

**TEXTBOOK OF
HOME CARE
MEDICINE**

Editorial Planning and Editing by
Textbook of Home Care Medicine Editorial Board

Public Interest Incorporated Foundation
The Yuumi Memorial Foundation for Home Health Care

Joint Statement for Enhancing Home Medical Care

November 23, 2015

General Incorporated Association	Home Dental Care Net
General Incorporated Association	Japan Network of Home Care Supporting Clinics (Home Cares Net)
General Incorporated Association	The National Association for Visiting Nurse Service
General Incorporated Association	Japan Home Care Supporting Pharmacist Liaison Meeting
General Incorporated Association	Japan Care Manager Association
General Incorporated Association	Japan Society of Care Management
General Incorporated Association	The Japanese Academy of Home Care Physicians
General Incorporated Association	Japanese Society for Homecare Medicine
General Incorporated Association	The Japan Home Nutrition Management Society
General Incorporated Association	The Japanese Academy of Home Care Physicians
General Incorporated Association	Japan Primary Care Association
General Incorporated Association	Japan Association of Home Visit Rehabilitation
Nonprofit Organization	Japan Doctor's and Citizen's Network for Home Care Supporting
Nonprofit Organization	Hospice Palliative Care Japan
Nonprofit Organization	Japanese Society of Hospice and Home-care
Public Interest Incorporated Association	Japan National Health Insurance Clinics and Hospitals Association
Public Interest Incorporated Foundation	Japan Visiting Nursing Foundation
Japan Home Hospice Association (In Japanese syllabary order)	

We, the 18 organizations, are a group of specialists who have been faithfully committed to delivering home medical care, dedicating ourselves to finding out the way it should be.

Based on the accumulated expertise and discussions so far, the 18 organization have now united to adopt the following statement.

-
- (i) We deliver, together with citizens, community care that takes root in the local community.
 - (ii) We set our eyes firmly on the principle of healthcare and aim at one that naturally esteems rightful life and human dignity.
 - (iii) We pursue interprofessional team care provided through cooperation and alliance among specialists in public health, healthcare, caregiving, and welfare.
 - (iv) We build a seamless healthcare provision system, from hospitals to homes.
 - (v) We actively develop specialists to sustain home medical care, the ones who have skills and sympathy to assist the lives of the individuals under care and their families.
 - (vi) We collaborate with each other to promote home medical care in Japan.
 - (vii) We declare November 23 as the Home Medical Care Day when we hold a forum for further enhancement of home medical care.
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Please contact our executive office if you are interested in signing up for the listing.

Note) The website only provides names with contact information of the physicians and medical facilities, which are not intended for recommendation.

On the occasion of publication of Textbook of Home Care Medicine

Isamu Sumino,

President

Public Interest Incorporated Foundation

The Yuumi Memorial Foundation

for Home Health Care



Since the 1st edition was published in April 2006, over 180,000 copies of *Textbook of Home Care Medicine* have been distributed.

The Foundation also celebrated its 15th anniversary this year, and I am extremely grateful to the advisors and experts who have helped us so much to publish the revised edition of *Textbook of Home Care Medicine* in such a memorable year.

Additionally, this time we have supplemented the textbook with an e-learning environment so that you can also learn it visually on PC, iPhone, or smartphone.

I hope that *Textbook of Home Care Medicine* will motivate health care professionals to gain knowledge of or work on home medical care.

The textbook also provides considerable expertise on home medical care for children.

We are also going to publish an English version of the textbook to distribute the Japanese home medical care from our Foundation to the foreign countries that are following Japan in terms of population aging.

Toward the year 2025, when the baby boomers become 75 years old, there will be an increasing interest in neighborhood building (integrated community care) that embraces an alliance between home medical care and in-home daily care through collaboration with public administrative bodies.

Unfortunately most people don't know what home medical care is, although they do understand in-home daily care.

Addressing a question to citizens, "do you know home medical care?," I would like to suggest that their primary care physicians actively take part in the discussions for people to decide how they wish to put an end to their lives.

If a patient prefers to end his/her life at home, I'd like his/her physician to try to meet his/her will. I also hope that people do not see planning about "deathwatch" as a taboo and instead, consult their families and physicians about their dying to finish their lives in content.

To achieve that, wouldn't it be good that health care professionals ask patients to prepare living wills (advance health care directives)?

I am very hopeful that we will see a society in which we can live up to the very end of our lives at home and at peace while patients, families, and health care professionals all feel proud and that *Textbook of Home Care Medicine* will help deliver home medical care to a greater population.

I owe deep sense of gratitude to Mr. Satoshi Hirahara, Chief Editor of the Editorial Board, Mr. Fumitake Sakamoto for his advice and suggestions on e-learning, and Ms. Ayumi Sato for her editing and proofreading in this revision of *Textbook of Home Care Medicine*.

住野 勇

On the occasion of publication of Textbook of Home Care Medicine

Shinichi Ohshima

President Emeritus

National Center for Geriatrics and Gerontology



The National Center for Geriatrics and Gerontology was established in March 2004. Next year, in 2005—after I was introduced to Dr. Akira Sato by Dr. Tetsuo Tsuji (then Health, Labour and Welfare Deputy), came to know the Yuumi Memorial Foundation, and joined a group to promote home medical care—I, as the first president of the institute, initiated my activity of recognizing home medical care as a keystone of healthcare in the aged society and positioning it as one of the major initiatives in the institution's projects.

In retrospect, those days were the dawn of home medical care when, as a sense of crisis was building, the pioneers who began to work on home medical care in the community were struggling for an exit. At the monthly meetings of our group, *Tame-no-Kai*, we already reached a consensus that interprofessional alliance in the community is crucial for home medical care, which is the core concept of today's integrated community care. As the pioneers raised issues at the meetings, our awareness about problems built up by sharing information about how we will increase our comrades nationwide, which developed toward a direction for how we should change the society.

In 2012, the Japanese government defined the orientation of Japanese healthcare in the future as to how it should stand, thereby also clarifying the positioning of home medical care. Thus, we are entering a new phase where we seek to find out how we are going to develop home medical care as a system, and therefore the need for revising *Textbook of Home Care Medicine* in accordance with the shift that arose.

This is the 3rd edition of *Textbook of Home Care Medicine* published with support from the Yuumi Memorial Foundation. Transition from the 1st version is evident; this edition covers a broader range encompassing aggregated and accumulated expertise, showing a considerable advance in regard to the insight provided by the contents. Moreover, this edition has presented a clearer perspective on the position of home medical care in medicine/healthcare and in the society. Quality of this textbook is so excellent that stakeholders may have difficulty finding a better one for them to keep close at hand as an indispensable handbook in actual clinical settings.

I now reflect on how great a contribution this textbook has made to home medical care in Japan, which is well proven by its historical circulation. I'd like to take this opportunity to express my deep gratitude to the editorial board members who undertook the task of editing and to the experts who contributed the respective articles for their time and labor.

大島伸一

On the occasion of publication of Textbook of Home Care Medicine

Tetsuo Tsuji,

Project Professor, Institute of Gerontology,
the University of Tokyo
Former Administrative Vice Minister of Health,
Labour and Welfare



In Japan, ultra-aging of the population unprecedented in the world has been continuing. To meet the escalating demand for hospitalization in urban areas where the number of the middle/old-old people is rapidly growing, re-engineering of the healthcare provision system is crucial.

Meanwhile, looking to the year 2025, when the baby boomers will join the age group of middle/old-olds, a scheme of integrated community care based on in-home care is ongoing to provide care to older adults, aiming to allow them to continue living in place and feeling safe, even after they become frail.

In such circumstances, there was a system re-engineering to facilitate an overall reform of the healthcare/caregiving program, in which the critical key to determine success or failure of the reform is the enhancement of home medical care.

Today, it has become common for us to undergo, after we have reached an old age, a certain period of time in a more or less frail condition before we die. The traditional “healthcare to cure,” which has been provided largely by hospitals, has achieved a remarkable aspiration, i.e., materialization of a long-life society. As a consequence, however, it is inevitable for us from a historical viewpoint to develop the achievement further and present a clear positioning of home medical care to deliver “healthcare to support” through interprofessional alliance involving nursing care, etc.

Many physicians, nurses, etc. undertaking community care have visited the homes of patients and come to believe that addressing the anxiety of patients and their families and assisting their lives can significantly help to bring happiness to the patients and their families. This, at the same time, gives a sense of great fulfillment to the health care professionals themselves. It has also been proven how much the older adults can maintain their dignity if they are able to spend their terminal period at home, as one phase of the intrinsic aspects of being a human, i.e., birth, aging, illness, and death, and how significant it is for their families who are left behind.

I count on health care stakeholders to lay a path to re-establishment of community medicine by endeavoring to encourage home medical care for the sake of the nation’s well-being.

This textbook is a practical quick guide assembled by the individuals who have dedicated themselves to implementing home medical care standing by or engaging with patients and their families. It is my earnest hope that this textbook will be read by as many people as possible and leads to greater provision of home medical care. I’m also hopeful that we’ll go further and establish an academic genre of “Science of Home Care Medicine” in which Japan—being at the forefront because of ultra-aging in world history—will be the first in the world to explore a greater picture of community medicine.

辻 哲夫

Introduction

- On the occasion of publication of Textbook of Home Care Medicine 3rd Edition -

Textbook of Home Care Medicine was edited and written by volunteers in April 2006 with the hope that it will help promote knowledge and skills required for implementation of home medical care. Later, we verified the contents and worked out the 2nd revision in 2009. To date, as a practical and concise textbook, it has attained wide circulation of over 180,000 copies, largely among physicians and nurses engaged in home medical care, giving much greater social influence than initially expected in prevalence of the Japanese home medical care.

Publication of *Safe with Home Medical Care 2012* in 2012 marked a new phase of home medical care as we entered a new stage, “home medical care in the era of integrated community care.” Referred to as expansion from a point to a plane, or systematization of home medical care, it constitutes integration in every level, eliminating the segmentation between healthcare and care in each region in Japan.

Obviously this integration cannot be accomplished overnight and is not fostered until interprofessional education (IPE) is provided on a regional basis—more specifically, until stakeholders such as public administrative bodies, medical associations, and local organizations of specialists in each specialty organize productive interprofessional seminars as they committed to doing.

Under the circumstances, in recent years, there are many interprofessional seminars taking place in each region looking to establishing a integrated community care system. This has provoked a growing need to develop reliable, inexpensive, and versatile learning tools that encourage self-learning in specialists including physicians.

Therefore, we decided to implement the 3rd revision of Yuumi Memorial Foundation’s *Textbook of Home Care Medicine*, the most popular handbook of home medical care, so that it will work as a standard textbook meeting the contemporary needs.

In *Textbook of Home Care Medicine 3rd Edition*, newly written articles have been added to many chapters. We also verified the existing articles in 3 stages, i.e., the first, the second, and the third, in order to enhance its validity.

Additionally, e-learning materials compatible with the textbook were developed for the 3rd edition to make it a more versatile learning tool. Furthermore, as a developed county with one of the best home medical care systems in the world, wishing to make a contribution to Asian countries that will undergo population aging in the future, we are working on preparing an English version of *Textbook of Home Care Medicine* and the e-learning materials.

I hope that this textbook will contribute to equal healthcare service in the new home medical care as well as its prevalence, thus sustaining the era of integrated community care.

October 31, 2015

Satoshi Hirahara

Chief Editor of the Editorial Board of Textbook of Home Care Medicine 3rd Edition

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Chapter I.

General Introduction to Home Medical Care

Home medical care is a systematized medical technique in which physicians, nurses, etc. make house calls to patients to conduct medical practices. Home medical care is also “the third healthcare” along with inpatient hospital health care and outpatient health care. Having come under an ultra-aged society, we are seeing a growing focus on home medical care in Japan as an option for patients who have difficulty attending hospitals or for those who prefer to remain at home in the final stages of life to live under care in comfortable surroundings and maintain a good quality of life (QOL). Home medical care is a type of healthcare service conducted in the patient’s home. While it is built on the basis of common medical techniques, “the way the techniques are applied” in home medical care is significantly different from the ways used in inpatient hospital healthcare or outpatient healthcare. This chapter of general introduction will provide a simple description of these basic features of home medical care.

(Tadashi Wada)

The Yuumi Memorial Foundation for Home Health Care website has a section providing a listing of medical facilities dedicated to home medical care.

Please contact our executive office if you are interested in signing up for the listing.

Note) The website only provides names with contact information of the physicians and medical facilities, which is not intended for recommendation.

1. Present Significance of Home Medical Care

Constituting the basic form of the present-day home medical care that is provided, Home Medical Care in Modern Times comprises regular house calls by physicians and 24-hour on-call care. Home Medical Care in Modern Times has its origin in hospitals, where it initially emerged from, in one aspect, a need to compensate the limits of inpatient hospital health care. Meanwhile, home medical care performed by primary physicians was provided, with clinics as its base.

Traditionally, physicians and nurses were the major players in home medical care. However, particularly after the Long-term Care Insurance System was established, physicians and nurses have come to perform home medical care by forming coordinated interprofessional alliances. In the future integrated community care, the house call physicians will perform their activities, thus further enhancing their interprofessional collaboration.

Home Medical Care in Modern Times

A. Transition in the Level of In-home Healthcare and Home Medical Care in Modern Times

In Home Medical Care in Modern Times, the house call physicians make house calls regularly, giving patients the dates of their calls in advance. This mode of medical care has traditionally been referred to as “regular house calls” in many medical facilities (or “home-visiting medical care” in the present-day insured medical care terminology).¹⁾ The “regular house calls” and the “24-hour on-call care” are the fundamental components of the physicians’ responsibilities in Home Medical Care in Modern Times.²⁾ Home Medical Care in Modern Times is different from the healthcare services given in the conventional “emergency house calls” (or “house calls” in the present-day insured medical care terminology) for acute illness.

In the era with simple diagnostic/therapeutic technology and limited clinical testing instruments, “the level of in-home healthcare” was adequate compared with “the level of medical care provided on an outpatient basis.” In those days, the “house calls” was a very common practice; if a patient presented with an acute disease, a physician would be called to the patient’s house. However, technological innovation such as image diagnosis since the 1970s has led to “emergency outpatient service departments” providing advanced healthcare services using fast and accurate diagnostic tools for treatment. Conversely, the in-home medical care provided with limited diagnostic tools became less effective in terms of diagnostic accuracy, which resulted in a rapid decrease in the number of physicians who make “emergency house calls” to patients with acute diseases.

B. The Light and Dark Side of Inpatient Hospital Health Care

The advancement of diagnostic/therapeutic technologies including emergency medicine from the 1970s through 1980s brought great prosperity to inpatient hospital health care. However, it also gave rise to criticism of its dark side, i.e., issues of excessive treatment-oriented principles or the way physicians and nurses dealt with treatment-refractory patients. These problems were symbolically described as “spaghetti syndrome,” “vegetative state,” “issues of hospital transfer,” etc. Around that time, the right and wrong of resuscitation was also highlighted in Japan, provoking a debate about the issue of “Do Not Attempt Resuscitation Order.” It was during this period that we were introduced to the “hospice campaign” organized out of sympathy for cancer patients dying in pain. Around 1980, Akihiko Okamura introduced us to the idea of hospice.³⁾ In 1981, the first hospice in Japan was opened at Seirei Mikatahara General Hospital.

Treatment-refractory patients were left to suffer from severe disorders, and incurable cancer patients were forced to remain at hospital, even though they wished to spend their remaining time at home. Then, highly motivated clinicians emerged in various regions in Japan. They endeavored to have these patients discharged from the hospital to provide them with continuous healthcare services at home. These individuals included Akira Sato from Tokyo Hakujuji Hospital in Higashi Murayama City, Tokyo; Kazuteru Hayakawa from Horikawa Hospital in Kyoto; Takuo Kuroiwa from Yukiguni Yamato Hospital in Yamato-cho, Niigata; Kiyoshi Imai from Suwa Central Hospital in Chino-shi, Nagano; and Tadamichi Mashiko from Yanagihara Hospital in Adachi-ku, Tokyo.^{4),5)} Meanwhile, home medical care conducted by primary physicians was being provided in parallel, with clinics as its base. Later in 1986, the “regular house calls,” which provides medical management by making regular house calls to patients, was listed as insurance-covered medical care, classified as “home-visiting medical care,” thereby attaining its technical significance as a chargeable service.

Today, home medical care is provided mainly by clinics, which is partly because primary care physicians mostly undertake the task as part of their responsibility as the patients’ personal physicians and partly because the current system gives clinics an advantage in charging medical service fees. However, as mentioned earlier, Home Medical Care in Modern Times essentially owes its origin to hospitals from a historical point of view. It was probably because they needed to ensure that refractory patients were rehabilitating life in the comfortable surroundings of their homes as well as out of medical technological necessity that “multiple physicians are needed.”

C. Social Background

Home Medical Care in Modern Times emerged over the 1970s and 1980s. Since then, the pioneers have accumulated practical expertise in various regions. Today, home medical care is again attracting attention in the aforementioned context of “continuous medical care for those who have difficulty in attending hospitals because of various challenges.”

A part of the reason is the marked aging taking place in the demographic structure. A variety of attitude surveys have also shown that a majority of the patients prefer their homes as for rehabilitation and to spend the terminal period of their lives. This phenomenon is observed not only in seniors but also in patients who have diseases with unfavorable prognosis. These factors constitute the need for home medical care in modern times. Additionally, in the Home Medical Care in Modern Times provided to these patients—unlike in the conventional “home medical care on the basis of emergency house calls”—the patients’ conditions are mostly already identified to a certain extent at hospitals, which makes it characteristically relatively easy to maintain the level of healthcare when continuous medical care is given to these patients at their homes.

D. Twenty-four-hour On-call Care

Individuals receiving home medical care are frailer than those who can make outpatient visits and therefore may develop pathological changes at any time in a day. Additionally, quite a few of them wish to end their lives at home. Therefore, Home Medical Care in Modern Times requires 24-hour on-call care. This is not confined to simply dealing with physical emergencies but meant to encompass addressing the anxiety of patients and their families 24 hours a day and to provide assistance for them to continue in-home rehabilitation, eliminating their concern.

The 24-hour on-call care is a difficult duty for house call physicians. The authors conducted a survey with the managers of the 13,012 home care support clinics in Japan. Respondents who responded to “Hurdle(s) for physicians to continue home medical care as their occupation” with “Difficulty to fulfill 24-hour on-call care” were as high as 75.3%, confirming it as the biggest hurdle.⁶⁾ However, among the physicians who are actually engaged in home medical care, the sense of psychological burden of the 24-hour on-call care is not necessarily significant, which reflects that the physicians who are not involved in home medical care tend to have a fear of

excessive burden. In fact, by experiencing the facts that “there are usually precursory signs in the daytime that predict changes in patients’ conditions at night and on holidays” and “most of the calls at night can be avoided by making arrangements in the daytime based on the prediction,” the concern and sense of burden can be often reduced over time.

To address the difficulty of a single general practitioner performing the duty of 24-hour on-call care, there are initiatives going on in each region. The first of the initiatives is to form a collaborative alliance with visiting nurse stations delivering 24-hour on-call care services. The second approach is for the physicians from multiple clinics to cooperate for handling 24-hour on-call care. This method has turned out successful in the form of a system of “Functionally Enhanced Home Care Support Clinics.” Other initiatives undertaken by public groups, etc. include the activities of the Onomichi Medical Association in Hiroshima, the Nagasaki Dr. Net run by Nagasaki City, and the programs attempted by Sosa Medical Association in Chiba.⁷⁾

Table. Historical Classification of Home Medical Care

Home Medical Care		Period	Features	Social Background
Conventional Home Medical Care		around 1965	- Physicians make house calls (medical care at clinics and house calls) for acute diseases (infections, stroke)	- Extrinsic diseases (infections, maternal–fetal) - Acute diseases such as stroke - Life expectancy up to the 60s
Home Medical Care in Modern Times	Emerging Period	1970–1992	- Twenty-four hours, systematic assistance for patients with disorders and terminal patients - On the premise of caregiving by families (Sprouting of home medical care in modern times)	- Healthcare/inpatient hospital care to treat adult diseases (cancer, heart diseases, stroke) - Life expectancy 70–75/75–85
	Embryonic Period	1992–2012	- Home medical care in the Long-term Care Insurance System (to support senior families) - Increased supply (long-term care insurance, home medical care, the Gold Plan) - Prevalence of services - Establishment of academic systematization and education systems	- Adult diseases + gerontological diseases - Life expectancy 79/87
	Developing Period	2012 onward	- Home medical care in the era of integrated community care (targeting single-person households, etc.) - Interprofessional alliance (horizontal integration) and in-home care as much as possible combined with occasional hospitalization (vertical integration) - Systematization of home medical care (city/ward/town/village, medical association) - Encourage seminars/enhance quality	- Gerontological syndrome - Life expectancy 80/90 - Increase in the number of old-olds (over 85 years) - Increase in the number of seniors living alone - Weak family relationships - Neighborhood building

(Historical classification of home medical care by Satoshi Hirahara)

Interprofessional Collaborative Alliance

In the preceding section, I described the historical background and transition of home medical care conducted by physicians. Another significant feature of Home Medical Care in Modern Times is alliances with a broad range of professionals.

For a certain period from the 1970s through 1980s, when Home Medical Care in Modern Times arose, the primary players of home medical care were physicians and nurses. In the same period, motivated dentists, pharmacists, dietitians, etc. were engaged in home-visiting activities, which were beginning to be included in the national health insurance schedule.

Against this fundamental backdrop, the Long-term Care Insurance System went into effect in 2000. The enforcement exerted a powerful influence on the on-site activities of home medical care, i.e., home-visiting activities of health care professionals other than physicians/nurses as well as the activities of in-home service providers other than health care professionals were dramatically increased. Thus, home medical care has come to involve diverse activities, not only the services provided mainly by physicians and nurses but also the home-visiting activities of dentists, pharmacists, rehabilitation staff, dietitians, etc. Additionally, the house call physicians have come to conduct their activities utilizing a variety of social resources for home medical care/in-home care—not only working in alliance with care managers and caregivers but also attending meetings such as service providers' meetings, etc.

Furthermore, the idea of integrated community care has been introduced, according to which all cities/towns/villages are projected to implement the home medical care/in-home daily care alliance enhancement programs commencing in 2017. Home medical care will be positioned as an integral component of integrated community care, and at the same time, the house call physicians will conduct their activities on the basis of further integrated interprofessional collaboration.

Recent Trend

Since 1990, academic societies and study groups related to home medical care have been organized one after another, which has established a platform to accumulate evidence on home medical care. The medical procedures performed in home medical care around 1990 were mostly simple. However, as pharmacists became increasingly involved in the area, the contents of the medical services provided in home medical care have advanced, with an increasing number of patients receiving tube feeding, total parenteral nutrition, or continuous administration of narcotics.

(Tadashi Wada)

References

- 1) 川上武：内科往診学. 医学書院, 1967. Kawakami, T. (1967). *Internal medicine for house calls*. Igaku-Shoin Ltd.
- 2) 和田忠志：在宅医療とは何か. 明日の在宅医療 第二巻 在宅医療の諸相と方法, 中央法規出版, 2008. Wada, T. (2008). What is home medical care? In *Home Medical Care for Tomorrow, 2, Features and Approaches of Home Medical Care*. Chuohoki Publishing Co., Ltd.
- 3) 岡村昭彦：定本ホスピスへの遠い道. 春秋社, 1999. Okamura, A. (1999). *Faraway road to hospice: The standard edition*. Shunjusha Publishing Company.
- 4) 佐藤智：在宅老人に学ぶ—新しい医療の姿を求めて. ミネルヴァ書房, 1983. Sato, A. (1983). *Learning from seniors living at home: Looking for a new mode of healthcare*. Minerva Shobo.
- 5) 増子忠道：地域医療の現場から—寝たきり老人・医療思想・医療費. 勁草書房, 1985. Mashiko, T. (1985). *From the field of community medicine: Bed-bound seniors, ideology of healthcare, and healthcare costs*. Keiso Shobo.
- 6) 被災地の再生を考慮した在宅医療の構築に関する研究 平成 24 年度～26 年度 厚生労働科学研究

- 究費補助金（地域医療基盤開発推進研究事業），2015. Study of construction of home medical care considering restoration of the disaster area. (2015). Health, Labour and Welfare Grants-in-aid for Scientific Research (Program on Study of Enhancing Development of Community Medicine) Fiscal Year 2012-2014
- 7) 片山壽 編著：地域で支える患者本位の在宅緩和ケア．篠原出版新社，2009. Katayama, H. (2009). Community-based in-home palliative care for patient's own benefit. Shinoharashinsha Publishers Inc.

