Emergency response
- Management of advanced medical devices (e.g., mechanical ventilator)

(Cited from Fujii M, et al. Journal of the Osaka Pediatric Association. 2013;165:35.)

[4] Home visit by a doctor because of bloody feces: Follow-up consultation, 380 points + doctor's visit, 720 points = 1,100 points

[5] Examination, [6] provision of treatment information (I), and [7] conference for the homecare patient in emergency situations, etc.: These are all included, 0 points

Consequently, the claimed medical fee totals 4,600 points for the month before discharge and the month of discharge.

As mentioned above, there is a distinct difference in the claimable fee for medical actions which are exactly the same according to whether or not the clinic is accepted as claimable for pediatric outpatient care fee. Unless home-care pediatric patients who receive regular home-visit care are excluded from coverage of the pediatric outpatient care fee (in the fee schedule, only the claim for home-care instruction and management is excluded from coverage of the pediatric outpatient care fee), further spread of home medical care in the pediatric field seems, unfortunately, to be rather unlikely.

Problems with Hospital-clinic Collaboration: Confirmation of Role Sharing, Clinical Pathway for Home Care, and Project of Introducing Family Physicians for Home Care

Home-care pediatric patients often require specialized medical services, necessitating coordination between hospitals and home-care providers. Role sharing by hospitals and clinics (**Table 3**) is important for reducing the burden on the clinic side.^{8,9} The division of roles should be confirmed before discharge of the patient. If this procedure is definitely followed, the barriers hindering the participation of general pediatricians in home medical care would likely be lowered.

In Osaka Prefecture, operation of the clinical pathway for home medical care in which cooperation of multiple professions is addressed under a time schedule while the patient is still hospitalized is now proceeding.³ The results of the questionnaire survey suggest that there are substantial numbers of members willing to provide home medical care but who have not yet initiated such practices due to a lack of requests. However, within the scope of the Osaka Pediatric Association, we have developed a "homecare pediatrician registration form" with clear notification of their available time zones and medical actions (home care provider side) and "home-care pediatrician request form" with the system and content of practice desired for the family physician and the system of practice that can be provided by the hospital (hospital side), with the aim of formulating a matching system between family physicians and hospitals. At present, this system is in the trial operation stage, and we anticipate that an increasing number of practicing pediatricians will participate in home medical care.9

Conclusion

Home care for children is a type of specialized care which aims to support the growth and development of children in their local communities, unlike home care of the elderly which is a form of terminal care management in the community. Many infants around 1 year of age return from the NICU to their own local communities. Local pediatricians who are familiar with the community are good at supporting their growth and development, and these goals constitute pediatricians' obligations.

According to the report issued by Osaka Prefecture,³ the number of children who require home care under mechanical ventilation or tracheotomy is estimated to be in the range of 300-500. If each local pediatrician takes part in

home care of 1-2 pediatric patients in the community in cooperation with other specialties and home care support clinics which are better skilled in home care, it would greatly facilitate providing care for these children at home. To encourage the involvement of local pediatricians in home care, role sharing with the hospitalbased doctor in charge of the child is important. In addition, when regular home-visit care is provided, it is desirable to take thoughtful measures such as excluding the case from pediatric outpatient care fee coverage, which is currently applied by nearly 75% of practicing pediatricians.¹⁰

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Efforts of Medical Associations to Support Home Medical Care Services: Case of the Nagasaki City Medical Association^{*1}

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Introduction

Through the Nagasaki Home Care Dr. Net (hereinafter referred to as "Dr. Net") and OPTIM Project, the number of cases of patients being transferred from hospital to home care and the rate of patients dying at home in Nagasaki City have both increased, and regional medical collaboration is acknowledged to have made a huge step forward.