Reference. Transition of Various Systems Related to Enhancement of Home Medical Care

Medical Service Fees	
1980	Guidance and Management Fees established in home medical care The fee for guidance and management of self-injection of insulin at home established
1984	Establishment of additional fees for emergency house calls
1986	Introduction of the idea of home-visiting medical care on regular basis The Fee for Home-visiting Medical Care for Bed-bound Seniors established Various Guidance and Management fees established
1992	A prototype of the comprehensive point-counting system for home medical care created The fee for in-home general medical care for bed-bound seniors
1994	Various guidance fees and management fees established In-home General Medical Management Fee, In-home General Terminal Medical Care Fee, Additional Fee for Terminal Care
1996	Evaluation of in-home terminal care enhanced Application of the In-home Terminal Care General Medical Care Fee broadened The fee for Home-visiting Nursing and Guidance for Home-bound Terminal Patients established, etc.
2000	Evaluation of the system for providing 24-hour on-call home medical care The Additional Fee for 24-hour Collaborative Alliance established
2004	Enhancement of home medical care for patients with severe disorders/terminal patients Evaluation of in-home terminal care enhanced Evaluation of multiple house calls for home-visiting nursing to patients with severe diseases
2006	Establishment of the function of the personal physicians for patients rehabilitating at home and enhancement of in-home rehabilitation Home care support clinics established
2008	Enhancement and evaluation of home medical care in accordance with the establishment of the healthcare system for older adults Home care support hospitals established
2012	Enhancement and evaluation of home medical care Functionally enhanced home care support clinics/hospitals established
The Medical Care Act/Budget	
1985	The 1st reform of the Medical Care Act The Regional Medical Care Plan established
1992	The 2nd reform of the Medical Care Act Position “home” as a place where medical care is provided
1997	The 3rd reform of the Medical Care Act Community medicine support hospitals established
2000	The 4th reform of the Medical Care Act Purpose of usage of hospital beds classified
2004 -	• The scheme for promoting home-visiting nursing services (¥57 million)
2006	The 5th reform of the Medical Care Act • Specialization of healthcare functions/collaborative alliance • Initiatives for ensuring home medical care incorporated into the Medical Care Plan
2011	• The scheme of hubs of home medical care alliances (¥108 million)
	• Guidelines for establishing systems related to home medical care issued
2012	• The scheme of hubs of home medical care alliances (¥2.1 billion)
Others	
1973	The Act on Social Welfare for the Elderly reform Healthcare provided for free to older adults
1980	The Act on Social Welfare for the Elderly reform Healthcare provided for a charge to older adults
1982	The Health and Medical Services Act for the Aged enacted Comprehensive implementation of health and medical service programs for prevention/treatment of diseases and function training
1986	The Health and Medical Services Act for the Aged reform

	Facilities for health and medical service programs for older adults established, etc.
	General Principles of the Measurements to Long-lived Society decided by the Cabinet Reinforcement of in-home care services
1989	The Gold Plan Urgent enhancement of in-home welfare programs in cities/towns/villages
1990	The Eight welfare acts reform Omnibus reform of the 8 acts to facilitate in-home welfare services
1991	The Health and Medical Services Act for the Aged reform Home-visiting nursing stations established
1992	Acts for Assurance of Welfare Human Resources and Assurance of Human Resources Including Nurses enacted Welfare human resources to accelerate implementation of the Gold Plan ensured
1994	The Health Insurance Act, etc. reform Position home medical care as “benefits for medical treatment” The Designated Home-nursing System established
	The Vision of the 21st Century Welfare Establishment of a new caregiving system toward the 21st century
1995	The Basic Law on Measures for the Aging Society enacted A platform for providing proper care services reinforced
	The New Gold Plan Target values for the Gold Plan raised
2000	The Long-Term Care Insurance Act enacted
	The Gold Plan 21 A substantial increase in home-visiting care services, etc.
2006	The Long-term Care Insurance System reform Focus on preventive caregiving, etc.

(Source: Ministry of Health, Labour and Welfare)

2. Eligible Diseases and Clinical Issues

People eligible to receive home medical care as insurance-covered medical care are patients who cannot attend hospitals alone. These patients are divided into two major groups, i.e., patients who have physical disability and/or cognitive disorder due to diseases associated with aging and relatively young or pediatric patients with disabilities. Home medical care is not only an indispensable measure for general practitioners/family physicians but also a fundamental element of community medicine.

Individuals Eligible for Home Medical Care
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A. About Inability to Attend Hospitals Alone

Home medical care is for those who have difficulty in attending hospitals. They are the ones who are unable to travel to hospitals alone because of “impaired activities of daily living (ADL) due to diseases, trauma, or aging,” or “disorder caused by dementia and other psychiatric disorders.” These patients have severe disorders or life-threatening illness, and thereby, their prognoses are relatively shorter than those of outpatients. Therefore, house call physicians have to continually confront the death of patients. In that respect, in a broader sense, home medical care constitutes the provision of end-of-life care.

The reasons for patients’ inability to visit hospitals are diverse and involve the situations of their caregivers as well. In the insurance-covered medical care system, patients who are eligible for “home visiting consultation for bedridden seniors” are defined as being “in bedridden status or a status conforming to it.” However, no clear definition is provided for the contents of “conforming to bedridden status”; therefore, it is at the discretion of the medical facilities.

To put it simply, even a patient on an artificial respirator can be transferred for an outpatient visit if an ambulance vehicle belonging to a private ambulance service is used. Conversely, although a patient can marginally walk, if there are physical obstacles such as stairs or if the patient is at a distance from the nearest medical facility and, at the same time, has no caregivers to help him/her go there, he/she can be eligible for home medical care. However, given that delivering home medical care as insurance-covered medical care to patients who have the ability to travel to nearby medical facilities alone is not permitted, which is a point to be noted.

B. Underlying Diseases

Cross-sectionally, in a majority of the medical facilities providing home medical care, 90% or more of the patients receiving home medical care are noncancer patients. However, in relation to the medical facilities that are actively undertaking home medical care, with respect to the time of initiating home medical care in each patient, in many of these medical facilities, terminal cancer patients account for approximately 20%–50% of the total patients for whom home medical care was initiated.

The survival time of homebound patients is short when their underlying disease is cancer; most of the times the survival time of these patients after start of home medical care is approximately 1 month in many medical facilities. In contrast, noncancer patients largely live for a longer period of time after the start of home medical care than cancer patients. For instance, Ota investigated the in-home convalescence periods in 200 patients who died after receiving home medical care, dividing them into cancer patients and noncancer patients. The results showed that the mean periods from the start date of home medical care to deaths were 107.1 days and 782.4 days in cancer patients and noncancer patients, respectively.¹⁾ This explains why a majority of the patients receiving home medical care are found to be noncancer patients in a cross-sectional approach.

Common Ground between General Medical Care/Family Medicine and Home Medical Care

A. General Practitioner/Family Physician/House Call Physician

In the U.K., people form the “General Medical Services” contract with physicians working in their communities (general practitioner, GP) as a first point to consult about various medical conditions. GPs also refer patients for specialist treatment or admission. Being called GPs, these physicians possess broad clinical skills based on accumulated training as the patient’s “personal physician.” In addition, there are specialist systems in family medicine in the United States and Canada. In Japan, we have the systems of Japan Primary Care Association certified family physician and Diplomate in Primary Care of the Japan Primary Care Association, operated by Japan Primacy Care Association. A home medical care specialist system has also been run by the Japanese Academy of Home Care Physicians.

Apart from “the concept representing techniques” such as general practitioner or family physician, the author would like to stress the importance of “the concept representing relationships,” i.e., “personal physician,” who is chosen by the patient as his/her own doctor, who works on solving the issues of the patient and his/her family, thus building trust. At the same time, however, it is also desirable for the physicians who work in the community, including house call physicians, to possess not only (1) knowledge/skills/attitude as a general practitioner or family physician and (2) connection with patients and their families as their personal physician but also (3) ability to discover various healthcare needs in the community and alter themselves in accordance with the community needs. Furthermore, if they can attain (4) the capability to change the community through their own activities, they will be able to make greater contribution to the community.

Table. Five Principles of Primary Care

I.	Accessibility	1. Geographical 2. Economical 3. Temporal 4. Mental
II.	Comprehensiveness	1. From prevention to treatment and rehabilitation 2. All-inclusive healthcare 3. Common-disease-centered cross-disciplinary healthcare 4. From infants to older adults
III.	Coordination	1. Strong relationship with specialists 2. Collaboration with team members 3. The patient request approach (cooperation with neighbors) 4. Optimization of social healthcare resources
IV.	Continuity	1. “From the cradle to the grave” 2. In sickness and in health 3. Continuous care at the time of illness, i.e., outpatient department-ward-outpatient department
V.	Accountability	1. Audit system to substantiate the contents of healthcare 2. Lifetime education 3. Sufficient explanation to patients

From References 2)

B. Primary Care and Home Medical Care

Five principles have been presented for primary care, which constitute the foundation of general medical care and family medicine (**Table**).²⁾

These principles can be the major guiding concepts for physicians who work in home medical care. From this point of view, home medical care is one of the foundations of the techniques used

by general practitioners and family physicians. Therefore, there will be no accomplishment in the work of general practitioners and family physicians without being involved in home medical care. The knowledge/skills/attitude of a general practitioner/family physician is also indispensable when providing home medical care.

C. “Home Medical Care Allowing Presence at the Deathbed” and “Personal Physician”

The phrase, “home medical care allowing presence at the deathbed,” may sound strange to many physicians. It means that being present at the deathbed of a patient is not a “purpose” that is given in advance, but it is essentially something that the patient asks his/her personal physician out of the ultimate trust that has been built up between them; in essence, the patient is saying, “I want you to feel my last pulse.” Being asked to do so by patients or their families is the highest honor as a physician. It is a deed that makes physicians feel professionally satisfied.¹⁾

(Tadashi Wada)

References

- 1) 太田秀樹, 和田忠志: 在宅医療をサポートする医師研修カリキュラム. 日本医師会, 2008. Ota, H., & Wada, T. (2008). Curriculum for training physicians supporting home medical care. Japan Medical Association
- 2) 一般社団法人日本プライマリ・ケア連合学会: プライマリ・ケアの5つの理念 Five Principles in Primary Care. General Incorporated Association Japan Primary Care Association. (<http://www.primary-care.or.jp/paramedic/>)

3. Initiation of Home Medical Care

The following explains the procedure for initiating home medical care with regard to 5 aspects, i.e., shifting to in-home placement from outpatient care, introductory interview, joint guidance meeting for hospital discharge, collection of information in the first house call, and in-home convalescence planning.

Shifting to In-home Placement from Outpatient Care

As far as the patient's physical condition is marginally well enough to attend hospitals—not to mention the case where the patient has historically been seeing the physician as his/her personal physician on an outpatient basis—it is reasonable for the physician to see him/her on an outpatient basis. This is true even in the case where home medical care services were requested. Some patients, including frail seniors and patients with dementia, are able to make outpatient visits usually but have difficulty traveling to hospitals when feeling ill, as in presenting with pyrexia. In these instances, it is desirable that their personal physicians make house calls in a flexible way.

Making one house call to the patients—including those with advanced cancer but able to attend hospitals—in a relatively early stage is a good approach because it provides the physician with some benefit of grasping the patients' home environment, situation of daily living, familial circumstances, etc.

Introductory Interview

Setting up an introductory interview with the patient's family before initiating in-home convalescence is a good method to start home medical care smoothly.

A. Preliminary Collection of Information

Prior to the interview, it is preferable to obtain information required to initiate in-home medical care from the most recent attending physician. The information includes the clinical course related to the historical diagnoses/treatment, the contents of healthcare to be continued, and a forecast of pathophysiological conditions in the future as well as the contents of the explanation about the patient's condition given to the patient himself/herself and his/her family. Because the information provided in the Patient Referral Document is often insufficient, it will be practical to have communication through the referral service section, etc. for additional information needed.

There are no templates of how to conduct the introductory interviews. At the author's clinic we take more than 1 hour for these interviews in which 3 parties, i.e., physician, nurse, and clerk, participate. The nurse asks about overall symptoms including medical history, current physical status, and the situation of living, and explains the procedure of home medical care such as the method for emergency contact. The clerk is in charge of the explanation about paperwork including the medical service fees and other systems as well as the method for collecting copayments.

B. Family's Request about the Therapeutic Care Plan

The physician is in charge of mainly the consultation related to the therapeutic care plan. At that point, the family is asked to tell, in their own words, how the patient and family perceive the current situation because, more often than not, the author sees a gap between the contents of the explanation given by the hospital about the patient's condition and what is perceived by the

family. On the basis of these, a common understanding is formed regarding the purpose of the in-home convalescence and a viable therapeutic care plan. Above all, the most important is the familial circumstances of the household the patient will live in. The physician should try to identify who is the main caregiver and who is the influential person to represent the patient's benefit.

Additionally, areas that should be confirmed in detail include (1) hospital(s) where the patient attended for primary care, (2) how to deal with urgent illness, and (3) measures when the death is imminent. When asking about a hospital where they want the patient to be seen as necessary in the future, it would be useful if they can mention more than one hospital, if possible. It is also good to grasp nuances of their thought toward urgent illness, i.e., whether the family wants to have the patient transferred to the hospital immediately or, conversely, wants the physician to consider the feasibility of treating him/her at home as much as possible. Furthermore, it will help when taking action at the time of acute illness, if the physician can know, as much as reasonably possible, the family's wishes or position about how they would like the patient to be dealt with when death is imminent.

Joint Guidance for Hospital Discharge

When there is a request for initiating home medical care for an inpatient, as much effort as possible should be made to organize a joint guidance meeting for discharge. When planning the meeting, a healthcare social worker, etc. belonging to the hospital's community alliance department should be contacted for them to coordinate the schedule with the physician in charge of the patient at the hospital. It is desirable that, along with the patient and his/her family, the home visiting nursing station, in-home long-term care support provider, and dispensing pharmacy that will be in charge of the patient after discharge be contacted to seek attendance.

Areas that should be covered at the meeting include: confirmation of the medical history and the contents of the current treatment/care, thought of the patient and his/her family about the place for convalescence, deliberation about how to make the treatment/care less complicated as necessary to a method suitable for in-home convalescence (simplification of treatment/care), confirmation of the status of the guidance on medical procedures and techniques to the patient and his/her family, the long-term care support planning after discharge, the paperwork and preparation required by discharge, measures and a plan in the case of readmission, and decision of the discharge date considering the overall situation (**Table**).

For the calculation of the joint guidance for discharge fee, it is necessary to make a record of the contents of the joint guidance provided and keep it in the medical record at both the hospital and the clinic, as well as to provide in writing the contents of the guidance to the patient and his/her family.

Table. Areas to Be Ascertained in the "Joint Guidance for Discharge"

- Confirmation of the medical history and the contents of the current treatment/care
- Thought of the patient and his/her family about the place for convalescence
- Simplification of treatment/care
- Guidance on medical procedures and techniques
- Paperwork and preparation required by discharge
- Measures and a plan in the case of readmission
- Decision of the discharge date considering the overall situation

Collection of Information in the First House Call

After the introductory interview, the physician makes the first house call for home visiting medical care. During this time, conducting the same medical interview, physical examination, and diagnostic testing as in outpatient medical care may reduce the fundamental value of home medical care, which enables the physician to see the patient at his/her home. This article provides a simple description of the areas that should be conducted in the first house call other than the minimum medical care.

A. Patient's Cognition and Wishes about the Therapeutic Care Plan

When making the first house call, the physician should try to grasp not only the patient's pathophysiological condition but also his/her own sentiment. Although the family's intent can be known in advance at the introductory interview, it goes without saying that the patient's own wishes or values should be more respected when determining any plans. In the first home visit, the physician should attempt to make the patient speak in his/her own words about how he/she perceives the current situation himself/herself and what sentiment or wishes he/she has.

B. Home Environment

The physician assesses the patient's home environment including presence of barriers or danger when the patient goes out of the entrance or moves from the bed to the dining table or toilet as well as the structure of the bathroom, etc. considering the traffic flow of the patient and gives appropriate advice from the standpoint of safety assurance and maintenance/improvement of quality of life. The physician should also give attention to the need for supportive devices and home modifications such as an electric adjustable bed, bedside commode, wheelchair, railings, and cane that are suitable for the patient's activities of daily living (ADL) as well as a viable method for bathing.

C. Situation of Living and Familial Circumstances

The physician should find out where the patient has meals and excretes, whether he/she has opportunities for going out, and the actual use of care services, thereby knowing his/her daily and weekly routine. This way the physician can grasp the risk of disuse syndrome and cognitive function deterioration, likelihood of therapeutic intervention, the patient's will to fight the disease, etc., which constitute integral information to determine a therapeutic care plan.

Additionally, the information about familial circumstances is something that can be obtained during the home visit. Through the conversation between the patient and the caregiver(s) as well as the way he/she receives custodial care, etc., the physician can feel, to a certain degree, the familial circumstances including their mutual trusting relationship and affection. Economic issues are also an inevitable aspect to assist the convalescent life of the patient. Giving consideration to privacy, the physician should grasp to a certain extent the various issues the family has including economic circumstances.

In-home Convalescence Plan

When calculating the In-home General Medical Management Fee, a comprehensive in-home convalescence plan is required to be designed per patient. The following explanation is based on the form of the in-home convalescence plan created in the author's clinic (**Figure**).

A. Information about the Patient and the Introductory Interview

First, from the standpoint of appropriate continuation of healthcare, attention should be paid to the important prescription given by the most recent attending physician, diagnostic testing data to be followed continuously, examinations to be considered in the future, and so forth. Then, the family's request about the therapeutic care plan expressed in the introductory interview is

recorded. In particular, their basic thought including the selection of hospitals for primary care, measures to be taken at the time of urgent illness, and how to deal with imminent death should be clarified. Afterwards, at the time of the first house call, patient's own perception and his/her wishes about the therapeutic care plan should be grasped. In addition, the information obtained during the home visit such as home environment, the patient's situation of living, and the familial circumstances is recorded.

To continue in-home care, the organizational names of the collaborating home visit nursing station, dispensing pharmacy, and the care manager's office as well as the names of the individuals in charge should also be clearly identified. What is important is to have cognition that the four parties including the personal physician form an "in-home convalescence support team" and build up collaborative efforts.

B. Agreed-upon Therapeutic Care Plan and Advance Instructions for Potential Situations

Subsequent to the introductory interview and the first house call, a rough therapeutic care plan to initiate medical care is determined based on the family's request about the therapeutic care plan and the patient's cognition and his/her wishes about the plan as well as the assessment from the medical point of view.

Additionally, it is crucial to give an explanation to the patient's family about the advance instructions on what changes in his/her pathophysiological conditions, complications, or troubles are expected to occur in the future. For instance, with respect to acute exacerbation and occurrence of complications that can be predicted to a certain extent based on the clinical course—such as cardiac failure, bronchial asthma, or aspiration pneumonia—the potential situations should be supposed in advance and concrete instructions should be given on the points to be noted and the timing for notifying the event. Because the troubles related to medical devices such as gastrostomy feeding tubes or urethral catheters are also predictable, precautionary measures should be taken in advance supposing potential risk per patient in advance, such as keeping spares in the home for contingent replacement.

(Shohei Kawagoe)

In-home Convalescence Plan

Patient Information

Primary Care Physician

Date of Recording 20 / /

Main Disease 1 _____ Degree of Independence in Activities of Daily Living: J1, J2, A1, A2, B1, B2, C1, C2

Main Disease 2 _____

Main Disease 3 _____ Degree of Independence in Dementia: Independent, I, IIa, IIb, IIIa, IIIb, IV, M

Disease(s) Requiring Custodial Care

Disease(s) Requiring Custodial Care

Important Prescription

<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>

Concomitant Medical Care with Other Hospital(s)

Yes Disease Name(s) No

Prescription/Contents of Diagnostic Testing at Other Hospital(s)

Follow-up Tests

Items for Blood Testing/Other Indicators (Weight/Quantity of Urine, etc.)

Frequency

Every ___ month(s)
Every ___ month(s)
Every ___ month(s)

Examinations to Be Considered in the Future (Hospital(s) for conducting them)

Introductory Interview

Family's Request about the Therapeutic Care Plan

Items Confirmed related to Healthcare

1 Primary Care Hospital 1) _____ 2) _____

2 How to Deal with Urgent Illness

3 Measures When the Death is Imminent

In-home Convalescence Support Team

- Home visiting Nurse
Name of Station _____
Person in Charge _____
- Pharmacist
Name of Pharmacy _____
Home visiting Medication Management Guidance Yes No
- Care Manager
Name of Office _____
Person in Charge _____
- _____

First House Call

Patient's Cognition and Wishes about the Therapeutic Care Plan

Information Obtained by the First House Call

Home Environment

Situation of Living

Familial Circumstances

Agreed-upon Therapeutic Care Plan

Potential Pathophysiological Condition(s) and Predicted Instructions

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4. Basis of Medical Care in Home Medical Care

Needless to say, everything the physician says or does influences the patient and the family, which is true even in home medical care. This article outlines the general points to remember at the time of home visit in home medical care, what should be done in the first and a few subsequent house calls, and how to deal with the family's anxiety when initiating home medical care.

General Points to Remember at the Time of Home Visit
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The physician may or may not wear a white coat. However, if he/she is expected to perform a medical procedure, it is appropriate to wear a white coat. It is also preferable for the physician not to dress casually even when he/she is not wearing a white coat. Therefore, wearing T-shirt or sandals should be avoided.

When the physician is at the doorstep, ringing the doorbell several times as if rushing the individual(s) inside is inappropriate because, if the caregiver or the patient is elderly, it may take some time (approximately 1–2 min) for him/her to reach the front door even if he/she is inside. The physician should consider that the patient/caregiver may sometimes be using the toilet or the bathroom.

When “the family is out having the front door unlocked,” the decision on whether to enter the home is sensitive. Doing so should be avoided until certain agreement that “the physician may get in the home” without a greeting or any response from the patient or the family, after a trusting relationship with the patient/family is established through repeated medical care. Obviously, this is not true if the patient's condition is expected to be exceptionally unfavorable. Additionally, if the patient who is alone at home and is supposed to be unwell, sometimes “the physician should get inside (even through a window) to ascertain his/her condition even if the front door is locked.” These decisions are made considering the strength of the trusting relationship with the patient as well as the preference or life style of the patient/family, but mostly it will be appropriately determined based on the physician's experience.

It is preferable even for a physician to neatly place his/her shoes at the entrance way before getting inside. More often than not, having entered the home, it is wise not to look around too much until reaching the patient's room. The physician should be aware that “they do not want some room (or some part of the home) to be observed by the physician.” However, if there is something for a display, such as an ornament, a work of flower arrangement, or a framed testimonial, in most cases the physician may look at it because his/her looking at these things not only provides psychological satisfaction to the patient and the family but also is useful to know the interests or the past achievement of the patient/family. Before entering the patient's room, the physician should knock the door or tell him/her something like, “I am here for house call. I'm coming in.”

After entering the room, the physician starts medical consultation, at which time he/she should pay attention “whether the sight of consultation can be seen or the conversation can be heard from outside the room.” For instance, if a window curtain in the room is open, the physician should draw it before initiating the consultation. If a window is open, the physician should shut it before starting the consultation, as the conversation may be overheard from outside.

The First and a Few Subsequent House Calls

What the physician says and does in the first house call provides a strong impression to the patient/family, exerting substantial influence over the trusting relationship thereafter. It is ideal that the patient/family “cotton to the physician’s visit and begin to look forward to it” during the first few home visits. To achieve it, the physician should perform the consultation remembering what is described in the above section. During the first few visits in particular, the physician should try to ask the patient’s life history and the current situation of daily life to grasp his/her character.

Sometimes the family offers tea/sweets after consultation. In the first house call, the physician may have them expressing gratitude, at which time he/she may tell, “Essentially, no consideration is necessary from next time on,” thereby releasing the family from unnecessary consideration as well as reducing the time of consultation. In fact, taking tea/food will become painful for the physician if he/she has to be entertained at every home he/she visits. The reason for having stated “essentially” is that some patients/families look forward to chatting with the physician/nurse over tea/sweets. Further, offering tea/sweets may sometimes be a message, i.e., “I need someone to share my stories as I am tied up with caregiving all the time.” In these instances, accepting the offer itself is useful for mental care for the patient/family; therefore, in most cases, it is wise not to decline it.

Addressing the Anxiety of the Family Who Initiated In-home Daily Care

It is no exaggeration to say that, when in-home care is initiated, the family who has just begun to provide care is constantly struggling with anxiety. However, usually the realization, “probably we can do it,” comes as they are taught the caregiving method in detail by earnest professionals including nurses, gaining caregiving experiences, and get used to the life while providing care. Until the caregiving family reaches the realization, the physician should intently work on the “reduction of the family’s anxiety.”

The author would suggest that the physician provide positive encouragement to the family as much as possible. For example, he/she may say, “I hear your husband saying, ‘it’s good to be back home’ many times. It owes entirely to your efforts. He can do what he wants to do and eat what he likes. Your husband appears to be feeling safe and comfortable because everyone in your family is helping him so much,” or “Cancer is believed to be a painful disease, but your wife appears to have almost no pain now. It is probably because you and your family have been so devoted to taking care of her. It’s a real blessing.” The author believes that words such as these will bring out and enhance the family’s capability.

When in-home convalescence is started, additional home-visiting nursing or house calls are often required to counsel the family about their concern. In these instances, the family will obviously be relieved if a nurse or physician visits the home—even though knowing there is not necessarily medical urgency—instead of responding on the phone, and assures in front of them that there is no criticality in the patient’s status. Through a few dialogues with the physician (or the nurse) like this, the family acquire their own way of care and often come to feel “it’s all right” except in “the matters that really require urgent procedures.”

Therefore, there should be much deliberation before demanding a decision that bears a greater psychological burden such as “whether we have the intent to look after the patient until the end of his/her life” of “a family who has just begun to provide care with trepidation.” At first, as in-home care was initiated, it mostly produces a good result not to provide a psychological pressure of determining “whether we will continue care through the patient’s final moments” to the family, and just have them “experience caregiving for the time being.” As far as the situation allows, it is wise not to interview them on such intent until the family get used to caregiving. Sometimes

it is not even necessary to hear what they have to say about the issue because, even if health care professionals do not find it out deliberately, a mutual understanding is often spontaneously built between the medical staff and the family as they gradually become “determined.”

Physical Examination in Home Medical Care

Because only limited diagnostic testing measures are available in home medical care, the physician needs to assess many things through physical examination. The key points are to examine not only the vital signs and the status of consciousness but the whole body closely as necessary, and to take accurate information from the family.

A. Necessary Medical Equipment

In the ordinary home medical care, the equipment for consultation may be simple. The minimum equipment would be a stethoscope, a sphygmomanometer, and a pulse oximeter. Additionally, a flashlight, a disposable tongue depressor, and a reflex hammer should also be prepared. An otoscope and an ophthalmoscope are added as necessary.

B. Medical Interview and Obtaining the Patient’s Clinical Condition from the Family

In home medical care, unless especially prepared in advance, the medical interview and physical examination are the sole approaches to know the clinical aspects of the patient’s condition. The medical interview in home medical care has advantages over outpatient medical care because it ensures that the physician can obtain information from the family, who are directly giving care to the patient, and allows him/her to directly observe the patient’s life and convalescent environment. Given that home medical care largely deals with patients with severe disorders, it relies on the information mainly obtained from the family (care service employees) for patients who have lost the ability for verbal communication.

C. Physical Findings

Physical examination weighs much in home medical care. Comparison with usual conditions matters; therefore, accumulating the data obtained in each examination is important. In the usual physical examination, the author always carries out an interview regarding any changes in conditions, checking of vital signs including oxygen saturation, auscultation of the chest, and examination of lower extremities. Additionally, the author observes urine in patients with a urethral catheter and check wound in patients with a tracheostomy or gastric fistula.

(1) Observation of body movement at home

The consultation starts as the physician enters the home. Closely observing the patient’s movement at home in usual circumstances enables the physician to easily notice a change occurred during the illness. Sometimes mildly disturbed consciousness can be detected by observing the patient’s movement.

(2) Examination of the abdomen/chest/lower extremities

In home medical care, most patients are usually in the “ready-for-immediate-examination status,” and are usually lightly dressed so that their chest/abdomen can be easily exposed, are lying in bed or at bedside, wearing no shoes and examining their lower extremities and feet is easy. For patients who are lying in bed, the examination of the abdomen and lower extremities can be immediately started.

(3) Auscultation of the chest

In older adults and those who are in bedridden status for a long time, the physician usually hears various cardiac murmur or pulmonary sound in auscultation of the chest.

Murmur over lung field is often heard in the back/lower part of both sides of the chest. Unless these auscultation findings are recorded when the patient’s condition is stable, the physician cannot assess whether or not the abnormal findings are de novo, when the patient develops complications such as pyrexia or cough. Therefore, it is recommended that the physician

occasionally performs close auscultation when the patient's condition is stable, and record the findings. For patients lying in bed, examining murmur in the back may require much work, but auscultation in the back must be done if complication such as lower respiratory tract infection/pulmonary congestion is suspected.

(4) Check of pressure sore

Pressure sore is prone to develop if the family are not used to providing sufficient caregiving. In the first house call as well as when the patient's condition was aggravated, the physician must perform visual examination of the sacral region/the iliac crest region/the greater trochanter region/the back/around ankle joints, even though no information has been provided by the patient/family. When it turned out that the family got used to caregiving enough, or a home caregiver or home-visiting nurse is routinely observing the patient's skin, the early detection of pressure sore may be entrusted to them.

(5) Examination of the lower extremities

The lower extremities provide a lot of information, including the one about edema or peripheral circulatory disorder. Particularly in older adults, who are mostly affected with mild cardiac failure, observing lower extremities in every house call is of great significance.

D. Other Physical Findings

(1) Examination of conjunctiva/fundus

In home medical care, the physician is often asked to examine conjunctivae. For conjunctivitis, as long as the severity is mild, the house call physician may perform assessment. House call physicians do not necessarily need to be capable of examining fundus, but those who have techniques to examine it at the patient's home can release him/her from the stress of going out for outpatient visits.

(2) Examination of ears

Sometimes the physician is asked to examine ears or remove cerumen of the patient. General assessment of external auditory canal/tympanic membrane may be performed by the house call physician.

(3) Orthopedic examination

Many patients have low back pain; therefore, it is desirable for the house call physician to have basic skills for identifying pain in muscles, bones or joints, as well as neuralgia (sciatica). There are also many occasions to see patients who presented with fall. In regard to femur fracture, it is desirable that the physician is able to make a potential diagnosis before having the patient transferred to the orthopedic department. Femur fracture should be suspected if the lower extremity on the affected side sustain no load and coxalgia is experienced by supination of the lower extremity in dorsal recumbent position.

(4) Skin

Skin examination is also frequently requested. The physician should consciously learn dermatologic findings of scabies in particular.

(5) Rectal examination

It is desirable for the physician to be able to perform general assessment of anal/rectal membrane and prostate gland.

Positioning of Diagnostic Testing in Home Medical Care

A feature of home medical care is the absence of testing equipment that requires facilities. What is of importance is to wisely carry out the tests that can be done on the spot in home-care settings in accordance with the patient's clinical features and, simultaneously, have major collaborating hospitals in place and perform diagnostic testing, switching between home medical care and these hospitals as necessary.

A. What Tests Are Carried Out in Home Medical Care?

“Absence of testing equipment” is an aspect of home. Because of this restriction, clinical tests in home-care settings are performed using a methodology different to the one used for the tests performed in medical facilities. That is to say, usually, clinical tests are selected based on the criteria of what is most useful to make accurate diagnoses, in which being quick-and-easy-to-perform is taken into account when determining the order for carrying out the useful tests. On the other hand, what matters in home-care settings is “what can be most easily done at home.” Basically, the house call physician continues medical care, cleverly optimizing the tests on blood, urine, and collected stools/sputum/pus, as well as electrocardiograms.

B. Obtaining Information When Initiating Home Medical Care and Regular Diagnostic Testing

Certain homebound patients are introduced to home medical care by hospitals. Therefore, it is crucial for the house call physician to obtain as much test data as possible from the physician who made the referral at the time of discharge. If any information provided in the referral letter is insufficient, inquiries should be persistently made.

Additionally, if the patient “has an opportunity to visit the hospital (an opportunity to be admitted to the hospital) and if the hospital is a small hospital (which is not using the DPC/PDPS [Diagnosis Procedure Combination/Per-Diem Payment] system), the house call physician should request the hospital to perform additional test(s) that will provide the information he/she wants, besides the patient’s original purposes of going there. It is also useful for the patient to undergo examination at a hospital approximately once a year on a same-day basis or by a 1–2 day hospitalization. The test information should be aggregated in this way on the side of the house call physician, in the hospital-clinic collaborative alliance.

C. Tests on Acute Diseases

The most important test in home medical care is the blood test. In home medical care, the most common acute aggravation occurs as pyrexia, for which the blood test alone can provide valuable information. The most useful information provided by the blood test are white cell count, hemogram, and C-reactive protein (CRP), followed by electrolytes, and renal functioning panel. It is recommended that both complete blood count and hemogram be checked because sometimes a relative increase in neutrophil count is found without a rise in white blood cells (WBC). It is wise to include the hepatobiliary function panel because it is effective to make a diagnosis of hepatobiliary infection.

In addition to the blood test, a urinalysis, and a bacterial culture test should be combined as necessary. Additionally, blood gas analysis, electrocardiography using a portable electrocardiograph, and Holter monitoring are also possible.

Some house call physicians perform conventional radiography at the patient’s home. Development in computed radiology (CR) has now made performing in-home diagnostic testing easier than before. Besides, the ultrasound testing device has also been miniaturized, so physicians who have skills to use the equipment may perform the test.

(Tadashi Wada)

5. How to See the Elderly

Most of elderly who are receiving home medical care suffer from chronic diseases, and often have several geriatric syndromes. In addition to medical diagnosis, treatment and symptom relief, it is essential to perform care and life support based on a comprehensive functional assessment of their pain.

Features of Elderly Who are Receiving Home Medical Care

Most of the elderly who certified Needed Support or Needed Long-Term Care are 75 years old or older. The main reason they require support is debility due to cerebrovascular disorders, dementia, joint diseases, advanced age as well as fracture and fall (Comprehensive Survey of Living Conditions performed in, 2013). In this way, the physical function of the elderly decreases with age, and the prevalence of dementia is greater than 50% in persons 90 years old or older.

Many of the elderly requiring home medical care are suffering from chronic diseases, with several geriatric syndromes, such as gait disturbance, fall, incontinence, dementia and communication disorder. Although the cause of each geriatric syndrome is different, these diseases and syndromes affect each other, enter into a chronic state, and make independent living impossible. Eventually, these elderly persons require home health which results in them requiring care.

According to a survey conducted in the United Kingdom, the elderly want to their care to improve their quality of life (QOL) and mental health, reduce the burden of care, and maintain their daily activities and lifestyle.¹⁾ Although the main purpose of physicians is to diagnose and treat diseases, many elderly patients want to keep living with high QOL.

To deliver such healthcare, we need to provide rehabilitation and care in addition to medical diagnosis and treatment. The comprehensive geriatric assessment (CGA) is that multidisciplinary professionals assess not only diseases but also physical function, mental/psychological function, and social activities of patients from the aspect of special area. Performing this assessment in the elderly living in the community leads to decrease in physical function, maintains function of daily living, suppresses hospitalization or admission to nursing homes, and reduces the costs associated with medical care and nursing.^{2),3)} It has a large effect especially for the relatively frail elderly such as those who have chronic diseases, take many medications, or being living alone.⁴⁾

Features of the Symptoms/Syndromes of Elderly

An elderly person may suffer from several diseases and have atypical symptoms. Without understanding this, physicians may fail to diagnose diseases appropriately. For example, although a patient has pneumonia or urinary tract infection, he/she has no specific symptoms but has only less body motion or appetite, or not energetic. Furthermore, the elderly with advanced dementia cannot explain symptoms adequately, therefore it is difficult to diagnose their symptoms.

If a patient has mild dementia, a physician may fail to detect, and subsequently fail to suspect, the disease. In such a case, the physician needs to suspect dementia when he/she finds changes in daily living of the patient, such as unused medicines, unable to clean up or organize the room, and change in the contents of conversation. Therefore, it is important to check daily living of patients in addition to symptoms. Furthermore, if appropriate care is not provided to the elderly with dementia, not only that dementia progresses. It may result in decrease in activities of daily

living (ADL), motivation, and nutritional status. In this way, treatment, care, and physical function affect each other.

In addition to disease progression and decreases in physical function, the elderly are prone to psychological symptoms associated with changes in living conditions, such as bereavement and living alone. It is recommended to check whether a patient has depression actively because it may affect prognosis.

The elderly often have several geriatric syndromes. Geriatric syndromes are a series of symptoms and findings caused by various reasons. They pass into a chronic state, and make independent living of the elderly impossible. Geriatric syndromes are classified into main types:⁵⁾

- (1) Syndromes mainly associated with acute diseases
- (2) Syndromes mainly associated with chronic diseases
- (3) A series of syndromes which remarkably increase in occurrence in the elderly aged 75 or older and are closely related to decrease in ADL requiring nursing.

Most of the elderly subject to home medical care have less basic activities of daily living. Such elderly persons have more geriatric syndromes compared to those who can have independent living. Geriatric syndromes include: Decrease in ADL, osteoporosis, vertebral fractures, dysphagia, urinary incontinence, pollakisuria, delirium, depression, pressure sore, hearing loss, anemia, undernutrition, bleeding tendency, chest pain, and arrhythmia, which remarkably increase in the elderly aged 75 or older. There is no simple treatment, therefore, care and life support are required based on comprehensive daily functional assessment in addition to medical diagnosis and treatment.

Features of the Results of Diagnostic Test in the Elderly

Reference values of blood tests for the elderly may differ from that for the young. Treatment for the young may not always appropriate for the elderly even the same level was shown by a blood test. For example, low cholesterol level is preferred for the young to prevent arteriosclerotic diseases, but if an elderly person has low cholesterol level, under nutrition or hyperthyroidism should be suspected. In addition, water intake or position may affect result. Medications such as diuretics and antihypertensives often affect results, therefore the possibility should be considered. Furthermore, results differ substantially between individuals in the elderly in addition to differences between the elderly and the young. Therefore, it is important to know the result at normal state, and diagnose based on differences from results at normal state.

Comprehensive Geriatric Assessment in Home Medical Care

Most of the elderly subject to home medical care often have several diseases. They are also prone to have difficulty in daily functions. Therefore, care based on comprehensive functional assessment is required in addition to diagnosis and treatment. In the elderly, diseases, daily living functions, mental/psychological functions, and social status relate each other complicatedly, and may cause various problems. Hence, we need to understand whole context by comprehensive functional assessment. A physician alone cannot address such problems across several areas, therefore all members (such as nurses, pharmacists, dietitians, physical therapists, occupational therapists, speech–language–hearing therapists, certified care workers, and care managers) need to address these problems as a team in a coordinated effort.

Table. Items in Comprehensive Geriatric Assessment

1. Functions that Affect Communication (1) Vision (2) Hearing (3) Language functions
2. Physical Function (1) Basic activities of daily living (2) Instrumental activities of daily living
3. Mental/psychological Function (1) Cognitive function (2) Depressed state (3) Will/Motivation
4. Quality of Life
5. Social Status (1) Caregiver (2) Family structure (3) Residence (4) Contents of support
6. Nutritional Status
7. Situation of Treatment (1) Diseases (2) Situation of treatment (3) Medication compliance

Assessment is performed for the following variables in addition to medical status (such as diseases, treatment, and medication adherence): functions (vision, hearing and language function) effecting communication; physical function such as basic ADL and instrumental ADL; cognitive function; depression; mental/psychological functions such as motivation and a purpose in life; QOL; family structure and caregivers; house; the contents of support including formal and informal supports; and nutritional status (**Table**).

For physical function, assessment performed for both of the basic activities of daily living such as behavior related to personal life, and a higher life function, i.e., instrumental activities of daily living. At that time, we should focus on which ADL a patient should do or can perform in rehabilitation and care.

Hasegawa Dementia Scale and the Mini-Mental State Examination are often used to assess cognitive function. Clock Drawing Test is useful to assess medication management and self-care ability because it can assess executive function in a simple, useful in evaluating the medication management and self-care ability.

Geriatric Depression Scale -Short Version-. Japanese for 15 variables is often used for depression. Among the 15 variables, two variables for feeling low and loss of pleasure are also useful to screen depression.

For nutritional status, swallowing function including the state of oral care is assessed as well as changes in body weight and body mass index (BMI), physical measurement to estimate subcutaneous fat thickness and muscle area, and assessment by blood biochemical tests such as albumin.

To understand the living conditions of patients such as family structure, hobby activities, and interaction with society helps, treatment, rehabilitation, setting of the goal of care. Marital status, presence or absence of housemates, frequency and satisfaction to meet with children, and

frequency and satisfaction of social networks are known to relate to the risk developing dementia.⁶⁾ Higher level social networks suppress the risk of developing dementia. Furthermore, having a purpose in life suppresses the risk of developing Alzheimer's-type dementia and declining cognitive function.⁷⁾ Recently, social support in the community is recognized as an important determinant of health in addition to individual determinants of health such as living habits and suffering from diseases. Social capital means the concept indicating human networks based on trust and awareness of mutual aid among local residents. It is also important factor to build integrated community care system. When we provide required life support and care, we can provide preferred support by combining informal support with formal support.

Since physical function, mental/psychological function, and social status effect each other, we should understand the whole context based on the assessment of each function. It allows us not only to understand the support necessary for the elderly who are receiving home medical care, but also to explore effective support methods multilaterally.

It takes some times to perform comprehensive geriatric assessment. Therefore, ideally speaking, treatment and care policies should be discussed based on assessments by the various professionals in each area through sharing opinions and understanding changes in the patient's situation over time.

Assessment of Pain

Pain associated with cancer is well recognized, however, pain is frequency caused by noncancer diseases. Pain is often caused by diseases requiring home medical care, such as chronic heart failure and chronic respiratory failure. In some cases, pain is caused by underlying diseases, but most pain is caused by coexisting osteoarticular diseases. Therefore, diagnosis and assessment including that for coexisting diseases is essential. Moreover, in order to gain comfortable life and better QOL, symptom relief is required at the same time of treatment for diseases instead of separating aggressive treatment and palliative care by treatment period.

In addition to pain, the elderly also have various pain in their daily life including isolation from social activities as well as physical symptoms such as insomnia. Usually, they do not complain pain by themselves, therefore we should check main pain actively.

Approaches Based on Estimated Functional Prognosis

When the elderly are hospitalized, delirium, decline in cognitive function, decrease in physical function are prone to develop. In the elderly hospitalized with severe acute diseases, decline in cognitive function is often found during the follow-up period compared with the elderly not hospitalized. The risk of dementia is also higher in the elderly hospitalized with non-severe diseases.⁸⁾ According to a survey investigated the course of physical function for 1-year before death by type, the elderly who had progressively or persistently declining physical function were more than half of the decedents, and further decline was found in their physical function associated with hospitalization.⁹⁾

Thus, in order to support more comfortable daily life we recommend palliative care instead of hospital treatment for the elderly who have such a course. Therefore, it is important to have had enough discussion on a routine basis for treatment and care plans, and understand the risk associated with hospitalization while predicting prognosis of physical function and cognitive function in addition to life prognosis. It promotes appropriate decision-making for end of life. It is difficult to treat the elderly aiming to cure at acute care hospitals alone, therefore, the role of which supports the daily life of the elderly at their houses is important.

(Takashi Yamanaka)

References

- 1) Roberts H, Khee TS, Philip I: Setting Priorities for Measures of Performance for Geriatric Medical Services. *Age Ageing* 23(2): 154-157, 1994.
- 2) Stuck AE, Aronow HU, Steiner A, Alessi CA, Buella CJ, Gold MN, Yuhus KE, Nisenbaum R, Rubenstein LZ, Beck JC: A trial of annual in-home comprehensive geriatric assessments for elderly people living in the community. *N Engl J Med* 333(18): 1184-1189, 1995.
- 3) Stewart S, Pearson S, Luke CG, Horowitz JD: Effects of home-based intervention on unplanned readmissions and out-of-hospital deaths. *J Am Geriatr Soc* 46(2): 174-180, 1998.
- 4) Stijnen MM, Van Hoof MS, Wijnands-Hoekstra IY, Guldemond-Hecker Y, Duimel-Peters IG, Vrijhoef HJ, Jansen MW: Detected health and well-being problems following comprehensive geriatric assessment during a home visit among community-dwelling older people: who benefits most? *Fam Pract* 31(3): 333-340, 2014.
- 5) 鳥羽研二: 高齢者に特有な症候 老年症候群. 改訂第3版老年医学テキスト, 日本老年医学会編, メジカルビュー社, 66-71, 2008. Toba, K: Geriatric syndromes: Syndromes unique to older adults. In the Japan Geriatrics Society (Eds.), *Gerontology Textbook, 3rd edition*: 66-71, 2008. Medical View Co., Ltd.
- 6) Fratiglioni L, Wang HX, Ericsson K, Maytan M, Winblad B: Influence of social network on occurrence of dementia: a community-based longitudinal study. *Lancet* 355(9212): 1315-1319, 2000.
- 7) Boyle PA, Buchman AS, Barnes LL, Bennett DA: Effect of a purpose in life on risk of incident Alzheimer disease and mild cognitive impairment in community-dwelling older persons. *Arch Gen Psychiatry* 67(3): 304-310, 2010.
- 8) Ehlenbach WJ, Hough CL, Crane PK, Haneuse S, Carson SS, Curtis JR, Larson EB: Association Between Acute Care and Critical Illness Hospitalization and Cognitive Function in Older Adults. *JAMA* 303(8): 763-770, 2010.
- 9) Gill TM, Gahbauer EA, Han L, Allore HG: The role of intervening hospital admissions on trajectories of disability in the last year of life: prospective cohort study of older people. *BMJ* 350: h2361, 2015.

6. Diagnostic Tests Performed in Home Medical Care

The miniaturization and performance enhancement of test equipment in recent years have enabled us to perform various examinations on the spot at the patient's home in addition to outsourcing specimen tests to laboratories. However, the items tested and precision in these examinations are limited compared to those performed in medical facilities. Therefore, in home-care settings, we need to wisely combine medical interview and physical findings with examinations that are available. This article describes diagnostic testing in home medical care settings and its principles.

Specimen Tests Such as Complete Blood Count/Biochemical Test
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A specimen test such as the complete blood count/biochemical test is useful as an indicator of inflammatory response of white blood cells and C-reactive protein (CRP), which are indicators of pneumonia and urinary tract infection frequently observed in home medical care, as well as of diabetes mellitus or organ function test, or as a rationale for diagnosis. If pyrexia occurs in a patient who seldom complains, the physician should perform an examination taking account of electrolyte abnormalities such as hyponatremia as well as inflammatory response and abnormal white blood cell counts.

However, unlike in medical facilities, keeping specimens in a stable condition is difficult. In addition, there is always a time gap from sample collection to starting a test. Especially in outsourced tests, the results should be referred to taking into account effects that are unique to home medical care as seen in high levels of urea nitrogen and serum potassium caused by temperature and shock as well as in decreased brain natriuretic peptide (BNP), whose half-life is as short as approximately 20 minutes. Arrangements such as preparation of an impact-resistant cooler box are required in summer.

For certain test items, on-site Point-of-care testing (POCT) is also available in home-care settings. POCT refers to tests that are conducted beside the patient or self-tests performed by the patient himself/herself.¹⁾ POCT commonly conducted in home medical care includes the following: blood sugar, urinalysis, CRP, rapid diagnostic tests for infections such as influenza, troponin T, N-terminal pro-BNP (NT-proBNP), prothrombin time (PT), blood gas, electrolytes, D-dimer, creatine kinase-muscle and brain (CK-MB), and myoglobin [Photographs (1), (2), and (3)].

POCT is mostly for separate items, and the objectives are to prove a diagnosis made from physical findings, to ensure that nothing is overlooked, to make the results indicators for a specific treatment, and so forth. For specimens having short half-lives, the precision of POCT results is higher than those obtained from outsourced tests. Specifically for blood gas analysis, the physician needs to bring a portable analyzer because accurate results cannot be obtained unless measurement is performed immediately after blood is drawn. Testing on venous blood is also useful when electrolyte abnormality is suspected because it can simultaneously check not only respiratory status and tissue oxygen metabolism but also levels of sodium, potassium, and islet cell antibody.



(1) i-STAT1



(2) h232 (-400)

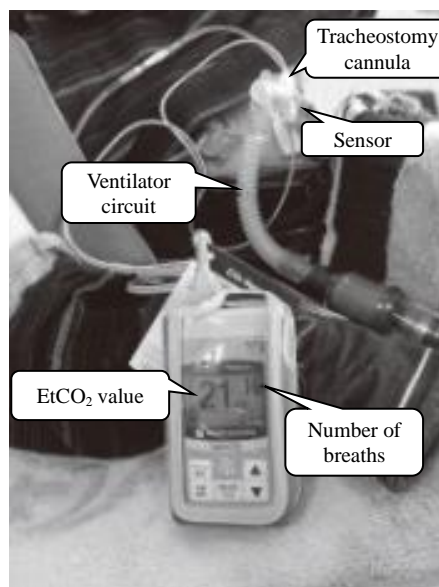


(3) Nycocard Reader2

Saturation of Peripheral Oxygen (SpO₂) and End-Tidal Carbon Dioxide (EtCO₂)

Percutaneous pulse oximeters have become quite small and less expensive; a majority of them can be carried in the breast pocket and cost only several tens of thousands yen. Although this device is useful as an indicator of respiratory failure, it occasionally displays inaccurate values when decreased blood flow or pyrexia is present. Attention should be paid to the pulse rate in particular because the values indicated verify nothing unless the displayed pulse wave rate is simultaneously compared with the pulse rate obtained on palpation.

The end-tidal carbon dioxide detector [Photograph (4)] has also been miniaturized and can now be carried in the pocket. Allowing noninvasive measurement of carbon dioxide, it is useful for the diagnosis of ventilatory failure as well as for the adjustment of the volume of oxygen flow and setting the conditions of the respirator in home oxygen therapy. The physician should not increase the concentration of the inhaled oxygen carelessly when EtCO₂ is increased. However, it should be noted that EtCO₂ may show a great discrepancy from partial pressure of carbon dioxide (pCO₂) when serious ventilatory failure or pulmonary infarction is present.²⁾



(4) EtCO₂ CAPNO Puchi (-200)

X-ray Examination

X-ray irradiation machines and digital imaging systems that can be transferred to home-care settings for on-site use have been introduced to the market. The disadvantages of the devices are that they are heavy and it takes so much time to assemble and disassemble them on the spot that someone in charge is needed for merely obtaining a conventional radiograph. Another problem

with these machines is that if the physician cannot bring the equipment to develop the film, he/she needs to take the films all the way back to his/her medical facility for the development.

Ultrasonography

There has been significant miniaturization and performance enhancement of ultrasonographic equipment. Recently, a convenient pocket-sized portable device with two types of probes [Photograph (5)] and a notebook-type device [Photograph (6)] with enhanced performance that is comparable to conventional large high-performance ultrasound units are available.

Ultrasonography is of great use to examine the cause of pyrexia, which frequently leads to emergency contact or house calls in home medical care. Urinary tract infection and biliary tract infection, which are prone to cause pyrexia, can be diagnosed by observing the presence of residual urine, hydronephrosis, or obstruction in the biliary system.³⁾ Additionally, observing marked vertical artifacts, i.e., “B-lines” (comet tails), in the dorsal lower lung fields helps to make a diagnosis of pneumonia, which occurs as frequently as aforementioned two infections.

The visual ejection fraction (EF), i.e., visually estimated cardiac contraction in B-mode imaging only, or observing clear B-lines in the upper lung fields and the middle cardiac vein are useful for the differential diagnosis of respiratory failure and cardiac failure—both being difficult to diagnose from only physical findings such as breathing sounds—as well as to follow up cardiac failure itself.⁴⁾

Ultrasonography is of great use to examine the presence of pleural effusion and ascites or to determine the puncture site.

Other than these, ultrasonography is extremely useful to diagnose diverse pathophysiological conditions and assist various procedures.³⁾



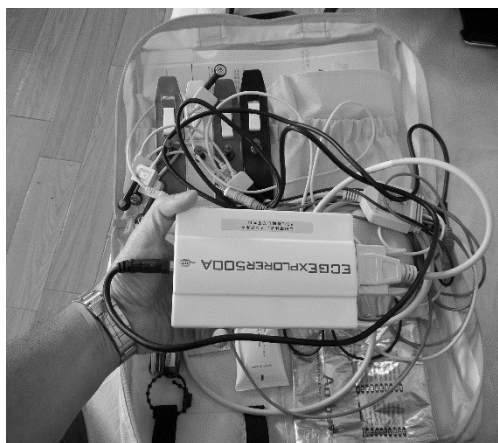
(5) VSCAN



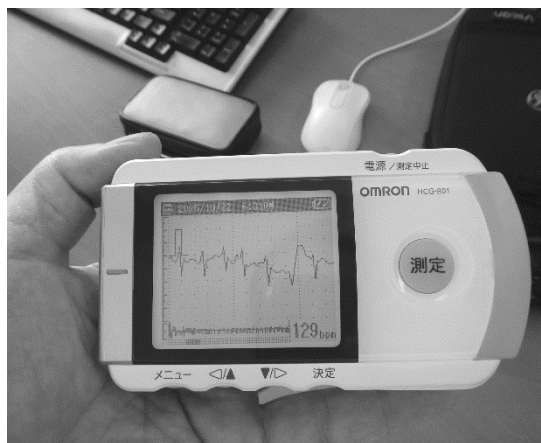
(6) SonoSite MICRO MAXX (-400)

Electrocardiogram

Electrocardiographic equipment is in widespread use, miniaturized and with a built-in rechargeable battery. For home-care settings, the ultra-small devices that record data in PC or PDA [Photograph (7)] are useful. For diagnosis of arrhythmia, the 1-lead electrocardiographic devices that can record using both hands or with a hand and the chest [Photograph (8)] are convenient and useful.