Nagasaki Home Care Dr. Net ("Dr. Net")

Establishment and structure

In order for general clinics with outpatient facilities to undertake home care services, it is essential that the burden be reduced through mutual collaboration. The Dr. Net was launched in 2003 as an organization for promoting clinicclinic collaboration. The network was created based on the idea of preventing patients from giving up on home care because no physician is available to oversee their care in cities where the number of clinics is large but the ratio of patients dying at home is low. In the case that a physician for home care cannot be found for a hospitalized patient who wishes to be cared for at home, the secretariat acts as a contact/liaison, introducing chief and sub-chief physicians to the hospital and patient. In concrete terms, coordinators located in 5 districts within Nagasaki City notify network members via mailing list regarding information about the patient's condition and the area where they are living—with all due care being given to the handling of personal information—and the both physicians are decided according to a "show of hands."

The chief physician newly provides the subchief physician with the patient's treatment information; the role of the sub-chief physician is to provide support should the need arise, and he/she does not carry out everyday home visits or visiting care. Since the sub-chief physician acts as back-up for the chief physician, the sense of burden for him/her is smaller and he/she is not inconvenienced. In addition to enabling 24-hour responses, the both physicians can also cover each other with their different areas of specialization. A questionnaire survey found that, although sub-chief physicians actually carried out home visits rarely, the existence of them gave the chief physician a sense of security.

Dr. Net was launched in 2003 with 13 physicians, and acquired a corporate status as specified nonprofit corporation in 2008, and then became an approved specified nonprofit corporation in 2010. Currently the network has more than 170 participating physicians, and it also doubles as a Nagasaki City Medical Association committee on home care.

Performance

As of December 2011, Dr. Net has been requested by hospitals to introduce a chief physician for

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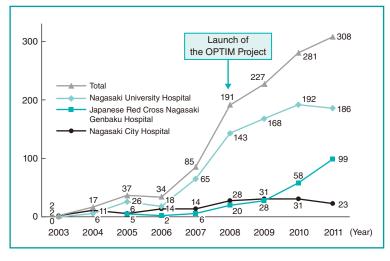


Fig. 1 Number of patients who began receiving visiting care after being discharged from a designated cancer care hospital in Nagasaki City (2003-2011)

home care in 549 cases.

The time required to decide on the chief and sub-chief physicians is 0.72 days on average, with 87% of the cases in 48 hours. Of the 435 cases that were possible to follow-up, the patient was deceased in 358 cases, and of these 185 patients had died at home (52% of all cases).

OPTIM Project

A regional project for spreading palliative care (Outreach Palliative care Trial of Integrated regional Model: "OPTIM Project") was conducted over three years beginning in April 2008. The project comprised before-and-after research on regional intervention in four regions throughout Japan: Tsuruoka, Kashiwa, Hamamatsu, and Nagasaki. The research target was cancer patients; the main evaluation items were quality of care, number of time the patients used specialized palliative care services, and home death ratios. In each region, combined intervention was carried out based on four pillars: (1) Improvement of palliative care knowledge and skills; (2) Provision of appropriate information to cancer patients and their families; (3) Promotion of comprehensive coordination and collaboration regarding palliative care within the region (establishment of regional counseling offices, introduction of post-hospital discharge support/

liaison programs, regional multi-profession collaboration conferences); and (4) Provision of medical examinations and care by palliative care specialists.

Based on the results of a survey conducted after the intervention, medical welfare workers' sense of difficulty regarding regional cooperation, support provided by specialists, and interprofession communication were resolved by experiencing the value of the network and acquiring knowledge regarding palliative care. Comprehensive regional palliative care programs under the OPTIM project made it possible to construct regional networks-despite the fact that this did not accompany organizational changes in systems and structures-and not only increased medical welfare workers' knowledge and reduced their sense of difficulty regarding palliative care, but also enabled patients to live where they desired, many of them at home. These results indicate that it is possible to indirectly improve the quality evaluation of palliative care by patients and their families and patients' quality of life as well. Centered on the "Nagasaki Cancer Consultation and Support Center" established at the association, the Nagasaki City Medical Association had been carrying out palliative care education for city residents and health care professionals; functioning as a comprehensive counseling window and liaising/

coordinating between related organizations; providing support for patients discharged early from hospital; and promoting regional cooperation. Furthermore, nurses and clinic physicians involved in the project attended Designated Cancer Care Hospital conferences on palliative care and highrisk (considering not only cancer, but also other medical cases in which risk screening in hospital indicated problems for the patient to be transferred to home care), working with hospital staff to think of how to achieve smooth transitions to home care, and these efforts led to many cases of post-hospital discharge support.