(7) ECG Explorer500A



(8) 1-lead ECG: OMRON HCG-801 (-400)

Small Diameter Endoscope

Portable ultra-small diameter endoscopes are useful for the endoscopic evaluation of swallowing and examination after replacement of a gastric fistula catheter. By directly observing the cause of dysphagia, the endoscopic evaluation of swallowing may successfully lead to oral care and swallowing rehabilitation rather than initiating tube feeding or parenteral nutrition without much consideration. It has also been recommended that after replacing a gastric fistula catheter, the proper position of the catheter should be confirmed by endoscopy or X-ray examination.

Clinical Cases

The following describe actual cases that involved diagnostic testing in home-care settings.

< Case 1: Diagnosis of the cause of pyrexia >

An 89-year-old woman presented with acute pyrexia of 39°C. The patient regularly expectorated copious amount of sputum and pulmonary murmurs were heard. Although POCT performed immediately after drawing blood showed CRP 4.0 mg/dL, it was not sufficient to make a definitive diagnosis of respiratory infection. Scanning of the abdomen using a portable ultrasound device revealed bladder tension and mild hydronephrosis. The patient was catheterized and administered with quinolone. Although the in-hospital complete blood count showed increased white blood cell and neutrophil counts, no abnormality was found in the results of a biochemical test, and the fever disappeared in two days. A urine culture revealed quinolone-sensitive *Escherichia coli*.

< Case 2: Differential diagnosis of asthma and cardiac failure >

A 78-year-old man, whose clinical course had been stable, developed aggravated wheezing, and hence a house call was requested. The patient was prescribed with Hokunalin Tape (tulobuterol), which was continued from the previous physician. His consciousness was clear, and face edema was observed. Marked stridor was heard on auscultation of the chest. The cardiac sounds were normal. SpO₂ was 88%, blood pressure was 110/50 mmHg, heart rate was 118 bpm, and temperature was 36.2°C. After drawing blood, ultrasonography was performed. Visual EF was approximately 30%, the inferior vena cava (IVC) was 3.2 cm, and no respiratory motion was detected. Marked B-lines were revealed in both upper lung fields. As ultrasonography was finished, results of POCT showed NT-proBNP at 5800 pg/mL, and troponin T was negative.

Therefore, a diagnosis of respiratory failure caused by acute aggravation of cardiac failure was made. Accordingly, a diuretic was administered, and in-home oxygen therapy was initiated. Wheezing tended to ease the next day and disappeared in three days. The room air SpO₂ value increased to 96%.

< Case 3: Diagnosis of aspiration pneumonia >

A 93-year-old man had dementia and lived alone. Dependence in ADL is at the level of requiring a wheelchair. The patient took foods that were pureed using a food processor with assistance from a caregiver. He frequently developed respiratory infection but rejected going to the hospital. A swallowing function test was performed using a small diameter endoscope, which showed food residue remaining in the epiglottic vallecula and laryngeal penetration. The patient received oral care performed by dental staff and swallowing rehabilitation. Meals processed for easy swallowing were introduced. Thereafter, the frequency of respiratory infection showed a marked decrease.

Closing

In home-care settings, diagnostic testing is performed in poor conditions with many restrictions compared with the ones conducted in the medical facilities. Additionally, not many examinations are performed even if they are medically necessary since many of the patients receiving home health care do not wish to undergo examinations. Therefore, diagnostic testing should only be considered as something to prove physical diagnoses.

(Keigo Yasukawa)

References

- 1) 日本臨床検査自動化学会 POC 推進委員会 : POCT ガイドライン第 3 版. 臨床検査自動化学会誌 38 (Suppl. 1) : 3-11, 2013. POC Enhancement Committee, The Japan Society for Clinical Laboratory Automation. (2013). POCT Guidelines, the 3rd edition. *Japanese Journal of Clinical Laboratory Automation*, 38 (Suppl. 1), 3-11.
- 2) 木村啓介, 高井一志, 梶原宣弘, 高橋英樹 : COPD 患者における非侵襲的二氧化碳素計測について. 日本理学療法学会 JAPANESE PHYSICAL THERAPY ASSOCIATION 2005 : D0509-D0509, 2006. Kimura, K., Takai, K., Kajiwara, Y., & Takahashi, H. (2006). Noninvasive measurement of carbon dioxide in patients with COPD. *Congress of Japanese Society of Physical Therapy, Japanese Physical Therapy Association 2005*. D0509-D0509.
- 3) 竹中克 : 小さいけれど強い味方のポケットエコー. 新興医学出版社, 2013. Takenaka, K. (2013). *Pocket Echo: Small but a powerful partner*. Shinkoh Igaku Shuppansha Co., Ltd.
- 4) 渡橋和政 : ポケットエコー —Vscan 活用法—, へるす出版, 2012. Orihashi, K. (2012). *Pocket Echo: How to make good use of Vscan*. Herusu Shuppan, Co., Inc.

7. Caring for the Family

To provide care in home-care settings, not only the illnesses affecting the patient but also the physical, time-related, and interrelated backdrop surrounding him/her needs to be assessed. The most involved “backdrop” is the family. It is of great importance to provide medical care embracing their existence.

The Family’s Role in Home Medical Care and Caring for the Family
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In home-care settings, the family plays diverse roles during the convalescence of the patient. The family members have individually different burdens: some don’t have much stress in their role as a caregiver but feel great strain because plans are left to their discretion, whereas some feel the opposite. While each family member is fulfilling a different role, burdens are accumulated, and one member of the family may collapse because of the stress, which makes it difficult to maintain healthcare and their daily life. This could constitute a major cause of bringing in-home care to a standstill. Therefore, efforts should be made to help reduce their burden in ways tailored to each family member.

The roles of the family can be classified as follows:

A. Role as Caregiver (Role as a Home Caregiver)

In in-home caregiving, the family takes on the role of delivering care such as preparing meals and diapering. While home-visiting care services and home-visiting bathing services are utilized in general to help reduce the family’s burden, things that they perceive as encumbrances are different for each family member according to the family relationship and his/her way of thinking. Additionally, the burden is felt differently as the physical status of the whole body changes. For instance, some people feel a psychological burden as they change diapers, whereas they experience none of it when assisting in eating or bathing. Or, even though they were usually able to previously change diapers without feeling any difficulties, it turned into a burden as the patient reached terminal stage (although the procedure of diapering remains the same). It is important to formulate care plans on the basis of the understanding of these differences in each family member and to review the plans in accordance with changes in stress.

B. Role in Coping with Changes in Symptoms (Role as a Nurse)

Managing the changes in symptoms is also a role of the family. These changes include providing a rescue dose for pain, inserting a suppository for pyrexia, and contacting health care professionals when an acute change has occurred. In addition, the family often needs to receive an explanation about the medical procedures from a physician, nurse, pharmacist, etc. or practice the skills to perform the procedures. Especially as complicated procedures impose a burden on the family, easy to understand manuals, etc. should be prepared to meet individual needs. If the procedures impose too much stress on the family, switching to the services provided by a home-visiting specialist should be considered.

C. Role in Making Decisions on Behalf of the Patient (Role as a Representative of the Patient)

If the patient is unable to indicate his/her own will, the family takes on the role of making decisions such as future care plans or a decision on admission on the patient’s behalf. The family members—as they are most familiar with the patient’s life history, disposition, and view on life—can respect the patient’s supposed intention. On the other hand, the family often feels the pressure of being forced to make critical decisions. After all, regarding the major planning of caregiving or the crucial decision in the last stage of life, it is hoped that the patient and the family can

discuss these issues together while the patient is able to communicate with the family rather than handing the burden over to them.

D. Role as the Patient's Family

The existence of the family, who best understands the patient, plays a significant role in reducing the patient's mental, social, and spiritual pain as well as in maintaining his/her comfortable convalescent life. However, all the more because they are the patient's family, conflicts are often caused more than necessary because of requesting excessive caregiving or denying the progression of the illness. On such occasions, the home-visiting nurse, for example, may be able to play the role of the patient's representative, especially from a mental aspect.

Family Caregiving and Mutual Energy Generation

While the family is playing various roles as described above, the family's burden increases. For instance, the home-visiting caregiver would ask the family to prepare some articles used for eating assistance or the nurse would let the family manage pyrexia by taking the temperature more often or the physician would tell the family to make a decision whether to admit the patient to the hospital when his/her condition changes. Although each professional individually means to entrust the family with a minor thing, as the requests are accumulated with time, they constitute a significant burden on the family. What is crucial is that the entire team that is involved should collaborate together to ascertain the physical and emotional changes that occur in the family over time. The in-home care specialist team should understand that the family is also a member of the team and should share information with them to ensure unified planning. They should also help the family focus on the role described above under "D," which is the most remarkable strength the family has.

At times, the family themselves develop illness in their interaction with the sick patient. However, more often than not, their care helps generate the energy to live in the patient, thereby strengthening the family unity and improving the quality of care. As seen in the latter case, helping the entire family generate energy in each other is what is referred to as the expertise constituting the basis of home medical care.

Grief Care

When in-home terminal care is provided, the family receives grief care.

Grief is a normal response to great loss (caused not only by loss of loved ones but also by death of a pet, divorce, unemployment, fire, etc.) Usually it lasts only temporarily and is not something morbid. Although a variety of symptoms are observed (**Table 1**), no medical intervention such as administration of medications is required. The process in which the loss is accepted, emotions are organized, and the psychological adaptation to a new environment is made is called grief work. Grief care is to help the grief work continue spontaneously. It is important to inform the individual that having various emotions and symptoms is normal. It should also be remembered that the symptoms may recur on anniversary dates or the death anniversary (anniversary reaction). To assist reminiscing about the deceased, it is suggested that certain opportunities be coordinated as necessary (paying a visit to the family for grief care, organizing an assembling of the bereaved family, etc.) so that they can have a talk.

Table 1. Symptoms of Grief

- Physical symptoms (sleep disorder, impaired appetite, fatigue, feeling of dyspnea, palpitations, headache, etc.)
- Emotional reactions (sorrow, anger, anxiety, lack of motivation, lonely feeling, etc.)
- Behavioral reactions (confusion, decreased mental concentration, etc.)
- Delusional phenomena (auditory hallucination, etc.)

Table 2. Risk of Developing Complicated Grief

- When the individual does not have much help or understanding by others after the loss.
- When the individual is socially/psychologically isolated.
- When the loss was sudden and happened unexpectedly.
- When the previous experience(s) of loss(es) has/have not been resolved.
- When the individual intrinsically holds emotions in check.

However, some people (approximately 10%) develop “complicated grief (pathological grief)” that should receive drug therapy or psychotherapy. In this status, the appropriate grief work does not begin within a few months after the loss and severe grief symptoms persist for a long time. It is a condition that hinders one’s life, occasionally leading to depression or alcohol dependence, for which consideration should be taken so that appropriate care is continuously provided. If a risk of developing complicated grief (**Table 2**) is noted, contacting the individual persistently at an early stage leads to prevention of complications and early detection (even briefly listening to him/her time and again is effective).

(Hiroyuki Beniya)

8. Witnessing a Loved One's Dying and Death

Witnessing dying and death of a loved one is an important rite of passage in the community to take over life. How support is provided to this witnessing is a crucial issue in home medical care. Additionally, people need to understand how to prepare the death certificate/certificate of postmortem examination correctly because there have been a lot of misunderstandings about them.

Significance of Witnessing a Loved One's Dying and Death

Everybody has death. In what manner one should die, or how one should live all the way up to the moment of death, are critical questions to anybody who is conscious of his/her imminent death. Everybody has different thoughts on the subject, which are mostly influenced by the memories of the dying and death of close friends and loved ones that one has experienced. Particularly, the ways the loved ones died have a strong impact on the way of living to those who witnessed the death in every detail besides the deceased. It is an unquestionable fact that, in whatever society or era, witnessing the dying and death of a loved one is a crucial opportunity to learn "how to live" and "how to die," as well as to look back or reflect on one's way of living. Additionally, the relationship between the witnesses and the dying, the place where the witnessing takes place, the symptoms of the dying, etc. have a great influence on the way of witnessing a death. Each of the ways of witnessing has each of its own features and differs by region, which is why respective regions are considered to have their own culture of witnessing dying and death.

However, over the past few decades the opportunities to witness dying and death of loved ones have intentionally been restricted in Japan, thereby blunting the sensitivity to living or to life, i.e., the opposite of death. Therefore, we need to recognize again that witnessing dying and death of a loved one is an integral rite of passage for communities.

Process of Witnessing Dying and Death of a Loved One

As we consider the process of witnessing a loved one's dying and death, what is fundamentally significant is for the community members including the family to watch a process in which a human is dying in a place for everyday living, which is not to confirm a death at a home including the patient's own home. Therefore, it is important to inform the family in advance that, if they have a great concern about witnessing dying and death at home, they can also do so at a collaborating hospital.

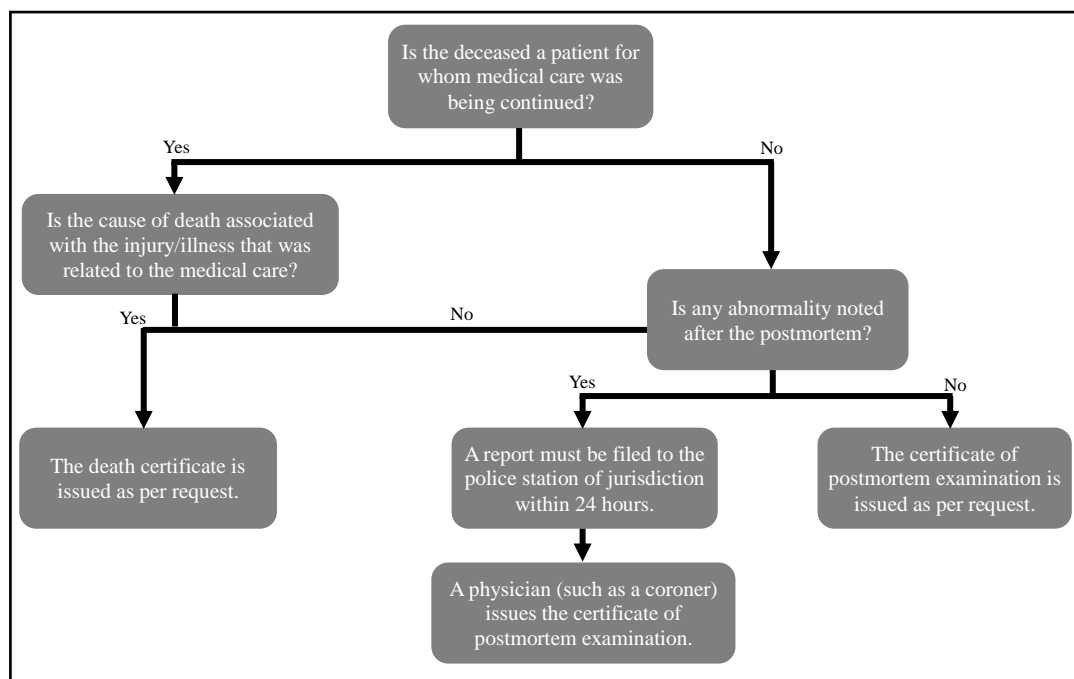
The witnessing must take place based on the premise that, when the patient's condition has worsened, the people concerned including the family have an understanding about the illness that "death cannot be avoided even with intensive life-sustaining treatment." Therefore, the physician has responsibility to assess the patient's condition and explain it to the family. When home care was initiated, mostly the explanation should have been given to the family if the patient is terminal. However, even though he/she is terminal, if his/her condition is stable or the illness is a noncancer disease, many families do not give it serious thought. Therefore, when the condition worsens, the physician needs to reiterate it. Thereafter, he/she should advise on points to remember and give guidance for caring on a continuous basis.

Points to Remember During the Terminal ill Period

During the terminal ill period, there are constant changes in the patient's condition and he/she occasionally shows expression of suffering, giving the family great anxiety and distress. Additionally, the more people present at the death, the more anxiety the family may have. Therefore, it is important for the physician to explain about the predicted conditions and measures to be taken, and assure the family that they can consult him/her by telephone whenever they have worries and that he/she will make an urgent house call depending on the patient's condition. Also, if the family is intently looking at every movement of the patient, the physician should give them advice that they may look at old albums or talk about memories of the past.

Furthermore, more often than not, "remote family members or relatives," who haven't visited them until that time, will turn up suddenly and press the caregiving family hard, demanding "why don't you take him/her to the hospital?", thus making the family upset. Therefore, at the point when the family decides to witness the patient's dying and death at home, it is also important for the physician to ascertain whether they have such family members or relatives, and advise them to consider how to manage these individuals in advance.

Figure. How to Distinguish the Use of a Death Certificate and Certificate of Postmortem Examination



Guidance on Witnessing a Loved One's Dying and Death

The most critical part during the end-of-life period is the guidance on witnessing dying and death of a loved one. The guidance is provided by a physician, nurse, care manager, etc., and it should be given repeatedly. The contents of the guidance include physical transitions (symptoms, etc.) at the time of death, how to presume death, recording of the time of death, and the method of emergency contact. For the family, this explanation constitutes the education to prepare for death. Significance of witnessing the patient's dying and death by the family only should also be explained, and consent should be obtained by the physician and the nurse for being absent at that

time. It should also be explained that the physician may be unable to come to the home immediately at the time of death. Depending on the situation, the physician may also explain about making the body neat before the death is formally confirmed.

He/she should also tell the family not to hesitate to give him/her a call in case of emergency, such as the patient's breathing is unusual or the family feels strong anxiety. They seldom in fact contact the physician as long as the explanation has been given repeatedly.

How to Complete the Death Certificate

The chart in the **Figure** below shows how to complete the death certificate when the patient dies at home. Points that need to be emphasized here are; (1) if the patient was receiving medical care on a continuous basis and the cause of death is the disease that was being treated, the death certificate will be issued, (2) issue of the death certificate is possible without confirming the death if the patient had received consultation within 24 hours prior to death, (3) the certificate of postmortem examination is issued when the cause of death is not the disease for which medical care was being continued, and (4) the case where the death must be reported to the police station of jurisdiction within 24 hours is when the cause of death is not the disease for which medical care was being continued and abnormality was found by a postmortem.

Additionally, the time of death is not the time when the physician confirmed the death but the time of biological death; hence the time is supposedly based on the family's observation and recorded. Therefore, it is preferable that the physician advise the family in advance how to presume death and how to record the time when the patient died.

(Yoshikazu Ashino)

9. Clinical Decision Support

To provide better terminal care, it is important to view the course of illness in as large a time frame as possible and start having satisfactory discussions as early as possible in a patient-centered team to establish the collective wishes of the patient, family members, and health care providers.

History of Advance Care Planning (ACP)

Since the 1980s, expression of patients' wishes by advance directives (AD) has been promoted in the Western countries. However, in the 1990s, its limits, including the unclear processes leading to decision making and the insufficient spread of AD, were also pointed out.

In 1995, Emanuel named the process of expression of patients' wishes in terminal care as "advance care planning (ACP)," which includes more than mere consultations or writing documents, and introduced the notion to the public. ACP is defined as "the process of discussion in advance with health care professionals about his or her preferences, wishes regarding treatment and medical care, substitute decision maker (surrogate), etc. in case he or she should become incapable of making decisions in the future" (National Health Service [NHS], 2007). ACP promotes continuous discussions about the patient's values and ideas and helps not only to select individual therapies but also to establish the overall goals to be shared between the patient, family members, and health care providers.

ACP has improved the quality of patients' communication with health care providers and boosted patient and family satisfaction about the care because the patient's wishes are respected. It has also reduced the rate of hospital deaths. In addition, the surviving relatives of patients receiving ACP have been shown to have less stress, anxiety, and depression.¹⁾ Thus, ACP is considered as an effective method for patient-centered medical practice.

ACP and Clinical Decision Support

To provide better terminal care, it is important to confirm the patient's wishes in a positive way as early as possible in view of the terminal course of illness in each case.²⁾

By repeating discussions regularly or according to the changes in circumstances, health care providers can deepen their understanding of the narratives of the patient and family members. On the other hand, the patient and family members can correct their misunderstanding and gain a better understanding. Furthermore, ACP regards the process of decision making as more important than the decisions themselves and allows for changes in decisions according to the circumstances. As the mutual understanding between the patient, family members, and health care providers deepens and the collective wishes of those involved in decision making are gradually formed, ACP enables substitute decision making that would best meet the patient's intention even in the case where the patient should become incapable of making decisions.

In the Japanese cultural context, people tend to consider the family as a group of the people who live with the patient and who are connected by bonds as a unit, while placing the patient's wishes at the center. Therefore, it is more important to respect the collective wishes of the patient and the surrounding people.

A. Actual Practice of Shared Decision Making (Ask-Tell-Ask Approach)

In terminal decision making, the health care providers ask the patient how he or she understands his or her own illness and its condition (“ask”) and grasp the level of the patient’s understanding as well as how misunderstanding and anxiety affect the patient’s attitude toward care. On such occasions, it is necessary to recognize that many home patients and family members wish the best to be done until the last moment. Attention should be paid because concluding that the patient is at the end stage or talking to them with a view to switch to palliative care often hinders the establishment of mutual trust. It is essential to speak to them about care without giving up the premise that the best treatment has been performed or is being continued. It is desirable, if possible, to learn from the patient and family members in the beginning about their wishes concerning treatment or care as well as their expectations regarding the future.

After that process, the health care providers give the patient, within the range of the patient’s wishes, the amount of information that would not be excessive (“tell”) and facilitate change that will help the patient to adapt to the circumstances by adding new information to the patient’s current knowledge or correcting the patient’s misunderstanding. On such occasions, it is recommended not to talk only about illness but to deal with the anxiety of the patient and family members about their lives and make concrete proposals that meet the patient’s values and wishes after explaining how the patient’s physical and mental functions and actual life will change and how they can adapt to the changes.

Finally, the health care providers should not fail to openly ask about the anxiety of the patient and family members (“ask”).

B. Hope for the Best and Prepare for the Worst

In terminal decision making, health care providers tend to give extreme explanations, either that of aggressive treatment or that of the complete absence of treatment options. As a result, a number of patients and family members feel totally unready for or simply hopeless about the terminal changes that will certainly occur in the future. What is important is to tell the patient and family members about the best clinical course that can be expected and is consistent with their wishes along with the bad information anticipated with medical validity (“Hope for the best and prepare for the worst.”).

C. Importance of Determining the Place of Care

It has been known that the quality of life of those who spend their last days at their preferred places is overwhelmingly higher than that of those who don’t. The place of care should not be determined only according to its level of medical technology or care-giving capacity. The patient’s wishes should be regarded as the most important in determining the place where he or she spends the last days of his or her life. Basically, the whole team must move and arrange the environment so that the patient’s last wishes are fulfilled.

D. Problems with Substitute Decision Making

Of the end-stage patients, 70.3% have already lost their ability to make decisions at the time of decision. Even in general medical practice, substitute decision making is supported in a number of cases. In home care in particular, which mostly concerns elderly patients with or without dementia, terminal decision making refers to substitute decision making in most cases. Substitute decision making has a negative emotional effect on at least 30% of the surrogates.³⁾ Supporting the substitute decision making of the family members who have to make decisions about the life of their blood relatives is considered to be one of the basic duties of health care providers.

Summary

On the premise that the accurate prediction of prognosis is impossible, it is of utmost importance to view the course of illness in as large a time frame as possible, to start having satisfactory discussions in a patient-centered team as early as possible, and to repeat the process of decision making.

(Satoshi Hirahara)

References

- 1) Karen MD, Andrew DH, Michael CR, et al: The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 340: c1345, 2010.
- 2) Davies E, et al (ed): *Better Palliative Care for Older People*. World Health Organization Europe, 2004
- 3) Wendler D, Rid A: The effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine* 154(5): 336-346, 2011.

10. Interprofessional Work (IPW)

In home care, it is important that workers from multiple disciplines look at the patient's condition, functions, mental status, and social problems comprehensively and work together for the common goal of giving the best (the happiness) to the patient and the family members. In other words, the success of interprofessional work (IPW) is the key that determines the quality of home care. Therefore, health care providers should do their best to build as good a team as possible.

Present Status of IPW in Japan

The Long-term Care Insurance System enforced in Japan in 2000 adopted the concept of interprofessional work (IPW) along with the methods for case management. Indeed, since the start of the Long-term Care Insurance System, the term “interprofessional collaboration” has been established in home-care settings, and its necessity has been widely recognized. However, Japan has only a short history of IPW, and thus, its methods are not sufficiently established and widespread.

Necessity for IPW in Home Medical Care

The World Health Organization (WHO) defines a health team as “a group of persons who share a common health goal and common objectives, determined by community needs, towards the achievement of which each member of the team contributes, in a coordinated manner, in accordance with his/her competence and skills, and respecting the functions of others” (1984).

In elderly patients at home, illnesses cause functional problems (disabilities). The illnesses and disabilities are closely related to mental problems, and these in turn cause social problems including abuse. Thus, physical, mental, and social problems often occur together. To obtain the optimal outcomes from the care of the elderly patients with complex needs, it is important that the team members share the same goals, the respective specialists make assessments from various viewpoints, and organic cooperation is realized.

Here are the reasons why IPW is recommended in the field of geriatrics: IPW enables the provision of the optimal support that meets the medical, psychological, and social needs of elderly patients and their families; as a result, IPW can contribute to the improvement of the health and quality of life (QOL) of elderly patients and reduction of the burden of their caregivers; furthermore, it facilitates the sharing of knowledge and skills between the team members and makes the teamwork more fulfilling and interesting.¹⁾ Therefore, it is not too much to say that the success of IPW is the key that determines the quality of care.

Moreover, in the current situation surrounding home care, the necessity for IPW has increased. One of the reasons may be that health care has shifted from the treatment-only model to the daily-life model. The number of incurable chronic diseases has been increasing, and more and more people live with disabilities. With an increasing demand for geriatric or palliative care, people's expectations regarding health care have also changed from the survival-first policy to support for maintaining their QOL. The second reason is the increase in the number of cases involving multiple problems, such as the decline of family function, represented by the rising number of elderly patients living alone, or the increasing number of families whose members have mental illness. The third reason is the weakened social network in this complicated society with growing friction. The complication of the systems, organizations, and skills for interpersonal assistance also boosted the necessity for IPW.

In the first half of the 21st century, Japan is facing the explosive demands created by the rapidly expanding population in need of care. At the same time, it is facing a serious workforce crisis: a shortage of medical and nursing care workers. The present situation of caregiving in Japan leaves no room at all for underestimating the separation between medical care and nursing care. As WHO has reported, the promotion of interprofessional education (IPE) does relate to this workforce crisis.²⁾

Roles of Physicians in Home Care

The basic roles of a physician in the home care team are to grasp the patient's condition; make and implement the treatment plan; predict the patient's prognosis (survival and functional prognoses), physical conditions, and daily life; and explain these to the patient, family members, and team members. The physician's rapid assessment and medical action at the acute stage in particular bring about a sense of security in the patient, family members, and team members and forms the base for care remodeling.

Physicians do not necessarily need to be the team leaders in individual cases. However, when it comes to creating high-quality teams in communities, physicians should play the role of the team leader. To establish the community care system, physicians (medical associations) should understand the roles of multiple professions and facilitate interprofessional collaboration.

Obstacles of IPW

One of the reasons why IPW is difficult may be that the goals of each profession differ. It is easily imaginable that medical professionals, who think only on the basis of treatment models, and caregiving professionals, who think on the basis of daily-life models, do not consider each other's opinions in some situations. In home care, it is important for different professions to see the patient's condition, functions, mental status, and daily-life problems comprehensively and cooperate for the common goal of giving the best (the happiness) for the patient and the family members, considering health care on the basis of daily-life models.

The difference in educational background, culture, and language between professions can also be an obstacle. In the United Kingdom, IPE has been a compulsory subject in the training courses for health care and social care professions including the faculty of medicine since 2003. In Japan, IPE has not been widespread in most basic educational courses for professionals including physicians. Therefore, the professionals have little experience in communicating with those of other disciplines, and they have to perform home medical care without sufficient understanding of the difference in specialty, educational/cultural background, and language between professions and work together without rehearsal.

Promotion of IPE and Planar Development of Home Care

For successful home care, neither time nor efforts should be spared to build up a good team.

WHO has shown in Framework for Action on Interprofessional Education and Collaborative Practice²⁾ published in 2010 that the promotion of IPE in the local context and implementation of collaborative practice will establish a strengthened health system in the community.

In other words, IPE in the local context offers an opportunity for local team building, which strengthens the health system for the whole community. To build comprehensive health systems in Japan, the most effective way would be to promote IPE in the local context by involving physicians (medical associations) and administrative bodies (municipalities) or more concretely

implement continuous high-quality IPE on home care, which would systematize community-based home care.

(Satoshi Hirahara)

References

- 1) Geriatrics Interdisciplinary Advisory Group: Interdisciplinary Care for Older Adults with Complex Needs: American Geriatrics Society Position Statement. *Journal of the American Geriatrics Society* 54(5): 849-852, 2006.
- 2) WHO: Framework for Action on Interprofessional Education and Collaborative Practice http://www.who.int/hrh/resources/framework_action/en/

11. Integrated Community Care

To promote integrated community care, which allows everyone to recover from their illnesses or receive medical care in places where they feel safe and are familiar with, it is important for local medical associations and attending doctors to reform their mind-set and collaborate with local municipalities and various service providers. This requires the development of a system that makes good use of the characteristics of the local area. This article discusses the history of the integrated community care systems as well as the roles of local governments and medical associations for promoting such care.

What is Integrated Community Care?

The integrated community care system is prescribed in Article 2 of the Act for Securing Comprehensive Medical and Long-term Care Promotion:

“The integrated community care system is a system that comprehensively ensures support for medical care, long-term care, care prevention, housing, and independent living of elderly persons so that they can lead independent daily lives as much as possible in areas where they are used to living according to their capacity to do so and the circumstances of the region.”

Care prevention here means preventing the state of requiring long-term care or support and reducing the state of requiring long-term care or support in those who already require such care or support as well as preventing their deterioration.

Figure 1 summarizes the viewpoints for building a integrated community care system. It uses the five viewpoints used for defining the integrated community care system in Article 2 of the above law, namely, long-term care, medical care, care prevention, support for daily living, and housing/residence. In the integrated community care workshop report released by the Ministry of Health, Labour and Welfare in 2014, these five viewpoints were revised by further combining them with other elements. Rehabilitation was added to long-term care, nursing was added to medical care, healthcare was added to care prevention, welfare services were added to livelihood support, and lifestyle was added to housing. The figure shows their relations using a potted plant as an example.

Figure 1. Relation of the “Five Components” of Integrated Community Care System



First, a plant with three leaves is planted in a pot. These leaves symbolize medical care and nursing, long-term care and rehabilitation, and healthcare and welfare. The soil in the pot is care prevention and livelihood support, and the pot holding the soil is “housing and lifestyle.” This not only includes homes but also housing complexes such as residences for elderly persons providing elderly care services. It depicts the diverse ways of living such as switching from one’s own home to residences for elderly persons.

The plate under the pot signifies individual's choice and the mental attitude of the individual and the family members. Mental attitude can also be substituted by the word “being prepared.”

This figure means that the potted plant lies on a plate, which symbolizes the choices made by elderly persons with regard to how they want to live their last days, their mental attitude, or their preparedness about the choices they make such as living in the same area until the end, staying at the hospital to the end, whether they want to extend their lives if they are terminally ill, etc.

Where is regional medical care positioned in the integrated community care system? First, when people become ill and require medical care, they would go to an acute hospital. If they are brought to the hospital by ambulance, they receive emergency medical care and are hospitalized if they require surgery. Once they overcome their critical state, they start acute rehabilitation from an early stage and switch to recovery stage rehabilitation once their conditions stabilize. In case of chronic patients, their attending doctors provide support for the management of daily medical conditions and prescribe the necessary medications such as hypotensive agents. This is the flow of medical care patients usually receive.

How are the lives of elderly persons to be supported? After they are discharged from the hospital, they go back to their homes or move to a residence for elderly persons providing elderly care services, thus continuing to live in an area in which they are used to. The medical care for supporting their lives there includes home medical care and nursing house calls. If they are able to make visits to the hospital, they will do so and visit their attending doctors. Those requiring long-term care receive care services such as home-visit care for elderly persons, home-visit nursing care, and ambulatory care. Alternatively, they may receive livelihood support or care prevention. Support is also provided at clubs for older persons and residents' associations (mutual care).

The entire mechanism is generally called “integrated community care system.” It is based on the concept of medical care, including home medical care for supporting older persons, to continue living in places they have lived for a long time.

Integrated Community Care and Home Medical Care: Changes in Integrated Community Care
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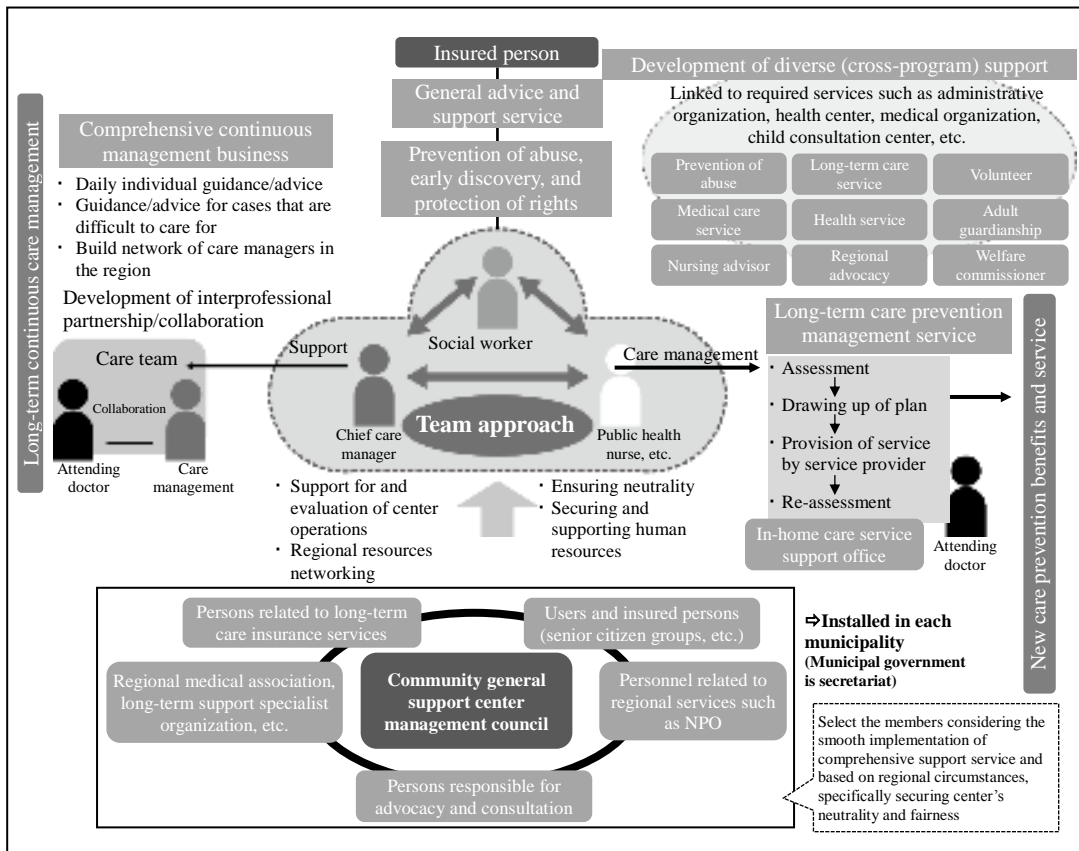
A. Integrated Community Care in 2005

First, integrated community care was proposed in 2005 during the first review of the Long-Term Care Insurance Act in 2005 (**Table**). As a result of the review, the new care prevention benefits and service system was established, and community general support centers were introduced. Assigned with three professions (public health nurse, social workers/psychiatric social workers, and chief care managers), these centers serve to support community support program, prevent elder abuse, prevent financial exploitation of elderly persons with dementia, protection of human rights, and guardianship (**Figure 2**).

Table. Main Contents of Revision of Long-Term Care Insurance Act in 2005

(1) Reviewing services for mild patients → Switch to system focusing on care prevention (Creation of new care prevention benefits and service and regional support activities)
(2) Enhancing/reinforcing home services for supporting moderate/severe patients → Creation of community-based services such as “multifunctional small group home” and “night time home-visit long-term care” and establishment of integrated community care system
(3) Securing/improving service quality → • Introduce laws requiring disclosure of service information • Reassessment of service provider regulations (designated renewal system, service provider whose designation was canceled, introduction of disqualification period of directors, and provision of rights to inspections by municipalities) • Renewal system of care managers and checking of programs of each care manager
(4) Ensuring fairness with regard to burden of users of home care services and facilities → Reassessment of facility living costs and food costs

Figure 2. Image of Community General Support Center (2005)



B. Integrated Community Care in 2015

A report by the Elderly Care Association titled “Elderly Care in 2015” proposes the following three services under a new long-term care service system for maintaining the continuity of life.

(1) 365 day/24 hour security at home

This is a proposal of a continuous home service (set up small-scale multi-functional service center).

(2) New “housing”

This is the realization of a diverse “way of living” other than at home or facility.

(3) New roles of facilities supporting life at home for elderly persons

Regional expansion of facility functions, spread of unit care, and consolidation of facilities

C. Integrated Community Care in 2025

According to a report by the Integrated Community Care Association issued in March 2013, from 2025 onward, when the baby boom generation (about 8 million people) reaches 75 years and above, the public demands for medical care and long-term care are expected to increase even more than present. The Ministry of Health, Labour and Welfare is therefore in the midst of establishing a system in 2025 for providing comprehensive regional support and services to enable elderly persons to continue living in places they are used to living as much as possible and continue living their ideal life to their last days, with the aim of protecting the dignity of elderly persons and supporting their independent living.

Progress of Aging Population and Home Medical Care

Japan is facing a rapidly aging population with declining birthrate. In 2025, elderly persons aged over 65 years will account for 30% of the entire population. The figure is predicted to reach about 40% in 2055. In addition, given that more than 60% of the people wish to spend their last days at home, the establishment of a system for providing medical care and long-term care that takes into account this increase in the elderly population is an urgent task. However, it is an accepted view that it would be difficult to maintain a social system that accommodates elderly persons requiring long-term care or those who have dementia, etc. at hospitals and facilities in such an ultra-aged society.

On the basis of this situation, the government has introduced policies to differentiate/integrate hospital and bed functions as well as enhance home medical care. In this way, given this need to build a community where even elderly persons can continue living in places they are used to as much as possible even if they require long-term care, receive the required medical and long-term care services, and realize the life they want to live with security and peace of mind, the government has proposed a national policy, unparalleled anywhere in the world, for overcoming Japan’s imminent ultra-elderly society. It established a system that provides comprehensive regional services, specifically, a system that provides comprehensive support to elderly persons in terms of medical care, long-term care, care prevention for senior citizens, housing, and independent living, according to the characteristics of that region, so that elderly persons can continue living in places they are used to on their own.

Regional Medical Associations and Integrated Community Care

Regional medical associations, which are groups of specialists responsible for providing regional medical care, are expected to participate in the proposed comprehensive regional medical care regardless of whether they agree with the system or not. They, especially attending doctors, are faced with the challenge of having to provide medical care and service across the boundaries of

medical departments. Regional doctors are required to adjust to this paradigm shift; in other words, they face the need to change their awareness and mindset.

At the end of 2013, a Social Security Council medical committee meeting was held, where the final proposals for decisions to be made on the revision of the Medical Care Act were summarized. The basic view of the report drawn up was to position the enhancement of home medical care and long-term care service systems and the construction of an integrated community care system as important tasks and to call for regional medical associations to collaborate with municipalities and various professions and review actions as soon as possible.

To establish systems for effectively and efficiently providing high-quality appropriate medical care according to the health needs of the patients amidst the increasing demands for medical and long-term care services following the predicted rapid growth of the aging population, it is indispensable to implement measures such as differentiation/linkage of medical organizations, invest the necessary medical resources according to the required medical functions, and enhance hospitalization medical care in general, as well as enhance the systems providing home medical care and long-term care services for supporting the lives of patients who have been discharged from hospitals. Integrated community care systems are also essential because of the prospects of the increase in elderly persons with dementia, those who live alone, the number of elderly households consisting of only elderly couples. To realize this, medical care and long-term care services based on various regional characteristics must be provided integrally.

Collaborations between Regional Medical Associations and Municipalities

It is crucial for the establishment of integrated community care systems to be led by municipalities, given the need to build the facilities required for providing such care in the daily life sphere of the patients requiring the care. Regional medical associations need to work with municipalities, and based on this, collaborate with various professions. They are also required to work toward providing home medical care while considering the respective characteristics of their regions.

Important aspects for enhancing the system for providing home medical care are securing and nurturing the human resources for providing home medical care. For this, enlightenment activities that motivate doctors and professionals to want to take part in home medical care and training for improving the quality of medical practitioners involved in home medical care are necessary. There is also the need to foster leaders playing central roles in promoting home medical care and to foster coordinators familiar with medical care and long-term care. Furthermore, it is important to establish backup systems that secure sub-attending doctors, reduce the burden of doctors providing home medical care, secure collaboration hospital beds, and link with emergency medical care.

Home medical care is not limited to elderly persons. Medical care and welfare services required at home are also available to patients with final stage cancer or intractable neurological diseases and infants with disorders who required long-term medical treatment at a neonatal intensive care unit (NICU), etc. Systems supporting home medical treatment regionally, linked to welfare and educational facilities, are thus needed for such patients to recuperate at home with a sense of security.

Case Study: Efforts of Chiba Prefecture Medical Association

The Chiba Prefecture Medical Association consists of officers in charge of home medical care from the 23 district medical associations in the prefecture as members, ministerial officers as observers, and executives from district home medical care associations who meet on a regular basis. This joint meeting aims to promote a unique home medical care system by the district

medical associations, making good use of the characteristics of each district, and hope to expand it to activities that serve as the infrastructure for building integrated community care systems in each district.

The association has built a new prefectural medical association building. On the first floor is a center that provides general regional medical care support using regional medical care revitalization funds. This center has a model room that permanently exhibits cutting-edge home medical care and long-term care equipment in the aim to educate and promote the growth of home medical care. Presently, it is used for the training of not only doctors but various professions and medical and welfare related students. Open to the public, the center is dedicated to enlightenment activities with the aim to establish integrated community care widely in Chiba.

(Takao Tashiro and Masahiko Tsuchihashi)

12. Health Care Services Provided by Health Insurance and Various Systems

Modern day home medical care is carried out by wide-ranging interprofessional collaboration. The systems that make up home medical care are extensive and complicated. Focusing on home medical care provided by doctors and the care insurance system, this article discusses the basic facts of home medical care that all those providing home medical care should know about.

Home-Visit Service by Doctors and Related Medical Care Systems

A. Home-Visit Medical Care and Doctor Visits

The core systems that make up home medical care are home-visit medical care service (fees for medical care services provided to patients at home) and doctor visits (fees for doctor visits).

Home medical care was conceptualized by Takeshi Kawakami in 1967 as “regular house calls”¹⁾ and established after incorporating in the system home-visit activities carried out by Akira Sato et al, in 1986.²⁾ The service in which home-visit dates are planned and patients are visited as notified is called “home-visit medical service.” On the other hand, “doctor visits” is the act of the doctor visiting a patient who is not feeling well and has called for the visit. “Home-visit medical service” is referred to as “regular house calls” and “doctor visits” as “emergency house calls” at most medical facilities in Japan. Home-visit medical service is charged on a daily basis while doctor visits are charged on a visit basis. The fee differs according to the visited time. It also differs between clients living in detached houses and those living in apartments.

B. Medical Care Management Fees for Home Medical Care Provided by Doctors

The most important medical care management fees are the “at-home integrated medical care fee.” This management fee is calculated on a monthly basis for two visits a month and covers not only continuous medical care management but also 24-hour management. Notifications are required for calculation. There are many other types of management fees, but these are not discussed in this article.

C. Home Care Support Clinics/Hospitals

(1) Home care support clinics/hospitals

The home care support clinic program was established in April 2006. Home care support clinics are medical facilities that are capable of providing 24-hour doctor visit or nurse visit service by themselves or by collaboration with others. Doctors and nurses who can respond to requests 24 hours a day are designated, and their contacts are provided to patients. Emergency admissions are also secured.

In 2008, the home care support hospital program was established. The facility criteria are similar to the home care support clinic program, but the hospital program secures doctors providing home medical care in addition to doctors on duty and beds for emergency admission.

Both home care support clinics and hospitals can charge higher fees.

(2) Home care support clinics/Hospitals with enhanced functions

This system was established in 2012. To qualify, clinics need to have at least three full-time doctors independently or by collaboration and must be able to provide doctor visit or nurse visit services independently or by collaboration 24 hours a day. In addition, they must have provided ten or more emergency home visits and four or more witnessing of a patient’ death in the last year. These requirements can be met by the multi-facility collaboration, but in this case, each

facility must have provided four or more emergency doctor visits and two or more witnessing of a patient's death in the past year. In addition, the emergency contact number must be centralized, and the collaborating medical facilities must hold one or more conferences in a month among themselves. The same applies to home care support hospitals. Hospitals must have at least three doctors in charge of home medical care and provide doctor visit service around the clock.

Collaboration between Home-Visit Nurses, Pharmacists, Dentists, and Rehabilitation Staff

A. Home-Visit Nurses

The program for home-visit nursing stations for the elderly was launched in 1992. At the beginning, it was intended for elderly persons, but since 1994, the service has been opened to all ages. It is not too much to say that home-visit nurses provide main specialist services in home medical care. They not only provide care during recovery, but are also involved in establishing the environment for recuperation, supporting the decision-making and empowerment of patients and families, and supporting recuperation to the end. Priority reimbursement is given to home-visit nursing care by the "health insurance system" or "care insurance system." Home-visit nursing may be provided by medical facilities or home-visit nursing stations. When provided by home-visit nursing stations, doctors must issue the "visiting care instructions." Home-visit nursing care service fees are reimbursed under the care insurance system in priority to the health insurance system. For example, when patients recognized as requiring nursing service request home-visit nursing care, they receive nursing care under the care insurance system and not the health insurance system.

When services are provided for those who are not certified as in need of care service, client conditions need special visiting nursing care instructions, such as acute aggravation or clients have illnesses designated by the Ministry of Health, Labour and Welfare, such as terminal cancer or amyotrophic lateral sclerosis, fees for home-visit nursing care services can be reimbursed under the health insurance system. As these patients can use the whole amount of their care insurance allowance for services other than home-visit nursing care, the total fees may in effect exceed the upper limit of allowance for home-visit nursing care.

Patients can use home-visiting nursing care service under the health insurance system in the following cases: (1) If they are not recognized as requiring long-term care under the care insurance system, (2) During the duration of the special visiting care instructions, and (3) Illnesses designated by the Ministry of Health, Labour and Welfare, etc. (Illnesses given in appendix 7 of the special medical fee standards by facility)

B. Pharmacists

(1) External prescription

Separation of pharmacy and clinic is the sharing of external prescription roles between medical facilities and health insurance pharmacies. When patients want to choose the pharmacy, they can do so as they can use the prescription issued by one medical facility at any health insurance pharmacy. This is called "area-wide separation (of pharmacy and clinic)."

(2) Management and guidance for visiting pharmacy services to in-home patients/Management and guidance for in-home medical service

The hospitable activities of keen pharmacists seen to bring prescriptions to elderly patients who used to be their customers whose ADL has dropped because of old age are reflected in this system. The pharmacists would explain to the patients at their homes regarding the drugs, check dosage situation, and assess actions and adverse effects. Collaborations with pharmacists are especially effective for tubal feeding and total parenteral nutrition, cancer pain control, etc.

This system was first approved under the health insurance system, and then management and guidance for visiting pharmacy services to in-home patients was incorporated in the care insurance system when it was enforced as management and guidance for in-home medical service.

C. Dentists

(1) Application of home dental care

There are many home care patients who are not able to brush their teeth because they are bed-ridden or have dementia. Many also have silent aspiration. In this sense, it is no exaggeration to say that most home care patients are eligible for dental care service.

(2) Home care support dental clinics

This system was established in April 2008. To qualify, dental clinics must have experience in the calculation of home-visit dental care service fees, have at least one full-time dentist who has completed appropriate training for understanding the physical and mental characteristics of elderly patients, managing the oral cavity, and providing emergency response, as well as dental hygienists. They need to collaborate with medical facilities providing medical care covered by health insurance and persons in charge of adjusting collaboration with other medical services covered by health insurance and welfare services.

D. Rehabilitation Staff

Rehabilitation at home is provided by physical, occupational, and speech-language-hearing therapists. Their role is to appropriately assess patient behavior, determine efficient and safe movements from the standpoint of specialists, and help patients maintain and enlarge their living space through rehabilitation programs. Home-visit rehabilitation is provided under the health insurance system or care insurance system. Specifically, it is provided as “home-visit rehabilitation” when provided by medical facilities and as “home-visit nursing” when provided by home-visit nursing stations.

Use of Social Resources

A. Long-term Care Insurance System

(1) Outline of system

Citizens above 65 years of age are called first insured persons. Persons insured by the system between 40 and 65 years old are called second insured persons. First insured persons have no allowance limits, while second insured persons are eligible for allowance under the system when they have been diagnosed with a “special illness” and are indicated so in the primary doctor judgment on long-term care.

The state of requiring care is called “in need of care.” A state where the disorder is more moderate and chances of recovery are higher is called “in need of support or care.” The in-need-of-care state is divided into five categories, 1 to 5, in the increasing order of need for care. The in-need-of-support or care state is divided into two categories. Allowances for those receiving “care” are called “care benefits” while allowances for those receiving “support/care” are called “care prevention benefits.”

Services are provided for those receiving in the following four manners:

- 1) In-home service: Received at home
- 2) Facility service: Received at facilities (prescribed in Long-Term Care Insurance Act)
- 3) Purchase of equipment for home long-term care covered by public insurance/remodeling of home for long-term care
- 4) Community-based service: Received at home or facilities (lived in) but limited to municipalities

(2) In-home service

- 1) Visiting nursing care: Home help service
- 2) Home-based bathing service: Bathing service using bathing equipment brought to the home
- 3) Home-visit nursing (Already described)
- 4) Home-visit rehabilitation (Already described)
- 5) Management and guidance for in-home medical service: Medical care provided by doctors and dentists and home-visit guidance provided by pharmacists, dietitians, and dental hygienists
- 6) Ambulatory care: Day service. Daycare service provided by facilities for the elderly covered by public aid providing long-term care and day service centers
- 7) Ambulatory rehabilitation: Day care. Day care focusing on functional training provided by medical facilities
- 8) Short-term cohabitation and care: Short stay at facilities for the elderly covered by public aid providing long-term care
- 9) Short-stay medical treatment and nursing care: Short stay at long-term care health facilities, hospitals, and clinics, etc.
- 10) Living care for the elderly admitted to a special facility for preventive long-term care service: Provided to residents of facilities certified as special facilities such as fee-based, assisted-living home for the elderly, low-cost home for the elderly (care house), elderly housing with supportive services, etc.
- 11) Loaning/sales of equipment for long-term care covered by public insurance

(3) Facility service

- 1) Facility for the elderly covered by public aid providing long-term care: Facility designated to receive car insurance benefits at special nursing homes for the elderly
- 2) Geriatric medical care facility for the elderly: Provides care centering around rehabilitation under the supervision of doctors
- 3) Designated medical long-term care sanatorium: Long-term care beds covered by care insurance system

(4) Community-based service

Available only to residents of concerned municipalities and special districts. Facilities under the care insurance are generally designated by the prefectural governors, while community-based services are designated by heads of municipalities.