Following the conclusion of the OPTIM Project, Nagasaki City established the *Nagasakishi Hokatsu Kea Machinnaka Launji* ("Nagasaki City Comprehensive Care Center-of-Town Lounge") in April 2011 as a comprehensive counseling window providing a "healthcare support function"—which had been provided by the Nagasaki Cancer Consultation and Support Center—as well as a "comprehensive support function" for counseling regarding nursing and welfare to enable patients and their families to select a place for treatment with peace of mind. Operation of this facility has been delegated to the Nagasaki City Medical Association, and results are gradually being achieved.

Impact on Community Healthcare

The number of patients receiving visiting care after being discharged from Designated Cancer

Care Hospitals in Nagasaki has been increasing rapidly since 2008 (**Fig. 1**). Furthermore, the home death rate for Nagasaki City was 7.3% in 2005—the lowest in Nagasaki Prefecture—but by 2010 this figure has increased to 10.5% propelling the city into 4th Place. Dr. Net and the OPTIM Project are believed to have played major roles in these changes. Dr. Net style clinic-clinic collaboration can also be applied in other cities where there is a sufficient number of clinics.

Conclusion

If face-to-face relationships such as Dr. Net and the OPTIM Project (promoting collaboration) are built up and education, edification, and support from specialists are incorporated, it is possible to construct a regional network that needs not accompany structural changes. In such cases, network-building is thought to be even more effective when carried out under medical association leadership. Expectations are held for the application of such networks for not only palliative care but also diabetes, CKD, and other medical conditions.

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Home Medical Care That a Local Medical Association Works On: The Case of Itabashi Medical Association, Tokyo, Japan^{*1}

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Megumi SATO,¹ Satoshi AMAKI²

Introduction

Home care has been promoted nationwide in Japan in order to provide necessary medical care for people in a familiar living environment. In Fiscal Year (FY) 2006, at-home long-term care support clinics were newly established as part of the national social insurance medical fee system. Recently, home medical care has come to be recognized as the third field in medical care, after ambulatory care and in-hospital medical care.

People's attention tends to focus on the unique characteristics of being treated as patients at home rather than the care they receive at medical institutions. Since physicians in general medicine, practicing at hospitals, clinics, or patient's homes, are responsible for community medicine and people's health and general welfare, home medical care should have been included in the practice of general physicians. The location of their practice may vary, but the nature of home physicians is undeniably a "family doctor" trusted by patients. Therefore, it is the authors' belief that various activities that a local medical association can provide for health professionals, multidisciplinary staff, home care patients, and their families are directly linked to home care support.

This paper introduces the main projects of Itabashi Medical Association relating to home medical care support. Before proceeding further, the authors would first point out that our projects do not distinguish between physicians in outpatient care and those in home care.

Itabashi City in Tokyo has a population of 530,000, and 21% of the population is over 65 years old. A mega apartment complex was built 40 years ago in the Takashimadaira area in the city, and many of its residents are early-stage elderly (ages 65-74). The proportion of *elderly-only households* in this community will reach its peak in the near future, just as in many other areas in Tokyo. Itabashi City is rich in medical resources; there are over 30 hospitals, including 2 university hospitals and 2 former Tokyo metropolitan hospitals, as well as many private clinics.

Itabashi Medical Association supervises all these medical institutions in Itabashi City, and only we have a medical association hospital among the Tokyo's 23 special wards. We also have the Itabashi Medical Association Home Medical Care Center, which integrates various home care departments (including a comprehensive community support center, an at-home longterm care support office, a home-visit nursing station, and a medical care counseling room). We had foreseen the need for multidisciplinary collaboration, so we started promoting home medical care years ago and have been carrying out projects that support both medical treatment and long-term care at home. By the end of FY 2012, Itabashi Medical Association successfully completed the government project in pro-

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moting home care collaboration bases (within the reconstructed budget framework), which was initiated by Ministry of Health, Labour and Welfare (MHLW).

Preparing Home Care Infrastructure

Building a collaboration system between acute, chronic, and end-of-life care

Regular collaboration/liaison meetings with hospitals

A regular collaboration and liaison meeting is being held in order to exchange information with the 4 major hospitals in the city (Nihon University Itabashi Hospital, Teikyo University Hospital, Tokyo Metropolitan Geriatric Hospital and Institute of Gerontology, and Toshima Hospital). This meeting has become an important place for constructing a medical network for preparing a patient's discharge or admitting an acute patient.

Dementia management

Dementia care occupies a great proportion of home care, so we provide regular training sessions for dealing with forgetfulness. Family physicians bear the main responsibility for early detection, early treatment, and care support. These training sessions are also helpful in collaborating with dementia specialists in the city. **Seminars on opinion letters of attending**

physicians for long-term care insurance service

We visit the aforementioned 4 major hospitals in the city and provide awareness-raising activities about filling out opinion letters for the patients. Inpatients may encounter problems in their daily lives after being discharged from hospitals. We believe that informing hospital physicians who are discharging potential home care patients about such difficulties will lead to the provision of practical support when preparing discharge. Furthermore, residents who are accepted under the community medicine training program are required to audit a board meeting for approving applicants for the long-term care insurance service. **Workshops in cancer care**

Regular workshops to review case studies are held for physicians of Itabashi City Cancer Care Collaboration Core Hospitals, family physicians, visiting nurses, and other relevant staff, in order to support cancer patient care (e.g., anti-cancer drug treatment, palliative care, end-of-life care, etc.). This workshop has been beneficial for all parties, providing opportunities to exchange information that is useful for patient care.

Building multidisciplinary collaboration

Community medicine workshops

We invite lecturers from various fields and offer workshops for multidisciplinary professions. The themes of the workshops vary each time, and include topics such as dementia, cancer, rehabilitation, and information about prescription drugs. **Itabashi Medical Association Medical Society meetings**

Itabashi Medical Association Medical Society offers an annual academic meeting. Participants from various fields can join this meeting. A symposium is also held, with a different theme each year, in which multidisciplinary participants can share.

Home Care Network Forum

A multidisciplinary forum for a network of over 10 different occupations is regularly held. Family physicians, hospital physicians, dentists, nurses, physical therapists, pharmacists, social workers, staff from long-term care institutions, support specialists for long-term care services, staff from comprehensive community centers, and representatives from the public administration, gather and discuss a different topic each time. Each occupation group takes turns to plan the gathering, decide the topic, and hold the event. Each group, such as hospital staff, home care staff, or long-term care institution staff, proposes a topic based on the challenges that they face in each field. These social gatherings have enabled a multifaceted approach and realized a collaboration in which the parties involved can actually meet face to face.

Preparation of a list and map of home care resources and available functions

We have prepared a list and map of medical resources, including physicians, dentists, and pharmacists who provide visiting care, home nursing stations, hospitals that can provide home care support, and institutions that are likely to accept patients with high medical needs, as well as their service functions. The list and map are available from our homepage. This list has proven to be useful in the preparation of care plans.

Counseling room for home care

We have opened a counseling room for home care services as part of the FY 2012 project by

MHLW that aims to promote home care collaboration bases. This counseling room has been successfully serving as a one-stop solution that connects medical and long-term care, allowing a multifaceted approach. The staff members are nurses with experience in care management and visiting nursing or social workers who are licensed specialists in long-term care service support. This allows the staff to assist in home care from the multiple viewpoints of care management, visiting nursing, long-term care, and welfare support.

Support for Visiting Physicians and Reducing Their Burden

Itabashi Medical Association Visiting Physicians Group

Itabashi Medical Association Visiting Physicians Group was launched to provide frameworks and information that facilitate collaboration and promote participation for visiting physicians throughout the city. In addition to workshops, participating visiting physicians enjoy opportunities to exchange information and refer patients through the use of the mailing list. The network of main attending physicians and assisting physicians, who work at home care support clinics with an enhanced function, also support the Group.