- 1) Periodic/ongoing visits by a long-term care provider or nurse: Day care service based on 24-hour supported regular visits by professional caregivers and nurses and temporary visits to respond to occasional needs.
- 2) Daytime nursing care for patients with dementia: Day service for patients with dementia
- 3) Small-multi-care facility care: It is care provided by facilities with three functions: home-visit care, ambulatory care, and stays.
- 4) Group home care for patients with dementia: So-called group home care activities
- 5) Community-based daily life long-term care admitted to a specified facility: Applies to private residential homes accommodating 29 or less residents
- 6) Community-based care for the elderly covered by public aid providing long-term care: Applies to special nursing homes for the elderly accommodating 29 or less residents
- 7) Complex type service: Service with both small multi-care facility care and nursing functions

- (5) Care prevention service
Services for those in need of support.
- 1) Home-visit care
 - 2) Bathing service
 - 3) Home-visit nursing
 - 4) Home-visit rehabilitation
 - 5) Management and guidance for in-home medical service
 - 6) Ambulatory care
 - 7) Ambulatory rehabilitation
 - 8) Short-term cohabitation and care
 - 9) Short-stay medical treatment and nursing care
 - 10) Living care for the elderly admitted to special facility for preventive long-term care service
 - 11) Loaning of equipment for long-term care covered by public insurance and sales of specified equipment for long-term care covered by public insurance
- (6) Community-case care preventive service
Provided to residents of municipalities.
- 1) Daytime nursing care for patients with dementia
 - 2) Small-multi-care facility care
 - 3) Group home care for patients with dementia

(7) Regional integrated community care

This system was created in 2006 with the revision of the Long-Term Care Insurance Act, and it provides general consulting service for the region. It is directly run by municipalities or as a subcontracted business. Assigned with social workers, public health nurses, and chief care managers, it provides consultation services, manages care prevention benefits, and is involved in other “care prevention” activities. At the same time, it protects the rights of elderly persons such as preventing the abuse of elderly persons, etc.

B. Other Systems

(1) Welfare service program for persons with disabilities

Care services under the care insurance system are provided to those above 40 years of age by the health insurance system. This welfare service program for persons with disabilities is a system that does not have age limits and is managed by tax not insurance. It is used by for those younger than 40 years old and those aged 40 years or older without illnesses designated by the Japanese government to prepare the environment for receiving nursing care at home (provided on the basis of the law to support home-based work by persons with disabilities). Although not discussed in this article, most eligible persons receive the same services as home-visit services under the care insurance system and ambulatory services. To use the system, persons with physical disabilities must carry the physical disability certificate, persons with intellectual disabilities must carry the medical rehabilitation handbook, and those with mental disorders must carry the mental disability certificate.

(2) Medical service for intractable disease

The act on medical care for intractable disease patients was enforced on January 1, 2015, resulting in the significant increase in illnesses designated as intractable diseases. Applying to a total of 306 diseases, subsidies for medical expenses paid by patients were started from July 1 of the same year. Medical subsidies differ according to the severity of the disease and household income.

(3) Public assistance system

This serves as the basis of the “right to live” prescribed in Article 25 of the constitution. It provides living expenses and allowances, such as medical costs, to those with little assets who do not have the ability to work. Although a national system, it is run by welfare offices of municipalities.

It consists of livelihood assistance (living expenses), education allowance (compulsory education expenses), housing assistance (rent, etc.), medical assistance (self-paid medical expenses), care allowance (self-paid care insurance costs), childbirth allowance (childbirth related expenses), unemployment allowance (costs required to start/enhance business or start working), and funeral allowance (funeral costs, etc.). These eight benefits are provided as deemed required by welfare offices and are provided independently.

(4) Adult guardianship

This is a system that recognizes guardians designated for those whose judgment ability has decreased because of dementia, etc. to protect their profits on their behalf. To use the system, applications are to be made to the domestic court via municipalities and comprehensive regional support centers. Persons designated as “guardians” are called “adult wards,” while those designated to carry out legal acts on behalf of the said persons are called “guardians of adults.” Guardians make judgements regarding issues related to the management of assets and personal supervision on behalf of the concerned subject and protect the said person’s rights and assets.

(5) Long-term livelihood support funds loan system

This system allows those owning land or homes to procure living and care funds. The borrower mortgages their real estate and receives a certain amount of cash from the lender every month. When the borrower passes away or leaves the land, the balance is calculated. This system is run mainly by the prefectural social welfare council in collaboration with financial institutions. The social welfare councils of municipalities serve as the window.

(Tadashi Wada)

Reference

- 1) 川上武：内科往診学。医学書院，1967。 Takeshi Kawakami: Home Visit Services by Internal Medicine Doctors, Igaku-Shoin, 1967
- 2) 佐藤智：在宅老人に学ぶ。ミネルヴァ書房，1983。 Akira Sato: Learning from Elderly Persons Cared at Home, Minerva Shobo, 1983

Chapter I References

1. Significance Today of Home Medical Care
 2. Eligible Diseases and Clinical Issues
 3. Initiation of Home Medical Care
 4. Basis of Medical Care in Home Medical Care
 - (1) 和田忠志：在宅医療臨床入門．南山堂，2009． Tadashi Wada: Introduction to Clinical Home Medical Care, Nanzando, 2009
 5. How to Examine Older Adults
 6. Diagnostic Tests Performed in Home Medical Care
 7. Caring for the Family
 - (1) 和田忠志：在宅医療臨床入門．南山堂，2009． Tadashi Wada: Introduction to Clinical Home Medical Care, Nanzando, 2009
 - (2) 松下明 監訳：家族志向のプライマリ・ケア．丸善出版，2006． Supervised by Akira Matsushita: Primary Care for Family members, Maruzen, 2006
 - (3) 広瀬寛子：悲嘆とグリーフケア．医学書院，2011． Hiroko Hirose: Grief and Grief Care, Igaku-Shoin, 2011
 8. Witnessing a Loved One's Death
 9. Clinical Decision Support
 10. Interprofessional Work (IPW)
 11. Integrated Community Care
 12. Health Care Services Provided by Health Insurance and Various Systems
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Chapter II. Clinical Issues in Home Medical Care

Chapter II describes the clinical issues in home medical care, roughly dividing them into two categories.

Section I (“Impaired Functioning and Home Medical Care”) illustrates the chronic-phase clinical issues surrounding elderly people who receive in-home care. Chronic clinical issues, including malnutrition, eating disorder/dysphagia, impaired urination, bowel problems, and dementia, can be regarded as impairment. Physicians involved in home care are required to have the ability to assess and deal with the impairments of elderly people who receive care at home.

Section II (“Acute-phase Issues in Home Medical Care”) describes the acute-phase clinical issues commonly seen in elderly people receiving home care, including pneumonia and dehydration.

Home medical care requires various new schemes to enable the proper assessment, treatment, and care of chronic- and acute-phase issues at home in non-medical environments.

(Satoshi Hirahara)

The Yuumi Memorial Foundation for Home Health Care website has a section providing a listing of medical facilities dedicated to home medical care.

Please contact our executive office if you are interested in signing up for the listing.

Note) The website only provides names with contact information of the physicians and medical facilities, which are not intended for recommendation.

I. Impaired Functioning and Home Medical Care

1. International Classification of Functioning, Disability, and Health and Rehabilitation

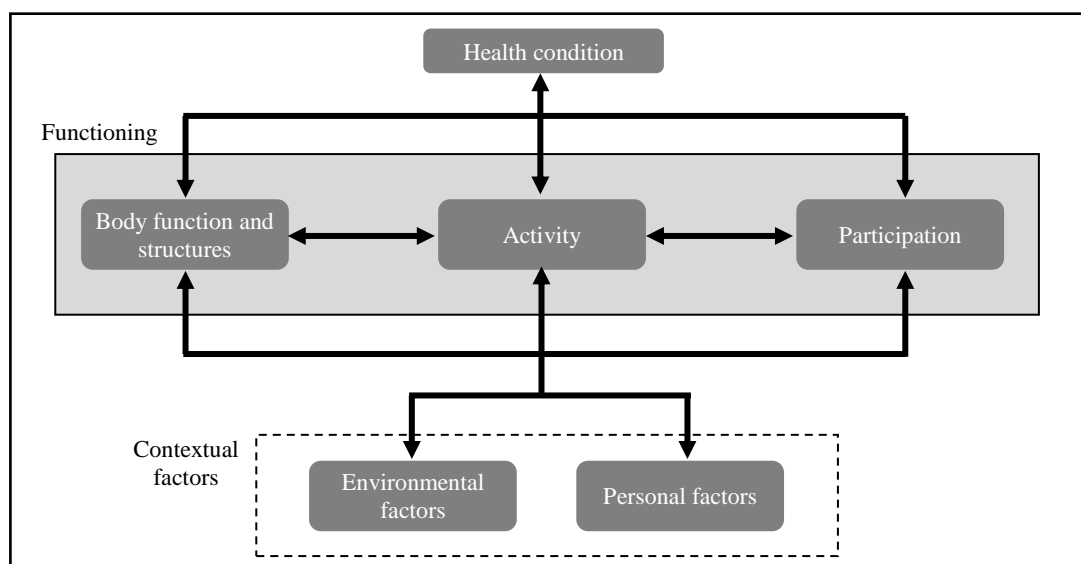
Rehabilitation-oriented mind (“rehab-mind”), which aims to improve the QOL, reduce the burden of care, and prevent secondary impairment, raises and enriches the quality of home care. Professionals involved in home care are expected to take part in rehabilitation in their respective disciplines and areas of practice, grasping the patient’s condition according to the International Classification of Functioning, Disability, and Health (ICF) model and respecting the teamwork.

Rehabilitation and the International Classification of Functioning, Disability, and Health

Rehabilitation medicine is a system of studies and techniques aiming at enabling medical rehabilitation for “impairment.”

The goal of medicine previously was to overcome illnesses, and the “medical model” of “etiology,” giving rise to “pathology,” giving rise to “manifestation,” particularly comprising a pathology that looks into the causes and manifestations of diseases, was presented. As a criterion for the international statistics of those diseases, the “International Classification of Diseases and Related Health Problems (ICD)” was used. However, although the survival rates of patients with conditions such as acute infectious diseases rose as medicine made progress, the rates of chronic diseases also increased. In addition, to deal with sequelae resulting from diseases, looking only at diseases became insufficient and the idea of looking at “impairment” became essential. Therefore, in 1980, WHO published the “International Classification of Impairment, Disability, and Handicaps (ICIDH)” as a supplement to the ICD.

Figure 1. ICF Model



The basic model presented by ICIDH was a “disease, impairment, disability, and handicap” model, classifying the dysfunction after disease into three phases. Until then, only impairment, a direct sequela of a disease such as paralysis or amputation, had been considered as dysfunction in most cases. This way of thinking had a significant influence not only on medicine but also on legislation and administration. ICIDH established a protocol for evaluating “disability” and the consequent “handicap” along with “impairment” and clarified the three phases of dysfunction. Thus, ICIDH presented a wider view of dysfunction, which should be marked as its greatest significance. Rehabilitation medicine addresses all three phases of dysfunction and advocates a “daily life model,” which aims to improve the QOL of those receiving care.

A revised version of the ICIDH is the ICF (**Figure 1**). In ICF, all the terms for the basic concepts were replaced with positive or neutral ones. Furthermore, the term “functioning” was newly created as a positive counterpart to the negative comprehensive concept of “disability” during the process of ICF compilation. This was a reflection of the shift in health concepts which re-prioritized what matters in health. Although longevity is certainly important, this term was adopted to show that what an individual is able or unable to do or “how to function on a daily basis (functioning)” is more important for having a healthy life.

The ICF model also takes “contextual factors” into consideration. They are deeply involved in functioning and can be classified into “environmental factors” and “personal factors.”

- (1) The term “impairment” is replaced with “body functions and structures” (and “impairment” refers to their disturbance).
- (2) “Disability” is replaced with “activity” (and “activity limitation” refers to its disturbance).
- (3) “Handicap” is replaced with “participation” (and “participation restriction” refers to its disturbance).

In addition, as the two-way arrows in **Figure 1** indicate, the ICF model is characteristically an interaction model in which “body functions and structures,” “activity,” and “participation” relate to each other.

In “WHO Family of International Classification (WHO-FIC),” which combines ICD, ICF, and several other supplements, it is recommended that health should be evaluated not only from the viewpoint of illness but also from that of functioning. The application of ICF as a classification involves the process of adding the decimal point and the subsequent numerals to the minute codes comprising alphabets and numerals. The “ICF Core Sets” have been studied and developed as tools to facilitate the use of ICF, but this process is not necessarily considered to be requisite for home medical care. What is important in clinical practice is a “model,” and it is advisable to attempt to use the ICF model as a method to grasp the whole image of disability or functioning.

How to View Impaired Functioning: Application of the ICF Model

The overall picture of the condition of people receiving home care has become more complex as they age. It is impossible to control their illness only by grasping their condition through medical examination. To plan or continue a better regimen, it is necessary to look at all the problems resulting from illness, that is, the whole disability. Examining an individual’s residual abilities on the basis of what he or she can do clarifies in particular what should be prioritized, what is possible, and the goals to be aimed at, which enables the sharing of perspectives between professionals from multiple disciplines. The ICF model may be used as a method to check the residual abilities.

Let’s take an example of a study of impaired functioning in the following case (**Figure 2**).

The patient was an 83-year-old man diagnosed as having right hemiplegia associated with cerebral infarction, prostate cancer, metastases to the thoracolumbar spine, and status post-surgery for right lung cancer.

Three years before, he had undergone a resection of the lower lobe of lung for right lung cancer but a part of the lobe still remained. At that time, he walked with a cane, his activities of daily living (ADL) were independent, and he visited the hospital alone. He experienced right hemiplegia with a sudden onset of inarticulateness and was hospitalized with the diagnosis of cerebral infarction. On that occasion, metastatic bone lesions were noted, which were diagnosed as metastases of prostate cancer to the thoracolumbar spine on the basis of biopsy findings. As he had cancer, he could not be transferred to a rehabilitation hospital and return home after being discharged from the hospital. Incidentally, he had stated that he would like to return home early if possible.

Two weeks after discharge, he expressed his wish to undergo rehabilitation for the right hemiplegia. He had lost weight by approximately 5 kg in a month. His grip strength was 18.9 kg for the right hand and 16 kg for the left. The right hemiplegia was mild and he was able to hold on to the handrail with his right hand. He was able to take a seated posture on the edge of the bed. However, he also had muscular weakness in the left lower limb because of thoracolumbar lesions and needed assistance to stand up. His nursing care level was 3. He had originally been self-employed and had his room on the second floor of his house. His family consisted of six members, including his wife and the members of his daughter's family. His main caregiver/key person was his daughter. She took care of him with his wife.

The assistance with toileting included the concomitant use of diapers. After he was discharged from the hospital, he had an increased appetite and irregular bowel movements, which posed difficulty in toileting care. During his stay in hospital, two or more nurses had helped him move to the toilet. No evaluation of bathing care was present because he had not taken a bath while in hospital. His future care remained undetermined as to home-visit nursing and medical care, and he only had a follow-up appointment for the prostate cancer in the urology department. He stated that he wanted to go out but he was concerned about bothering his family. His family members stated that they wanted to help him with bathing and toileting. His blood pressure was 135/62 mmHg and his pulse 102 BPM. He did not perceive any symptoms.

A. Impairment of Health Condition and Body Functions/Structures

In cases of elderly people, attention should be paid to secondary disuse because of hospitalization because they have geriatric syndrome which underlies illnesses. In home health care, there are also not a few cases in which the advanced age itself presents frailty and requires care equivalent to that for disuse syndrome. Needless to say, the first disease requiring rehabilitation is stroke. Meanwhile, rehabilitation associated with cancer has also been included in insurance coverage since 2010 as "Cancer Patient Rehabilitation Fee," although it is limited by facility criteria, etc. With regard to the rehabilitation associated with dementia, its data are being gradually accumulated as a representative of non-pharmacological approach.

In summary, the description of their health condition already requires multiple terms as in the present case, and the consequent impairments are even more complex. In such a situation, the first things to be considered are whether treatment is possible and what should be dealt with immediately, and the health care professionals, especially physicians, are to give a decision over these matters.

Figure 2. Examination of the Case Using the ICF Model

Health condition	Cerebral infarction, prostate cancer, metastases to the thoracolumbar spine, status post-surgery for right lung cancer, disuse after hospitalization, very advanced age
Impaired body functions and structures	Right hemiplegia, paraplegia, muscular weakness, inarticulateness, eating disorder, bladder disorder, rectal disorder
Activity limitation	Gait disturbance, impaired mobility, absence of bathing experience after hospital discharge, malnutrition
Participation restriction	Difficulty in going out
Environmental factors	Caregivers, family, house, financial issues
Personal factors	Wishes to go out, concerns about bothering his family
Residual abilities	Maintenance of a seated posture on the edge of the bed, use of the bilateral hands, expression of wishes, communication, family cooperation

Note: This scheme does not conform to the ICF model.

B. Activity Limitation and Participation Restriction

The living standard, hobbies, roles, reasons for living, and sense of belonging are considered here. The present case presented such problems as the absence of attempts at bathing, which is an important behavior at a daily life level to maintain hygiene, after the onset of physical deconditioning, as well as the impaired mobility and issues of toileting because of the mild hemiplegia and the metastases to the thoracolumbar spine. Malnutrition, probably because of cancer, was also noted.

C. Contextual Factors: Environmental Factors and Personal Factors

Family environment, mainly comprising caregivers, place of residence/room, and financial problems surrounding an individual, largely determines his or her care plan. Even more important are such factors as an individual's lifestyle, personality, way of thinking, and beliefs and values. In the case presented above, the patient appeared to have a concern about bothering his family while he expressed his wish to go out.

Through the above process, "activity," which is the most important, is reconsidered. In other words, what an individual is able to do and what he or she is actually doing is considered, instead of looking at what he or she is unable to do. This evaluation of residual abilities and prediction of prognosis are the very fields of study focused on in rehabilitation medicine.

In the present case, although the patient had mild right hemiplegia, he had the grip strength of more than 10 kg for both hands and he was able to hold things, take a sitting position, and support his own body. There were no problems in his communication ability and he expressed his wishes and his thoughts for his family without showing any psychiatric reactions such as depression. The family members were also very cooperative and motivated. On these bases, the final goal of "participation" would be tackled.

As illustrated above, the ICF model is useful in arranging and clarifying the problems. However, this is not a tool which automatically gives the answers, even if the problems are successfully presented according to the coding. It is of more importance to look at those problems comprehensively and to consider what to do, taking account of the interactions between the problems as well. This consideration should also include the issues of an individual's subjective ideas (thoughts) about disability and the secondary impairments of those involved, such as the physical, mental, and psychological burden (quitting a job for caregiving for instance) of the caregivers and family members. The actual setting of caregiving successively pauses ethical dilemma (oral intake or gastric fistula, absence of caregivers, poverty, etc.). The practice of

rehabilitation, which is a disability management, is expected to involve the participation of each professional and the full use of both formal and informal services.

Impaired Functioning and Home Medical Care: For Better Home Care

Most of those who receive in-home medical care are elderly, who is often limited to their place of living and who have to live with many illnesses and impairments until they pass away. Better home care for those people is the support for maintaining a sense of being healthy until their last moment despite their impaired functioning.

What is required here is not therapeutic medicine but supportive medicine, which entails having a viewpoint of an individual's daily living, arranging problems, and taking measures. As a tool for this, the ICF model was presented above. The conditions that can be medically treated in the place of living include eating and swallowing disorders, impaired body functions, sarcopenia, locomotive syndrome, excretory disorder, dementia, vascular lesions, and cancer. Each of them should be considered from various aspects amid the ethical dilemma, with the philosophy of community rehabilitation aiming at the improvement in quality of life (or quality of death), the reduction of the burden of caregiving, and the prevention of secondary impairments. The measures against these conditions should center on care planning. This is the very shift to integrated community care, and health care professionals can make a large contribution if they gain a viewpoint of daily living along with the new concepts of health.

(Fujiko Hotta)

2. Sarcopenia and Frailty

Maintaining and managing an individual's stable life under home care is an important role of home medical care. In terms of the concept of "frailty," maintaining a stable life under care involves preventing the progression of sarcopenia, which is a core element of the frailty cycle, as well as intervening in frailty from multiple aspects.

<h3>What is Sarcopenia?</h3>

In 1989, Irwin Rosenberg proposed the term "sarcopenia" (Greek "sarx" or flesh + "penia" or loss) to describe the age-related decrease of muscle mass. Since then, sarcopenia has been known as the loss of skeletal muscle mass and strength that occurs with advancing age. The mechanisms underlying its onset remain to be clarified. However, they are considered to involve aging, disuse, endocrine, neurodegenerative diseases, inadequate nutrition/malabsorption, and cachexia, which affect various mechanisms including protein synthesis, proteolysis, and neuromuscular integrity and result in the decrease of muscle mass and strength. In recent years, sarcopenia has been practically defined by the European Working Group on Sarcopenia in Older People (EWGSOP) as a geriatric syndrome characterized by progressive and generalized loss of skeletal muscle mass and strength with a risk of adverse outcomes such as physical disability, poor quality of life, and death.¹⁾

A. Criteria for Diagnosis and Assessment Techniques

EWGSOP recommends diagnosing sarcopenia on the basis of the documentation of criterion 1 "low muscle mass" plus documentation of either criterion 2 "low muscle strength" or criterion 3 "low physical performance" or both 2 and 3. With regard to the assessment techniques, criterion 1 is commonly assessed on the basis of the muscle mass estimated by dual-energy X-ray absorptiometry and adjusted for height. In Japan, it is recommended to set its cut-off points at 6.87 kg/m² for men and at 5.86 kg/m² for women (two standard deviations below the young adult mean). For criterion 2, handgrip strength is a good simple measure, and its cut-off points are set at 25 kg for men and 20 kg for women in Japan. Criterion 3 is mostly assessed by gait speed, and its recommended cut-off point is 0.8 m/sec.²⁾

B. Stages and Categories

Sarcopenia staging defines "presarcopenia" as a condition that meets only criterion 1, "sarcopenia" as a condition that meets criterion 1 plus either criterion 2 or criterion 3, and "severe sarcopenia" as a condition that meets all the three criteria.

Clinically, sarcopenia is categorized into "primary (or age-related) sarcopenia," in which no other cause is evident but aging itself, and "secondary sarcopenia," in which one or more causes are evident. "Secondary sarcopenia" is divided into "activity-related sarcopenia," "disease-related sarcopenia," and "nutrition-related sarcopenia" (**Table**).

Table. Sarcopenia Categories by Cause

Primary sarcopenia Age-related sarcopenia	No other cause evident expect aging
Secondary sarcopenia Activity-related sarcopenia	Can result from bed rest, sedentary lifestyle, deconditioning, or zero-gravity conditions Associated with advanced organ failure (heart, lung, liver, kidney, and brain), inflammatory disease, malignant tumor, or endocrine disease Results from inadequate dietary intake of carbohydrates and/or proteins, as with malabsorption, gastrointestinal disorders, or use of medications that cause anorexia
Disease-related sarcopenia	
Nutrition-related sarcopenia	

Cited from References 2).

What is Frailty?

Frailty is a condition characterized by the vulnerability to adverse health outcomes due to a reduced resistance to stressors, which results from the age-associated decrease of reserves in various physiological systems. This term has been proposed to refer to an intermediate stage between good health and disability. This stage includes not only an irreversibly senile state but also a condition that can possibly return to a healthy state (**Figure 1**).

The indices presented by Fried et al. are commonly used for assessing frailty; three or more of the following five characteristics support a frailty diagnosis: unintended weight loss, exhaustion, low physical activity, slow gait speed, and muscular weakness.³⁾ The concept of frailty encompasses the impairment of the overall functioning; it goes beyond physical factors and includes mental and psychological factors such as cognitive disorder and depression as well as social factors such as solitary life and financial plight.

“Slow gait speed” and “muscular weakness,” two of the indices of frailty, overlap with the diagnostic markers of sarcopenia. In frailty, the five indices are considered to correlate with each other and form a negative spiral called “frailty cycle,”⁴⁾ which results in exacerbation. “Sarcopenia” and “undernutrition” are the core elements of the frailty cycle, which are considered to trigger the aggravation of frailty (**Figure 2**).