Project for ensuring an inpatient bed for temporary emergency hospitalization for home care patients

One inpatient bed is always guaranteed at Itabashi Medical Association Hospital under the Itabashi City's project for home care patients in case a patient needs to be temporarily hospitalized in an emergency. The monthly occupancy rate of the bed has been close to 100% almost constantly for months. Ensuring the availability of beds for emergency care is essential for reducing the anxiety of home care patients.

Outreach Programs to Raise the Awareness of Itabashi City Residents

Open lectures for the residents

The aforementioned Home Care Network members periodically stage a short play called "predischarge conference" as part of their effort to raise awareness about home care among the residents of Itabashi City. This play has been very popular among the residents. The play incorporates information about various occupations that support home care, as well as raising awareness about closing years and end-of-life care. One thing that is worth noting is that the questionnaire survey conducted after the play showed that over 80% of the audience preferred an advance directive.

Questionnaire survey conducted at the Itabashi City Residents' Festival

Itabashi City holds an annual festival for its residents. A large-scale questionnaire survey with 2,000 participants has been conducted on this occasion as part of our outreach program.

Conclusion

In order to promote home care, the authors believe that it is essential to enrich the infrastructure for home care and reduce the burden on visiting physicians—and above all, we must provide information to the residents and raise their awareness because they are the main players in home care. It is important that medical associations and the public administration work together and continue to strengthen the basis of home care projects.

Efforts of Medical Associations to Support Home Medical Care Services: The Case of the Shizuoka Medical Association^{*1}

JMAJ 58(1·2): 59-61, 2015

Akira SHINOHARA¹

Introduction

On November 26, 2010, a Temporary Special Grant for Community Healthcare Revitalization (210 billion yen in total or ca. 1.8 billion US\$) was created as a supplementary budget for FY 2000. This was a measure to provide financial support for "measures for resolving broad-ranging problems within the healthcare delivery system, such as upgrading and improving advanced and specialized medical care facilities and strengthening the functions of community healthcare institutions that coordinate with such medical institutions" aimed at the 52 medical service zones nationwide (all zones) in order to resolve broadranging problems within the healthcare delivery system. In Shizuoka Prefecture, "Improving and strengthening the healthcare delivery system in the areas of emergency medicine, perinatal care, and home care" was established as a fundamental policy. Of these three fields, it is anticipated that county and municipal medical associations will take a central role in measures regarding home care-related activities, and so the Shizuoka Medical Association has taken on the main role in summarizing plan proposals and implementing measures as part of the "Shizuoka Prefecture Home Care Promotion Center Initiative."

Specifically, the following measures comprise the main pillars of the initiative: (1) Newly establishing the Shizuoka Prefecture Home Care Promotion Center within the Shizuoka Medical Association; (2) Establishing organizations, such as the Shizuoka Prefecture Home Care System Improvement and Promotion Council, that include members of different professions involved in home medical care/home care, and considering initiative implementation plans; (3) Clarifying the current status of home care functions/systems and considering countermeasures; (4) Constructing the Shizuoka Prefecture Home Care Collaboration Network System, a system for sharing patient information using Information and Communication Technology (ICT) in the home care/nursing care workplace, and promoting collaboration between multiple healthcare professionals, such as local medical associations, home-care primary physicians, and visiting nurses; (5) Building a system for coordinating organization involved in home care and developing human resources; and (6) Undertaking educational activities aimed at prefecture residents.

Of these measures, this paper specifically reports on items (3) and (4) above.

Issues Regarding Home Care Functions/ Systems and Countermeasures

In FY 2011, with the cooperation of the National Institute of Population and Social Security Research, a "Survey on Care Management at the Time a Patient Is Discharged from Hospital" was conducted on all home nursing support providers and care managers in Shizuoka Prefecture; in addition, with the support of the Japan Medical

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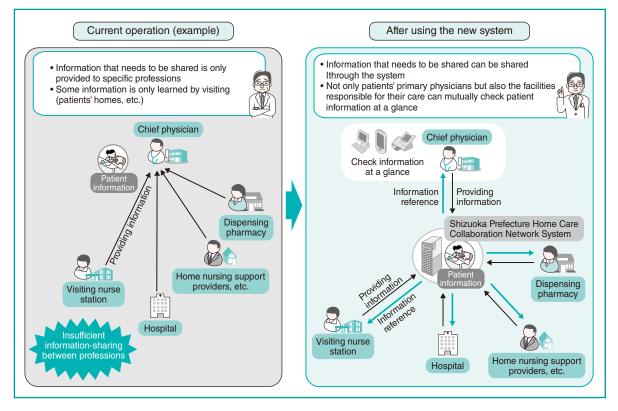


Fig. 1 Shizuoka Prefecture Home Care Collaboration Network System

Association Research Institute (JMARI), a "Survey on Home Care Functions" was also conducted on all clinics and hospitals in Shizuoka Prefecture. The following is a report of the results obtained from the latter fact-finding survey.

Results of the Survey of Clinics and Hospitals

In order to improve a home-care infrastructure, it is essential to secure and train physicians to provide home care with an eye to the future. Collaboration between home-care professionals and hospitals and strengthening of hospitals' preparedness to receive patients is also necessary to enable patients to be admitted to hospital smoothly, either in an emergency or for respite care when their condition changes. The quality of discharge support division (staff size, occupational composition, collaboration situation) differs greatly from hospital to hospital, and there are concerns that patient information is not necessarily being conveyed to the patient's family physician following their return home after being discharged.

For the above reasons, it is imperative that informational activities and training concerning home care be thoroughly provided for all physicians who are members of the Shizuoka Medical Association based on further deliberations by the Shizuoka Prefecture Home Care System Improvement and Promotion Council in future. There is a strong need to build common values premised on collaboration between hospitals and clinics, and based on this, determine the direction of practical collaboration systems for home care.

Results of the Comprehensive Community Support Center Survey

With regard to the purpose for collaboration between multiple professions, some 90% or respondents answered "Provision of information regarding medical institutions or medical services," alongside "Care management support" and "Countermeasure for dementia," indicating a high awareness for the necessity of healthcare collaboration. Although 100% of respondents said they felt collaboration with physicians was necessary, in reality collaboration was only being implemented in 70% of workplaces, showing that collaboration methods had not been established.

Comprehensive community support centers require collaboration between physicians and medical institutions. With regard to methods for collaboration between physicians and medical professionals, centers should provide educational opportunities through training workshops, etc. Furthermore, the involvement of family physicians in management meetings and community care committees at the present time cannot be said to be sufficient, and there is a need to verify the involvement of physicians in comprehensive community health care through precedents with the aim of establishing collaboration methods.

Construction and Operation of the Shizuoka Prefecture Home Care Collaboration Network System

The Shizuoka Prefecture Home Care Collaboration Network System (**Fig. 1**) was established as a mechanism using ICT for sharing patients' most up-to-date medical information and achieving smooth collaboration amongst related healthcare facilities—such as medical institutions providing home care/home medical care and visiting nurse stations. Currently, model programs are being implemented by six county/municipal medical associations (175 facilities, 494 users) as the system's functions, etc., are verified. By the end of FY 2013, the number of implementation zones is to be expanded to 10 county/municipal medical associations, and from FY 2014 onwards, the system is to become fully operational in all 23 county/municipal medical associations in Shizuoka Prefecture.

Conclusion

Home care is not a service provided exclusively by home care support clinics; rather, it should be regarded as an extension of everyday outpatient care. The Health, Labour and Welfare Ministry and Japan Medical Association have for several years now been drawing attention to the necessity of home care and encouraging the efforts of JMA member physicians and local medical associations. However, as yet it cannot be said that sufficient results have been achieved.