Figure 1. Positioning of Frailty

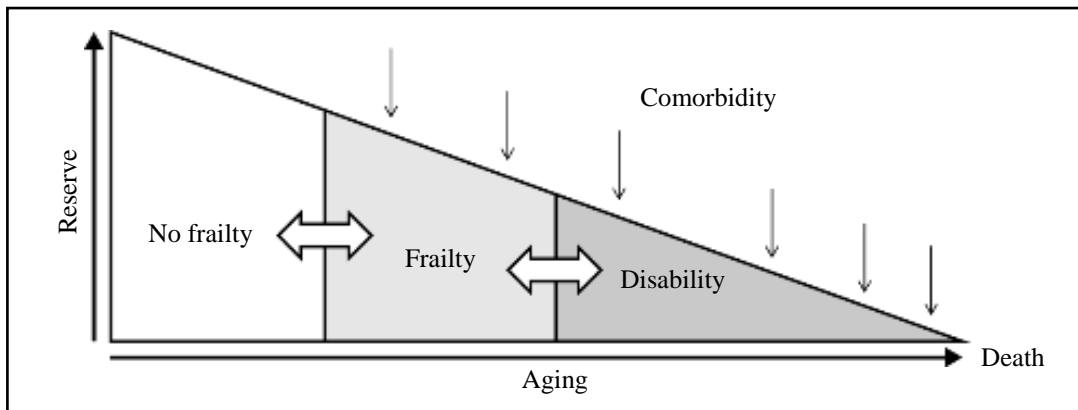
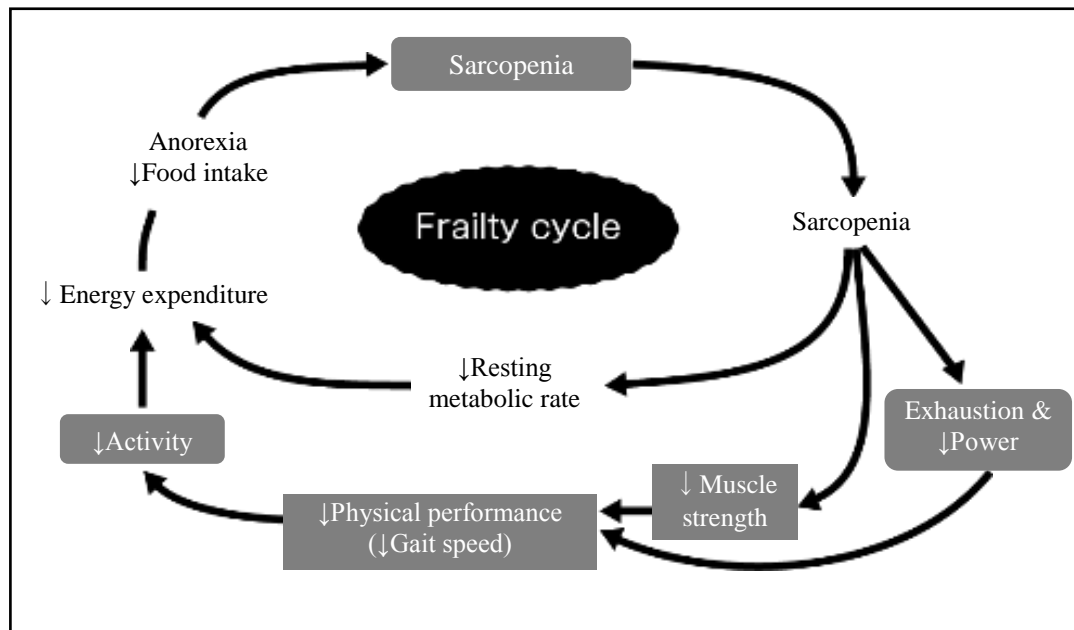


Figure 2. Frailty Cycle



Cited and modified from References 4).

Sarcopenia and Frailty in Home Medical Care

To maintain and manage an individual's stable life under home care, it is necessary to prevent the progression of sarcopenia, which is a core element of the frailty cycle, and thereby to prevent a shift to disability due to the aggravation of frailty.

The following are considered important to prevent the worsening of frailty: exercise recommendations as well as instructions on nutrition management given on a daily basis, early treatment and improvement of adverse events (pneumonia, falls/fractures, anorexia, etc.), management of dementia and prevention of shut-in life, and support for the introduction of proper nursing care services.

(Satoru Mochizuki)

References

- 1) Cruz-Jentoft AJ, Baeyens JP, et al: Sarcopenia: European consensus on definition and diagnosis. Report of the European Working Group on Sarcopenia in Older People. *Age Ageing* 39(4): 412-423, 2010.
- 2) 高齢者における加齢性筋肉減弱現象（サルコペニア）に関する予防対策確立のための包括的研究研究班：サルコペニア：定義と診断に関する欧州関連学会のコンセンサスの監訳と Q&A. 厚生労働科学研究補助金（長寿科学総合研究事業），2012. Study Group on the Comprehensive Research for the Establishment of Preventive Measures against Sarcopenia in Older People: Japanese Translation of “Sarcopenia: European Consensus on Definition and Diagnosis” with Q&A. Health Labour Sciences Research Grant (Comprehensive Research on Aging and Health), 2012.
- 3) Fried LP, et al: Frailty in Older Adults Evidence for a Phenotype. *J Gerontology*, 56: M146-157, 2001.
- 4) Fried LP, Walston J: Frailty and failure to thrive. In: *Principles of Geriatric Medicine and Gerontology* (Fourth Edition), McGraw Hill, 1387-1402. 1998.

3. Dysphagia

Stroke, intractable neurological diseases, and Alzheimer's type dementia are common illnesses in people under home medical care and are frequently complicated by dysphagia. Dysphagia occurs in approximately one third of people with acute-phase stroke. Lacunar infarcts of the bilateral basal ganglia in particular is highly likely to result in dysphagia. This article describes the techniques for swallowing function assessment and the actual practice of swallowing rehabilitation at home.

Problems Caused by Dysphagia

A. Aspiration Pneumonia and Asphyxia

People with dysphagia are almost 20 times as likely to have pneumonia.

B. Dehydration and Undernutrition

In hot summer conditions, in particular, oral intake decreases and dehydration can trigger a vicious circle of dehydration → cerebral infarction → aggravation of pseudobulbar palsy → aggravation of dysphagia → further dehydration → cerebral infarction.

The absence of oral intake also results in the progression of sarcopenia in the pharyngolaryngeal muscles. Malnutrition leads to pharyngolaryngeal muscle weakness, which further affects the ability to eat, thus tending to form a vicious circle of malnutrition → muscular weakness → inability to eat → disuse → aggravation of dysphagia → malnutrition.

Preventive medical care, such as the prevention of dehydration, malnutrition, and disuse, is important.

C. Loss of the Pleasure of Eating

Elderly people's greatest pleasure is that of eating. When artificial feeding has to be selected, the problem of dysphagia should not be considered merely as the all-or-none question of oral feeding or tube feeding. Even when tube feeding, including gastrogavage, has to be chosen, ways should be sought to enable them to safely enjoy having meals.

Diagnosis of Dysphagia

The most common chief complaint is emaciation. In addition, history should be taken regarding the presence or absence of coughing or choking while eating, prolongation of eating time, and intermittent pyrexia.

Physical examination should include measuring weight (percent standard weight, rate of weight loss) and body temperature as well as checking the level of consciousness and the respiratory status. Neurological examination should be focused on the presence or absence of mild paralysis (Barre sign), laterality in deep reflex, or morbid reflex of the upper and lower limbs suggestive of asymptomatic cerebral infarction.

Examination of the oral cavity is also important and should include checking oral hygiene, the presence or absence of dental caries, and the viscosity of the saliva. Deviation from the midline on tongue protrusion suggests paralysis on the side toward which the tongue deviates. The uvula deviates toward the stronger side because the pharynx is barely lifted on the affected side.

In physical examination, dry swallowing should be examined first: the physician asks the patient to swallow and sees whether the swallowing reflex occurs within 1 second.

As bedside assessment techniques, repetitive saliva swallowing test (RSST) and Kubota's 30-mL water swallowing test (WST) are commonly used. A patient unable to hold a glass will undergo the modified water swallowing test (MWST), in which the patient is given 3 mL of cold water in the floor of the oral cavity. Cervical auscultation, listening for the swallowing sound and the subsequent breathing sound with a pediatric stethoscope positioned at a site over the lateral border of the upper part of the trachea immediately inferior to the cricoid cartilage, is also widely used to assess the pharyngeal phase of dysphagia.

The most effective bedside assessment technique in home medical care is the simple swallowing provocation test (S-SPT) reported by Teramoto et al.¹⁾

The patient undergoes this technique in a recumbent position after having his or her oral cavity wiped clean. A thin extension tube is cut in half and connected to a 5-mL syringe filled with tap water. The tip of the tube is inserted into the mesopharynx, and 0.4 mL, 1 mL, and 2 mL of water are injected successively. The time from the water injection to the induction of the swallowing reflex (latency) is measured, and the assessment is made as shown in **Figure**. In healthy people, the swallowing reflex is induced with a small amount (0.4 mL) of water.

The S-SPT has the following characteristics and is very useful in home medical care: 1. the procedure can be performed easily with a syringe and a tube, which are included in the regular equipment of a doctor's bag; 2. little burden is inflicted on the patient and the procedure can be repeated; 3. the procedure can be performed also in patients who have difficulty in communication, whose level of consciousness is mildly decreased, who are bedridden, or who have quadriplegia; and 4. both its sensitivity and specificity are higher than those of the WST and the procedure is highly reliable (sensitivity, 76%–100% for the S-SPT vs. 70%–71% for the WST; specificity, 84%–100% for the S-SPT vs. 70%–72% for the WST).

A patient assessed as capable of oral intake and assigned to Group A on the basis of the S-SPT results undergoes food test evaluation. The food test is performed with pudding or water jelly if no choking is induced with 3 mL of cold water and no signs of aspiration or pneumonia are observed. If no choking occurs with the ingestion of pudding and no bolus remains in the oral cavity, the patient gradually undergoes direct swallowing training.

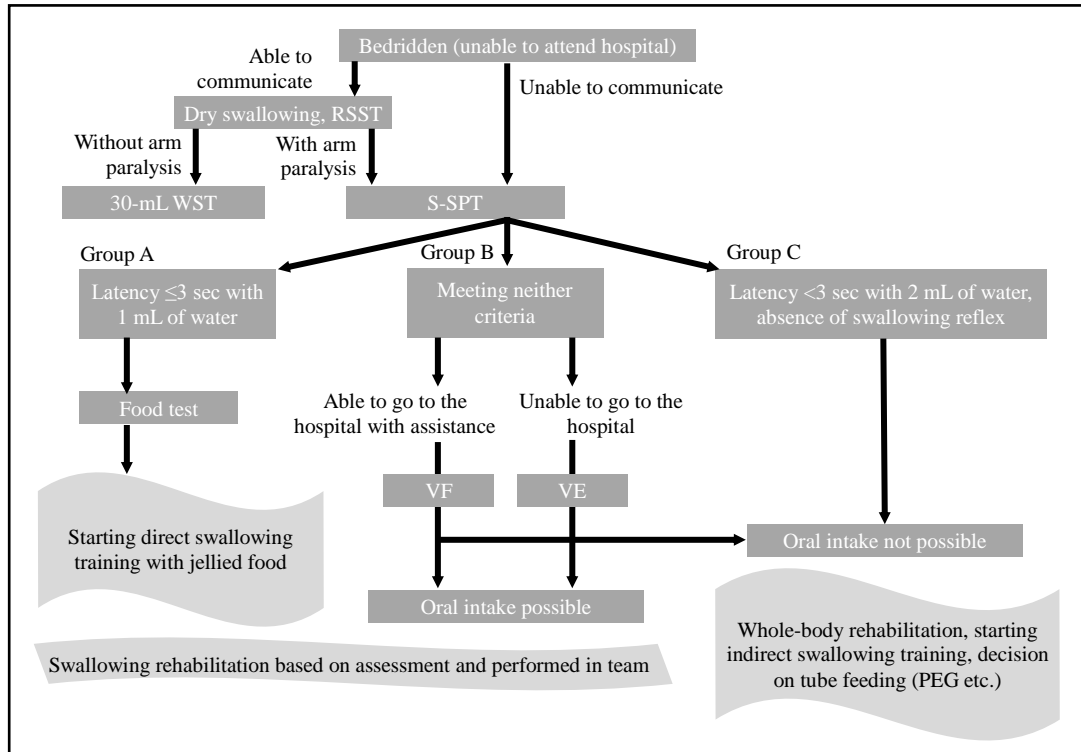
A patient diagnosed as having difficulty in oral intake and assigned to Group C on the basis of the S-SPT results cannot undergo direct swallowing training and thus undergoes indirect swallowing training within the safe range along with whole-body rehabilitation (**Figure**).

Detailed Examination of Dysphagia

Videofluoroscopic examination of swallowing (VF) is a gold standard for diagnosing dysphagia and provides a great deal of information. Of the patients diagnosed as needing detailed examinations on the basis of the S-SPT results (Group B), those who can manage to make outpatient visits for detailed examinations should undergo VF. VF not only reveals the presence or absence of dysphagia but also provides additional information, including its severity, the site of impaired swallowing function, laterality, differences depending on food texture, effective positions, and effective compensatory approaches.

Those who need detailed examinations for dysphagia but have difficulty in making outpatient visits can also undergo assessment by videoendoscopic examination of swallowing (VE) at home.

Figure. Dysphagia Assessment Chart



Treatment of Dysphagia

A. Medication

Multiple cerebral infarction impairs the dopamine metabolism in the basal ganglia. A decrease in dopamine results in a decrease in substance P in the pharyngolarynx. The sputum substance P level in elderly people is decreased to 1/7 of the normal level.²⁾ Increasing the substance P level in the pharyngolarynx with angiotensin converting enzyme (ACE) inhibitors improves the swallowing and coughing reflexes. Meanwhile, amantadine hydrochloride facilitates dopamine release and increases the substance P level in the pharyngolarynx, thereby preventing the onset of pneumonia. However, the effectiveness of those drugs in bedridden patients has not yet been established.

It is also important not to administer antitussives too easily to elderly people.

B. Philosophy of Swallowing Rehabilitation

The most important things to consider are the patient's motivation to eat via the mouth and that of the caregivers to assist it. To practice rehabilitation at home, the following should be taken into consideration: 1. the patient's swallowing function; 2. caregiving capacity (the caregivers' ability to understand as well as time restraints); and 3. medical/nursing/caregiving support systems.

The next step is to set the goals of the swallowing rehabilitation. It is important that the patient, the family members, and the professionals involved are aware of whether eating via the mouth just for pleasure is enough, whether the patient needs to take necessary calories via the mouth, and whether there is a need to prevent pneumonia.

In general, rehabilitation leads to the acquisition of a skill through the process of motivation and behavior change, followed by its establishment, retention, and transference. To successfully

motivate the patient or the caregivers, it is necessary to accurately know before starting rehabilitation how the patient or the caregivers think about eating.

Swallowing training can be divided into two types: direct training using food and indirect training without using food (**Table**). Direct swallowing training can lead to a better transference of the training task (acquisition of the skill) but entails the risk of aspiration and pneumonia because it uses food.

Table. Direct Swallowing Training and Indirect Swallowing Training

	Food	Risk of aspiration	Meaning and purpose of training	Task transference	Effect
Indirect training	Not used	Almost none	Difficult to understand	Small	Low
Direct training	Used	Present	Easy to understand	Large	High

C. Actual Practice of Swallowing Rehabilitation

a. Oral care

Oral care is important not only for preventing aspiration pneumonia but also for maintaining and improving the oral functions, retaining the sense of taste, and increasing appetite. Oral care before swallowing training has the purposes of facilitating salivation by intraoral stimuli and restoring the sense of taste as well as preventing pneumonia associated with the aspiration during training.

b. Food modifications

Food with the following characteristics should be used: a distinct taste, such as a salty or hot taste, or the patient's favorite taste; distinct temperature (cold or hot); and a homogeneous, agglutinative, not adhesive, and moldable texture created with the use of a thickener.

c. Compensatory techniques

(1) Rotation of the head during swallowing

In a patient with dysphagia, the site where the bolus is most likely to remain is the pyriform sinuses, and the rotation of the head before swallowing is effective when the laterality in the bolus accumulation in the pyriform sinuses is detected by VF. The rotation of the head to the affected side narrows the pyriform sinus on the affected side and prevents bolus accumulation there, whereas it broadens the pyriform sinus on the opposite, stronger side and facilitates the clearance of food.

(2) Lying on one's side during swallowing

By reclining backward at a 30–60-degree seat angle and lying on one's stronger side with the head rotated to the affected side (semi-lateral position), the bolus tends to be directed down the stronger side in the pharynx by gravity.

(3) Chin-down swallowing

This is a technique to clear the bolus remaining in the epiglottic vallecula. Retroflexion of the neck narrows the epiglottic vallecula and pushes out the bolus, and taking a chin-down posture during swallowing helps the clearance of food.

(4) Alternate swallowing

This is a technique to reduce the amount of pharyngeal residues by swallowing food of different textures alternately. For instance, the patient is instructed to take jelly and food of another texture alternately.

d. Indirect swallowing training

When performing the maneuvers such as breath holding and cold stimuli, attention should be paid to the onset of respiratory or heart disorders.

(1) Swallowing muscle training, massage, exercises

Swallowing exercises have the effects of removing spasticity and relaxing the muscles and are effective as warm-ups before meals or swallowing rehabilitation. In addition to the above, the patient undergoes range-of-motion (ROM) exercises of the perioral and lingual muscles, muscle strengthening exercises, coordination training, ROM exercises of the neck, or mandible massage.

(2) Articulation training

As the muscles involved in phonation and those involved in swallowing are almost the same, articulation training (singing, for example) is also effective as indirect swallowing training for food intake and clearance.

(3) Cold stimuli (ice massage)

This is a method to induce the swallowing reflex with cold or physical stimuli. In the actual practice of rehabilitation, this technique is used as a preparatory training before oral care, ingestion of a small amount of water, or direct swallowing training. A swab with a cotton ball sized 1 cm in diameter at the tip is prepared using a disposable wooden chopstick. The cotton ball is moistened with water, and the swab is put in a freezer. A small amount of water is put on the tip of the swab before use, and stimuli are given with the swab to the soft palate, the root of the tongue, or the posterior pharyngeal wall to induce the swallowing reflex.

(4) Swallowing pattern training (breath-holding swallowing)

This training aims at the acquisition of a swallowing pattern of taking a deep breath, holding one's breath, swallowing, coughing, and exhaling. By holding one's breath, the vocal cord closes and the subglottic pressure increases, which decreases the probability that food will enter the airway. Exhaling after swallowing has the effect of discharging the aspirate from the airway, and coughing consciously before exhaling further enhances the effectiveness.

(5) Glottic closure training

Glottic closure training is useful in preventing food from entering the airway and producing an effective cough. By straining the arms instantaneously and phonating simultaneously, the vocal cord closes and the glottis is strengthened.

(6) Training for patients with a reduced opening of the esophageal orifice

This training is indicated in cases of bulbar palsy in which the upper esophageal sphincter (UES) opening is reduced.

The techniques include the following: Mendelsohn's maneuver, in which the patient is asked to hold the thyroid cartilage up for a few seconds after swallowing; Shaker's exercise or head raising exercise, in which the patient is asked to lie flat on the back, close the mouth, and lift the head without raising the shoulders by tucking the chin as if he or she is looking at the big toes; and balloon training, in which the stricture of the esophageal orifice is mechanically dilated with a balloon catheter (a 14–18 F urethral balloon catheter).

e. Direct swallowing training

Direct swallowing training should be performed as much as possible, adopting a safe program and realistic goals on the basis of assessment. In a sitting position, the patient undergoes the training with his or her head rotated to the affected side without neck support. When undergoing the training in a reclining position, usually at a 30–60-degree seat angle, the patient puts a pillow under the head and leans the head forward to keep the chin down. Tilting the trunk slightly to the stronger side helps the bolus be directed down by gravity.

The training is performed according to a fixed program under the predetermined conditions of food texture, amount of food, position, and use of compensatory maneuvers. After a swallow, the presence or absence of hoarseness or cough and the respiratory status are checked. The presence or absence of pharyngeal residues or aspiration is also checked by asking the patient to phonate. In addition, the breath sounds in the neck and the lung fields are auscultated and the oxygen saturation as measured by pulse oximetry (SpO₂) is checked. When aspiration is suspected, treatments such as postural drainage and squeezing are given to the patient, and the caregivers are instructed to be watchful for pyrexia and to observe the patient's general condition. The standard duration of training is 30 minutes.

(Satoshi Hirahara)

References

- 1) Teramoto S, et al: Simple two-step swallowing provocation test for elderly patients with aspiration pneumonia. *Lancet* 353: 1243, 1999.
- 2) Nakagawa T, et al: Sputum substance P in aspiration pneumonia. *Lancet* 345: 1447, 1995.

4. Nutritional Assessment and Prescription

Many elderly people are at risk of malnutrition. In the field of home medical care, nutritional prescription and assessment are essential, along with proper coping with anorexia or tube feeding. This article describes nutritional management for elderly people who are unable to eat.

Introduction

Elderly people needing care at home constitute a majority of the people under home medical care, and 30%–40% of them are said to be in a state of protein-energy malnutrition (PEM). The early detection and prevention of this PEM are extremely important in terms of nutritional management in home medical care. The management of enteral nutrition is also an unavoidable issue in home medical care. It requires a wide knowledge of various topics including the ethical/social issues regarding the introduction of enteral nutrition, the problem of prescribing enteral nutrition, and the management of gastric fistula.

Nutritional management tends to be ignored or be empirical. However, understanding its basics and applying them to four of practice produce significant benefits. This article describes the practical methods of nutritional management in home medical care.

Nutritional management basically involves the following processes: 1. screening, 2. nutritional assessment, 3. consideration of the indications for nutrition therapy, 4. determination of nutritional doses, 5. determination of administration route, and 6. monitoring.

The whole process from the determination of nutritional doses to monitoring is called “nutrition care management.”

It is not realistic for a physician alone to take charge of home nutritional management involving these processes. Collaboration with visiting nurses, dietitians, family members, and caregivers is essential. The basic knowledge necessary for nutritional management is presented below in the order of actual practice.

Etiology-based Classification and Diagnosis of Malnutrition

In recent years, a clear classification of malnutrition has been established. Malnutrition is classified into three types on the basis of the presence or absence of inflammation as well as whether the inflammation is chronic or acute. The classification is shown in **Table 1**. The first step is to discern which type of malnutrition the patient has and to select a coping strategy. For instance, when no inflammatory reactions are noted and the albumin level is not decreased, although a decline in food intake and emaciation are noted, starvation is suspected, and the patient is likely to be successfully treated with active intervention. Meanwhile, when the patient has severe emaciation associated with a chronic disease that causes persistent slight inflammatory reactions, it is imaginable that improvement cannot always be expected even with active intervention. Excessive intervention in the progression phase of malnutrition related to chronic diseases, such as cachexia associated with cancer, can neither improve the probability of survival nor contribute to the patient’s well-being in some cases.

Table 1. Classification of Malnutrition

Types of malnutrition	Main causes	Probability of improvement	Albumin level	Emaciation	Inflammatory reactions
Starvation-related malnutrition	Decreased food intake due to social factors, etc.	Is easily improved with increased nutritional intake	Scarcely decreases	Is noticeable	None
	Decreased food intake due to dysphagia				
	Upper gastrointestinal stenosis, etc.				
Chronic disease-related malnutrition	Cachexia due to malignant tumors	Is hardly recovered in progression phase because of the causative disease that is unlikely to improve; Is successfully treated in most cases if intervened in the early phase.	Gradually decreases	Is not noticeable in the early phase but becomes noticeable later	Mild
	Emaciation due to COPD				
	Persistent chronic inflammation including chronic rheumatoid arthritis				
	Chronic infections (including tuberculosis)				
Acute disease-related malnutrition	Pneumonia, traumatic injury, thermal burn, acute infections	Improves with recovery from the causative disease.	Starts decreasing in the early phase	Is barely noticeable	Severe

Malnutrition Screening and Nutritional Assessment

The nutritional status should be assessed with the above diagnosis in mind.

Various indicators of malnutrition are known (**Table 2**). Among these indicators, the rate of weight loss and serum albumin level are the most commonly used indicators on a daily basis. Both are known to correlate well with prognosis and are effective indicators in the field of home medical care as well. It is important to grasp the nutritional status comprehensively. In actual practice, regularly measuring weight and evaluating food intake are important.

As a tool for nutritional assessment, Mini Nutritional Assessment Short-Form (MNA-SF), which has been proven to be useful in nutritional assessment for elderly people, is easy to use for elderly people in home care. MNA-SF can be downloaded from the Nestlé Health Science Japan website (<https://www.nestlehealthscience.jp/mna>). If malnutrition is suspected at the form, the details of nutritional intake should be heard and medical history should be taken. Particularly when a decline in food intake is noted, it needs to be assessed whether the malnutrition is related to starvation. As for the cause, drug-induced anorexia is common. Particular attention should be paid to anticonvulsants, diuretics, antiasthmatic xanthines, hypnotics, and antipsychotics. It is not rare that the inability to eat is attributable to the caregiving environment. Problems in the oral cavity such as dentures and dental caries are also major factors that impair appetite.

Second, the details of the weight change and eating environment during the past year should be asked. It is also necessary to evaluate the food intake as accurately as possible. The patient or the caregiver should be asked to write what the patient ate during the past three days in as much detail as possible. The dietitian then calculates the current food energy intake on the basis of that information.

Measurement of height and weight is very important for nutritional assessment. Arm circumference and triceps skinfold thickness are used as indicators to assess the nutritional status. The problem with the skinfold thickness is the possibility of a large measurement error. Therefore, it is advisable that the same person who is familiar with the operation should take charge of the measurement. On the other hand, body weight is a good indicator for nutritional management as its measurement error is small, although its value is influenced by the presence of edema. As it also correlates well with prognosis, it should be measured regularly. Measurement the body weight of a bedridden patient is also possible with some modifications in the measuring method.

As biochemical examinations, the following general tests suffice: the presence or absence of inflammatory reactions, total protein, serum albumin, total cholesterol, blood cell count, blood urea nitrogen, creatinine, electrolytes, and blood sugar. The measurement of rapid turnover protein, which is used as a nutritional indicator in acute care, is rarely necessary in the field of home medical care. In physical examination, attention needs to be paid to the presence or absence of edema as well as the degree of atrophy in hip and femoral muscles.

See **Table 2** for the reference value suggesting malnutrition for each nutritional indicator.

When malnutrition is detected in elderly people, there is some reason in most cases, and thus, the reason should be sought.

Table 2. General Indicators of Malnutrition

	Indicators of malnutrition	Life-threatening levels (reference)
Rate of weight loss	5% per month/10% per 6 months	4% per year 2-year mortality rate: RR 1.38–5.81 (95% CI)
BMI	< 19 (or 18.5)	< 23 6-year mortality rate: RR 1.69–6.39 (95% CI)
Serum albumin	< 3.5 g/dL	< 3.8 Annual mortality rate: RR 1.2–6.6 (95% CI)
Cholesterol	< 160 mg/dL	
Total lymphocyte count	< 800: severe malnutrition ≥ 800, < 1200: moderate malnutrition ≥ 1200, ≤ 2000: mild malnutrition	

Rate of weight loss:

$$(ABW - UBW)/UBW \times 100$$

UBW: usual body weight, i.e. the body weight consistent over 6–12 months

ABW: actual body weight

Body mass index (BMI):

$$\text{weight (kg)/height (m}^2\text{)}$$

RR: relative risk

CI: confidence interval

Estimation of Nutritional Requirements and Shortages

The next step is the actual determination of nutritional doses. As shown in **Table 3**, the patient's energy consumption is estimated on the basis of the measurements of height and weight as well as his or her levels of physical activity and stress associated with diseases etc. There are some predictive equations for energy requirements. Harris–Benedict's equation and the simplified method of multiplying the weight by a certain value is commonly used. In the predictive equations, the actual body weight is usually used, but the corrected weight [corrected weight =

ideal body weight + (actual body weight – ideal body weight) × 0.25] is used when the patient is emaciation or obesity of ≥20% below or above the ideal body. The simplified method is used when the stress level is high. The usual protein requirements are about 0.8–1.0 g per kg body weight per day, but they increase depending on stress such as that caused by infections. The requirements for other nutrients should be according to the Dietary Reference Intakes for Japanese.