Under the current situation, many problems such as the difficulty of clinic physicians being available 24-hours-a-day, 365-days-a-year for home care patients, the lack of visiting nurse stations - the practical core part of home care services and the difficulty of coordinating between hospitals and regional medical liaison offices have been pointed out. However, the Shizuoka Medical Association are determined to make all-out efforts to overcome these problems through the collaborative efforts of multiple medical professions involved in home care and improve Shizuoka's home care/home medical care system through the "Shizuoka Prefecture Home Care Promotion Center Initiative," which utilizes the Community Healthcare Revitalization Fund.

Efforts of Medical Associations to Support Home Care Services: The Cases of Ichikawa City and Chiba Prefecture Medical Associations^{*1}

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Masahiko TSUCHIHASHI¹

Introduction

In order to firmly establish and expand home care in communities, it is important to build systems taking regional characteristics into account in which the family physician trusted by the patient plays the leading role and affiliations with district medical associations and the municipality form the base. At the same time, prefectural medical associations should utilize the unique features of each region as they support the home care systems promoted by district medical associations with an individualized approach, rather than with uniform aid.

As examples of home care initiatives driven by medical associations, I will introduce the community supply center for home care equipment and materials, a program run by the Ichikawa City Medical Association, and the home care support program run by the Chiba Prefecture Medical Association in line with the community medical revitalization plan.

Community Medical Support Center of the Ichikawa City Medical Association

The Ichikawa City Medical Association set up a community medical support center in the Ichikawa City Medical Association's office building in October 1996 to support home care. The center's functions are to (1) provide referrals to doctors and specialists who make house calls, (2) loan and maintain sputum aspiration devices, (3) provide medical supplies in single units, (4) loan medical equipment, (5) loan home care books, (6) provide training facilities to those involved in health, medicine and welfare and (7) operate appropriate disposal systems for infectious medical waste.

Thus far about 2,700 home care patients have registered, covering ages from 0 to over 100. People under the age of nine account for about 3%, and home care for children, including children who are severely retarded from birth, is an important issue.

Community Supply Center for Medical Equipment and Materials

A key function of the community medical support center is the loan of sputum aspiration devices. The Center currently has about 120 devices, and some models are compatible with AC 100 v, DC 12 v and built-in DC battery so that they will not be affected by disasters. The devices are regularly collected and taken apart for cleaning, during which process they are sterilized with ethylene oxide gas, the oil and parts are replaced and the suction pressure is measured. This maintenance process ensures that they are loaned out in peak condition.

Home care patients requiring medical treatment also need a wide range of medical equipment and materials, but it is difficult for individual clinics to keep a constant inventory of a full array of equipment, and may also lead to waste.

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Fig. 1 Shelves of medical equipment and materials at Ichikawa City Medical Association's Community Medical Support Center

In particular, catheters and tubes come in many sizes, and buying more than necessary is uneconomical. The Center stores more than 100 types of medical equipment and materials needed in the home (**Fig. 1**) and provides and loans the necessary quantity of the optimal item as a single article. They are provided free of charge to the primary physician at the instruction of the primary physician. Moreover, this program submits notifications of the sale and loan of controlled medical devices requiring special maintenance to Chiba Prefecture in accordance with the Pharmaceutical Affairs Act.

Activities of Chiba Prefecture Medical Association and Concept of a Comprehensive Community Medical Support Center

Using emergency special subsidies for community medical revitalization, the Chiba Prefecture Medical Association set up a Comprehensive Community Medical Support Center to promote home care throughout the prefecture and raise community leaders in district medical associations. At present, plans are underway to set up a home care and nursing model room, training space and display space for medical equipment and materials within the Center, with plans to open in July 2014.

Chiba Prefecture has 23 district medical associations, and the Chiba Prefecture Medical Association established the joint committee of officers of district medical associations in charge of home care to promote home care services led by the district medical associations. This committee carries out activities regularly. The members of the district medical associations report on the achievements in home care in the districts and work for further development based on opinion exchanges with other districts.

Moreover, the Chiba Prefecture Medical Association carried out a survey of 3,087 member medical associations in April 2013 to clarify the situation of home care provided by family physicians who are not at home care support clinics. The effective response rate was 56.4%. The results (the figures were not finalized in the interim report) showed that 378 medical institutions provided visiting care, and of these, 54.2% were medical institutions other than home care support clinics. In addition, 475 medical institutions make home visits at the request of patients, and of these, 62.7% were medical institutions other than home care support clinics.

These results show that medical institutions who have not officially filed notification as home care support clinics are actually providing home care, and supporting family physicians who provide conventional home care will be a key issue going forward. The results of this survey are currently being analyzed, and there are plans to release details at a later date.

Conclusion

Home care support clinics have come under the spotlight as the main actors in home care, but we now know that family physicians who do not belong to official home care support clinics are also providing visiting care and making rounds to patients' homes. Collaborating with district medical associations and municipal medical associations, promoting home care by family physicians and appropriately evaluating it is an urgent issue to solve.

I have described programs by the Ichikawa City Medical Association and Chiba Prefecture Medical Association to promote home care in this article. I believe that in promoting home care, it is important to collaborate with district medical associations and municipalities and for municipal medical associations to build a meticulous support system that takes into account regional characteristics.

From the Editor's Desk

Home care services in Japan

There recently has been a certain kind of paradigm shift happening in the national health insurance system in Japan in terms of both medical and nursing care—from establishing medical or care service facilities isolated from one another to comprehensive networking of those facilities at the community level. New laws and additional policies proposed by the national government are accelerating this movement to prepare for the upcoming super-aged society, which will reach its maximum in 2025 and is expected to last for a few decades.

In addition to this general perspective, it must not be dismissed that the wide-ranging context of medical and nursing care is in need of better service with sustainability in each community. The fundamental feature of the Japanese medical and nursing care systems lies in the universal coverage of public health insurance as the government program. The difference is, the former is available as benefit in kind, whereas the latter is provided as a cash benefit.

The Japanese healthcare system, with its unique features founded on the universal health coverage and maintained by the medical workforce mainly of the private sector, was once estimated as efficient by the Wall Street Journal. If that is still true, the reformation of national healthcare to the multidisciplinary networking of various facilities at the community level should involve not only the public sector but the private sector as well. This also means that the involvement of local medical associations is essential to accomplish the goal. I hope that this JMAJ issue reflects these contexts for readers.

Nepal Earthquake in 2015

Nepal was hit by a major earthquake disaster in April 25, 2015. JMA has been actively involved in contributing necessary medical support with the international NGO, AMDA^{*1} on a humanitarian basis. I once developed the framework of the Japan Medical Association Team (JMAT)^{*2} program for nationwide medical support in a disaster, which worked considerably well after the Great East Japan Earthquake and Tsunami (March 2011). Recently, I also proposed a framework format for international support, *iJMAT*, for the better performance of mutual medical support with sufficient accreditation by both national medical associations and governments.

I sincerely pray for the well-being of those who suffered in the disaster and all the people of Nepal and other affected nations.

*1 AMDA (Association of Medical Doctors of ASIA). http://en.amda.or.jp/.

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^{*2} Ishii M. Activities of the Japan Medical Association Team in response to the Great East Japan Earthquake. JMAJ. 2012;55(5):362-367.



Principles of Medical Ethics

Japan Medical Association

The mission of medical science and health care is to cure diseases, to maintain and promote the health of the people; and based on an awareness of the importance of this mission, the physician should serve society with a basic love for humanity.

- The physician should strive to achieve a lifelong dedication to continuing education, to keep abreast of medical knowledge and technology, and to support its progress and development.
 - The physician should be aware of the dignity and responsibility of his/her occupation and strive to enhance his/her cultural refinement, education, and integrity.
 - The physician should respect the individuality of his/her patients, treat them with compassion, provide full explanations of all medical treatment, and endeavor to earn the trust of the patient.
- 4. The physician should maintain respect for his/her fellow physician, cooperate with medical care personnel and serve the cause of medical care to the best of his/her abilities.

5. The physician should respect the spirit of public service that characterizes health care, contribute to the development of society while abiding by legal standards and establishing legal order.

6. The physician will not engage in medical activities for profit-making motives.

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