Table 3. Methods for Estimating the Energy, Protein, and Water Requirements

Energy requirements	<ul style="list-style-type: none"> ● Caloric requirements = basal energy expenditure (BEE) × physical activity coefficient × injury coefficient Harris–Benedict’s equation Men: $BEE = 66.0 + 13.8 (W) + 5.0 (H) - 6.8 (A)$ Women: $BEE = 665 + 9.6 (W) + 1.8 (H) - 4.7 (A)$ [W = weight (kg); H = height (cm); A = age (year)] Physical activity coefficient: bedridden → 1.2; able to walk → 1.3 Injury coefficient: mild infection → 1.2; moderate infection → 1.5, etc. ● Simplified method Used in the presence of severe stress causing hypermetabolism Caloric requirements = weight × 25–30
Protein requirements	Protein requirements (g/kg body weight/day) Stress causing hypermetabolism: None → 0.6–1.0 Mild → 1.0–1.2 Moderate → 1.2–1.5 Severe → 1.5–2.0
Water requirements	25–30 mL per kg weight

**Determination of Nutritional Doses and Administration Route:
Consideration of Practical Methods—Nutrition Support Plan**

The energy, protein, and water doses are determined to meet the requirements. The requirements calculated with Harris–Benedict’s equation are often excessive for bedridden elderly people. For those people, BEE without being multiplied by the physical activity coefficient often suffices, which should be kept in mind when determining the doses. The determination of administration route is basically the selection between oral feeding and enteral feeding. In home medical care, the patient’s social environment, way of life, as well as the social resources of the community are deeply involved in the contents of nutritional prescription. Even an ideal prescription can end up being a pie in the sky if it is not practical. It is necessary to seek and implement a plan that fits with the patient’s environment and preference. It may sometimes be necessary to refrain from aggressive nutritional intervention and to observe the clinical course.

Monitoring

The nutritional doses calculated in the first step are based on speculation, and thus are not absolute. When the doses are calculated with Harris–Benedict’s equation, it is often the case that elderly patients in whom the physical activity level is low, and the muscle mass is markedly decreased begin to gain too much weight. Furthermore, it can never be known whether the nutrition support plan is properly implemented unless it is evaluated. Therefore, monitoring is an essential part in nutrition care management.

Among various indicators for monitoring, body weight is an important one. Body weight should be measured at least once monthly by all means. In addition to this, indicators such as skinfold thickness and body fat percentage are also useful for following up the changes over time. Among the biochemical tests, serum albumin is a good indicator. Its half-life is approximately 20 days, and it begins to show a change about a month after intervention. If an improvement is noted a month after the change in the nutritional prescription, the frequency of measurement may be reduced to once every three months.

Nutritional intakes should be assessed as needed. It is advisable to attempt evaluation of the nutritional intakes at least once weekly. The nutrition support plan has to be reviewed as needed on the basis of these monitoring results. When reviewing the plan, it is convenient to remember that the weight gain or loss of 1 kg corresponds to approximately 7000 kcal of energy excess or shortage. That is to say, if a patient loses 1 kg per month, it can be assumed that there was an energy shortage of approximately 7000 kcal during that period.

Actual Practice of Nutrition Support to a Person Unable to Eat

Many elderly people become unable to eat after catching a cold or because of the progression of dementia or the hot weather. A concrete approach to such elderly people with starvation-related malnutrition is described below.

As mentioned above, nutritional assessment and prescription involve the following steps: 1. measurement of height and weight, 2. evaluating the oral intakes (calculation of the mean intakes during the past three days), 3. estimation of shortages, 4. discussion on the coping strategy with the patient and the family members, 5. nutritional prescription, and 6. monitoring.

The actual practice of the processes 4 and 5 is described below in detail.

<Consideration of whether to perform nutritional intervention>

In not a few cases, the oral nutritional intakes prove insufficient and the intakes cannot reach the requirements despite the search for improvable causes and adequate measures taken. Such a situation is common in the “old-old” with dementia or in those with dysphagia associated with multiple cerebral infarction. The problem here is whether to decide on forced feeding including tube feeding. It is necessary to properly provide information to the patient and the family members and take the time in making a decision that seems to be the best for the patient.

The following are the examples of information that should be provided:

- (1) The nutritional shortages and anticipated course in case the condition persists → increased infection susceptibility, development of pressure sore, death.
- (2) The risks and benefits in case tube feeding is performed
 - incidence of death associated with gastrostomy: around 1%
 - incidence of serious complications associated with gastrostomy: 1%–3%
 - life expectancy in case tube feeding is properly performed: same as that in case of oral feeding as far as cerebrovascular disorder is concerned (in Japan)
 - life expectancy in case oral feeding becomes impossible because of advanced dementia: no evidence of prolongation even if tube feeding is performed (in the United States).
- (3) Management of the gastric fistula

The burden of the caregivers is more reduced when gastrogavage is introduced than when oral feeding is continued unstably, no cleaning operations are required and bathing is also possible, etc.

- (4) Ethical issues in case tube feeding is not performed.

It sometimes takes a considerably long time until the family members decide whether to select tube feeding. In such a case, it is necessary to wait for their decision while administering

concomitant fluid replacement to the patient from a peripheral vein. Although the family members often seek medical advice, there is no standard answer as to the introduction of tube feeding. On such occasions, the whole health care team should participate in decision making, taking into account the medical indications as well as the patient's wishes.

(Shigeru Onozawa)

5. Dietary Support Needed in Home Medical Care

“Eating” is “living” not only for humans but also for all organisms. Therefore, “dietary support” is an issue that physicians engaged in home medical care, who “care about their patients’ daily life,” should address with the highest priority.

What is Dietary Support in Home Medical Care?

“How to enable an individual to eat” is a big problem in home medical care. When a disease develops in a patient who has up until then been able to lead a stable life under care for a long time, whether he or she can continue receiving home care or must be hospitalized often depends on his or her ability to eat. For people with dementia or dysphagia, “eating or being served food every day” is an important issue for their life under care itself. For those approaching the end of their life, dietary support is the very action that confirms that “they are continuing to live” and thus is an essential part of care.

The occasions for physicians to be directly involved in “dietary support”—feeding a patient for instance—are very limited. Dietary support is interprofessional work, requiring the contribution of family members, caregivers, persons in charge of services such as professional caregivers and facility staff members, visiting nurses, physical therapists, occupational therapists, speech-language-hearing therapists, dentists, dental hygienists, registered dietitians, and care managers to the patient.

Patients Needing Dietary Support

A. Patients Who Need Dietary Support

The patients who need dietary support are as follows:

- (1) Those with impaired appetite, eating functions, or digestion/absorption functions due to the age-related decrease of physical functions, who often have sarcopenia (decreased muscle mass/strength and decreased physical functions);¹⁾
- (2) Those with cachexia, which is a syndrome caused by multiple factors, complicated by anorexia and metabolic abnormality, resulting in negative protein and energy balance (the causative diseases include cancer, chronic infections, collagen disease, chronic cardiac failure, chronic renal failure, chronic respiratory failure, chronic hepatic failure, and inflammatory bowel disease);²⁾
- (3) Those who have dysphagia because of congenital or acquired factors (diseases, such as cerebrovascular disorder, or injuries); and
- (4) Those with dementia.

B. What is Needed for Dietary Support?

The following are needed for dietary support:

- (1) Accurate evaluation of the status of food intake;
- (2) Estimation of nutritional requirements and actual nutritional intake;
- (3) Assessment of the condition of the oral cavity (inadaptation of dentures);
- (4) Assessment of dysphagia;

- (5) Assessment of cognitive functions;
- (6) Understanding of the patient's way of life, policies, and preferences; and
- (7) Assessment of meal preparation and caregiving status of the family members and caregivers.

Of the above items, (4), (5), and (6) can be directly performed by a physician. Other items require the contribution of professionals other than physicians and can be better performed by them. The physician should make a comprehensive assessment on the basis of the current condition, possibility of new illnesses, and above information.

When Practicing Dietary Support

The first professionals for physicians to collaborate with are 1. dental professionals (dentists and dental hygienists) and 2. registered dietitians. Dietary support for patients with dysphagia requires the cooperation of all the professionals involved in care, including physical therapists, occupational therapists, speech-language-hearing therapists, visiting nurses, and professional caregivers.

A. Collaboration with Dental Professionals

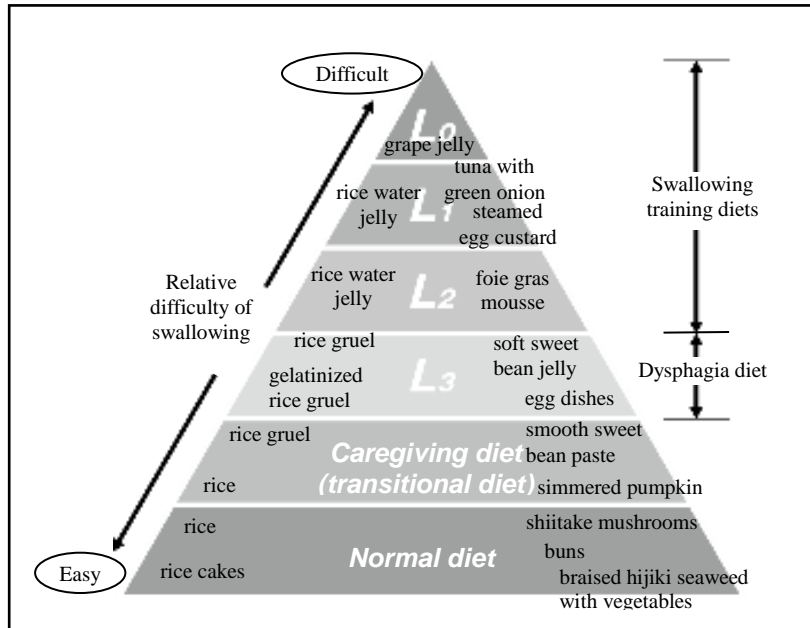
One of the major factors that affect the appetite of elderly people and people with disability is the problem of the oral cavity. Uncleanliness of the oral cavity, toothache, inadaptation of dentures, and the presence of periodontal disease or stomatitis often require direct assessment and treatment by dental professionals.

It should be emphasized that oral care is a basic care necessary for everyone, oral hygiene is a prerequisite for dietary support, is important for maintaining and improving the swallowing and communication functions, and is very important for the prevention of aspiration pneumonia. Some patients with dementia eventually refuse to open their mouths after experiencing traumatic injuries due to inadequate oral care. The most effective collaboration in home care is to involve visiting dentists and also to ask for special oral care by dental hygienists (both the current medical and long-term care insurance systems allow an individual to undergo oral care by visiting dental hygienists up to four times monthly). Even if it is impossible to introduce special oral care on a regular basis, it will be very beneficial for the whole dietary support if the professionals involved have occasion to share the methods and timing of oral care and thus provide seamless care to the patient.

B. Collaboration with Registered Dietitians

It is most effective to consult a registered dietitian about any matters regarding eating such as assessment of the actual status of nutrition and food intake, selection of proper food textures and feeding methods, consultation and notification about how to select ingredients and how to cook, and integration of eating assistance methods. A registered dietitian engaged in "home-visit nutritional and dietary guidance" can propose a nutritional plan that is compatible with the preferences of the patient and their family members, taking various conditions into account. To start, it is important to know whether any registered dietitian is available in the neighborhood. If no known registered dietitian can be found, it is advisable to inquire with the local dietitians' association. The Japan Home Nutrition Management Society website (<http://www.houeiken.jp>) is also helpful.

Figure. Dysphagia Diet Pyramid



(dysphagia diets.com and <http://www.engesyoku.com>)

As a reference for sharing a common knowledge among workers from different disciplines, the “dysphagia diet pyramid” by Setsuko Kanaya is presented in **Figure**. This classifies all diets into six levels from normal diet to dysphagia diet according to the relative difficulty in eating/swallowing and standardizes the food textures for each level. This pyramid is useful for quality management and is very widespread. It is also advisable to compare it with the “Japanese Dysphagia Diet 2003 (https://www.jsdr.or.jp/doc/doc_manual.html)” by the Japanese Society of Dysphagia Rehabilitation.

(Satoshi Furuya)

References

- 1) Hidetaka Wakabayashi: Rehabilitation Nutrition and Sarcopenia
<http://rehabnutrition.blogspot.jp/2013/12/20132.html>
- 2) Satoshi Furuya: Nutritional Care. Today’s Treatment Guidelines 2015, Igaku-Shoin, 1479, 2015.

6. Dementia

Nearly 50% of the elderly people in need of care in Japan have dementia. Community care services aim to help them live safely and comfortably in a familiar environment and as independently as possible. For this purpose, continuous medical support from onset to terminal stage is required.

Basic Knowledge on Diagnosis and Treatment of Dementia
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Dementia is a condition in which a person's intellectual ability that normally develops during the development period is chronically reduced because of acquired brain or physical disorders, adversely affecting social and family life. Its underlying diseases vary widely, and more than 70 diseases have been noted. In addition to medical diagnostic techniques to make a diagnosis of treatable dementia, proficiency in the diagnosis of four major dementia diseases—Alzheimer's disease (AD), vascular dementia (VD), dementia with Lewy bodies (DLB), and frontotemporal lobar degeneration (FTLD)—is required (**Table**). In particular, physicians need to be familiar with a diagnosis of typical AD, in which core symptoms take a certain course.

AD is usually detected by symptoms associated with declining recent memory such as "repeating the same story again and again." Then the core symptoms of AD follow a fixed course of progression; for example, disorientation deteriorates in the order of time → place → person. The average life expectancy of patients with AD is about 10 years from onset. AD patients with no complications, however, require few visits to medical services in the early stages because these patients can usually be followed up in the outpatient department as their motor cortex is kept intact until the disease advances into the late stages.

In patients with a history of arteriosclerotic diseases, including hypertension or episode of stroke, when a decline in cognitive function is observed within three months after the stroke, VD is suspected. Recently, the diagnosis of mixed dementia, defined as the coexistence of VD and AD, has increased compared with that of pure VD. The progression of VD typically follows a stepwise course, although there are a number of cases following a downhill course. VD patients have a shorter vital prognosis than AD patients; however, VD is different from other dementia diseases in that there are preventive measures such as antiplatelet therapy.

A diagnosis of DLB should be given if two out of the three symptoms of vivid hallucinations, fluctuation in attention and clarity, Parkinsonism are observed in addition to progressive cognitive impairment. DLB patients have characteristic symptoms including relatively preserved recent memory, rapid eye movement (REM) sleep behavior disorder, or autonomic disorders (orthostatic hypotension, fever, and others) while clearly showing constructional apraxia in the early stages.

FTLD is categorized into the following types: 1) behavioral disorder-type frontotemporal dementia (frontotemporal dementia: FTD), which is characterized by onset with character change/ behavioral change, and 2) language disorder-type frontotemporal dementia (semantic dementia: SD and progressive nonfluent aphasia: PNFA), which is characterized by onset with language disorder. FTD is commonly found in difficult patients with prominent BPSD (refer to page 94. FTD patients demonstrate both positive symptoms including behavior disorders, such as stealing or collectionism, irascibility, stereotypy (such as taking a walk in exactly the same route every day), overeating carbohydrates, and negative ones like apathy. Some SSRI are effective for stereotypy or disinhibition.

Table. Differential Diagnosis of Four Major Dementia Diseases

Disease	Alzheimer-type dementia	Vascular-type dementia	Lewy bodies-type dementia	Frontotemporal lobar-type dementia
Epidemiology	Common among women	Common among men	Common in men aged over 60	Common in the presenile period
Onset	Slow	Relatively acute	Slow	Slow
Progression	Like descending a slope	Progress stepwise after each episode (not always)	Progressive, labile	
Whole course	10 years (2–20 years)	7 years	Shorter than that of AD (7 years)	Clinical course is generally rapid
Memory impairment	Appear in the early stages	Relatively mild	Milder than in AD in the early stages	Milder than in AD
Physical symptoms	Does not appear until the advanced stages	Worsen before or in parallel with mental symptoms	Parkinson’s symptoms. Falling and autonomic symptoms	Incontinence appears in the early stages
Mental symptoms/signs	Delusion of theft (characteristic to AD. Appears in the mild stages)	Disturbances in motivation, consciousness, and emotion	Vivid hallucination, fluctuation in cognitive function, constructional apraxia, REM sleep behavior disorder, and delusional misidentification symptoms	Character change, flattening of emotion, disinhibition, apathy, stereotypy, and eating disorder
Prevention/treatment	Donepezil hydrochloride, galanthamine, rivastigmine, memantine are effective	Preventable by improving lifestyle habits, medication (antiplatelet therapy, etc.)	Donepezil hydrochloride and rivastigmine are effective in improving mental symptoms	SSRI are effective. Atypical antipsychotic drugs should be used for patients with severe BPSD
Others	Emotions and motor function remain normal until the advanced stages	Local neurological symptoms Arteriosclerosis risk factor	Hypersensitivity to antipsychotic drugs	

Diagnosis of Dementia and Sharing of the Diagnosis

A. Diagnosis of Dementia in Home-care Settings

The diagnosis of dementia is often made on the basis of observations by close family members, such as “he/she’s been acting strangely.” Symptomatology is the base of the diagnosis of dementia. It is most important to understand under which circumstances the episodes in question occur and what kind of cognitive problems the patient has by carefully taking histories of symptoms in a chronological order from the patient’s family members. Coexisting physical symptoms, past histories, trauma histories, alcohol consumption histories, and medication histories also need to be obtained.

When performing physical examinations, observe the patients’ facial expressions for neurological problems or signs during the general examinations. Head CT or MRI scans should be added to a blood test in the initial examination of dementia patients with unknown underlying diseases to differentiate chronic subdural hematoma, normal pressure hydrocephalus, brain tumor, and VD. MRI (voxel-based specific regional analysis system for AD [VSRAD]) or SPECT may be used when mild cognitive impairment or frontotemporal lobar-type dementia is suspected, and DAT scanning or MIBG myocardial scintigraphy may be used when DLB is suspected. As

neuropsychological tests, conduct the revised Hasegawa's dementia scale and mini-mental state examination. When DLB is suspected, assess constructional apraxia using the clock drawing test. Before conducting these neuropsychological tests, explain to the patients that these are to examine forgetfulness because some patients may feel insulted by the tests. The tests should be performed face-to-face with the patient in a quiet and calm atmosphere so that he or she can concentrate on the tests.

B. Support in the Early Stages

Most early-stage AD patients are aware of their forgetfulness. When it occurs frequently and becomes undeniable that something is wrong with them, they tend to restrict their activities in an effort to hide their condition from surrounding people, reasoning to themselves "I'm forgetful just because I have bumped my head." Their symptoms, however, worsen and are recognized by their family members. Finally, they visit medical institutions, persuaded by their family. Their trouble will remain unsolved if a correct diagnosis is not made at this point.

Although it is firstly required to make a correct diagnosis, do not be preoccupied with only naming the disease. What is more important is to share the diagnosis with the patients and their families after understanding their "explanatory models" and states of mind to start careful educational support. Administration of antedementia drugs like donepezil should be considered in this process of early-stage support. The patients and their families will be able to develop courage and power to live with this difficult disease only by going through this process.

C. Follow-up

In the community care services for elderly dementia patients, it is important to prepare an environment on which the patients can rely and in which they can feel safe.

Without any support, elderly dementia patients living alone would face difficulties even if their symptoms are mild. But they can live alone longer by using services like professional caregiving or day care from the early stages. In patients with moderate symptoms, however, living alone would be difficult as instrumental ADL are affected because of the progression of core symptoms.

On the other hand, patients can stay in their home until the end if there are caregivers. It is important to prepare a support system for the families, such as listening to the caregivers to find difficulties they are facing and arranging necessary interventions quickly.

a. Routine care consultation

The point in the follow-up of dementia patients is that the case management function and primary care doctor function consistently work together and quickly respond to various problems.

AD patients' ability to do the things they could do before reduces mainly because of the progression of core symptoms. It is important to develop new ways of care using the patients' remaining abilities by carefully observing their behavior and identifying what kind of cognitive or behavioral disorders caused the inability.

b. Responses to BPSD

Psychobehavioral signs associated with dementia diseases had been traditionally called "problematic behaviors;" however, this discriminatory term has been corrected to BPSD (behavioral and psychological symptoms of dementia). BPSD occurs as a result of a combination of various contributors, including the patients' congenital character, state of mind, and environmental factors based on the core symptoms of dementia. BPSD demonstrate pains of the patients and impair their QOL. Severe BPSD are often difficult to control and impose substantial burdens to caregivers and families, forcing the patients to give up staying at home.

Comprehensive measures are required to respond to BPSD, including educational support to caregivers and families, introduction of appropriate support services like day care, and

environmental improvement in addition to discontinuation of medication, which can adversely affect BPSD, and treatment and care of physical complications.

Drug therapy should be considered for the patients with moderate or more severe, or pathological BPSD. Underlying diseases, complications, types of BPSD, and urgency need to be comprehensively considered in selecting drugs. It has been known that some antipsychotic drugs such as risperidone (Risperdal®) can increase mortality by 60%–70% (FDA talk paper). BPSD can often be improved by effectively using other drugs such as antidepressants (SSRI and CHE-I) and a small dose of valproic acid, which are relatively safe for chronic administration. When it is inevitable to use antipsychotics, for instance for the patients with delusional symptoms, start with smaller doses, use only one agent, and carefully monitor the clinical course according to the guidelines.

SSRI are effective in most cases of depression that are associated with AD or DLB.

Donepezil hydrochloride (Aricept®) and Yi-Gan-San (抑肝散, Yokukansan) are effective for treating DLB patients with visual hallucinations. Utmost caution should be exercised when using antipsychotics in DLB patients as they have hypersensitivity to antipsychotic agents (exacerbation of extrapyramidal symptoms). If it is inevitable to use antipsychotics to treat patients with delusional misidentification symptoms, select olanzapine (Zyprexa®) 2.5 mg or quetiapine fumarate (Seroquel®) 25 mg as these drugs are less likely to cause extrapyramidal symptoms.

Fluvoxamine maleate (Luvox®) and sertraline hydrochloride (Jzoloft®) are useful in improving BPSD of FTD patients. Atypical antipsychotic drugs should be used to treat severe BPSD in FTD patients.

c. Whole-body control (early diagnosis and treatment of complications)

Complications are found in 90% of dementia patients and are common causes of their death. Many dementia patients have difficulties in recognizing their health problems and seeking appropriate medical care, and this increases mortality regardless of the severity of dementia. Circulatory diseases are common in the mild to moderate stages, and infectious diseases, such as pneumonia, are common in the more advanced stages.

The prognosis of dementia is mainly determined by concurrent medical diseases. It has been reported that the survival time of AD patients after receiving the diagnosis is approximately half of that of people in the same age group, and elderly dementia patients over the age of 85 with histories of wandering, gait disturbance, diabetes, and congestive heart failure have the worst prognosis.¹⁾

Whole-body control is required throughout the entire period of dementia. Careful observation by caregivers and healthcare workers, regular whole-body control by home-visit nursing, and early detection and treatment of complications by physicians are important to manage complications.

Palliative Care in Dementia

Palliative care should be considered of prime importance in patients with severe- to end-stage dementia.

A. Definition of End-stage Dementia

Hospice eligibility criteria in the United States (U.S.) and Gold Standards Framework GSF criteria in the United Kingdom have been known as the definition of end-stage dementia. According to the U.S. criteria, it is considered to be the end stage when severe dementia patients who are unable to move by themselves and hold a reasonable conversation; are almost completely dependent for all ADL; have urinary and fecal incontinence (corresponding to stage 7c or over on FAST); concurrently have aspiration pneumonia, urinary tract infection, sepsis, and multiple

level III to IV pressure ulcers that are worsening; have repeated fever after administration of antimicrobial agents; and/or weight loss by 10% or more in the past six months.

B. Palliative Care for Dementia

Five principal pillars in palliative care for dementia are as follows: (1) Observation and mitigation of symptoms, (2) Team approach, (3) Communication, (4) Support to the families (Beck-Friis Barbro), and (5) Support for eating. Objective pain assessment methods, such as PAINAD, are useful in assessing pains of the elderly patients with severe dementia. Abilities to assess the causes of the pain and to care and mitigate the pain are required. Taktil care, Validation therapy, and Humanitude are informative as a communication method. The swallowing reflex decreases in severe and end-stage patients. It is important to prevent pneumonia by oral care to maintain oral intake as long as possible and to prevent the onset of secondary sarcopenia by maintaining oral intake and good nutrition.

C. Decision Making Support

In most cases of end-stage dementia, a family member has to make decisions about treatment on behalf of the patient. Decision-making support for the surrogate decision makers is critical as more than one third of family members have negative mental impact.

As mentioned before, this support should be provided in the earliest possible stages.

Making decisions about treatment in the end-stage on the basis of a consensus reached during discussions between the patient's representative or family members and a physician or people involved in the patient's care is called "Consensus Based Approach (CBA)".²⁾ The purpose of this approach is to develop a consensus on the meaning of emotional terms, including diagnosis and prognosis, benefits and pains associated with treatment methods, inability of oral intake and associated pains, QOL, and dying. Selection of treatments should be made on the viewpoints of "estimated values of the patient," "pain-relieving effects of each option," and "balance between the pros, including the best possible QOL or dignity that can be obtained, and the cons, including burdens." Physicians will be able to mitigate pains of the families and help reach a convincing conclusion by being aware of CBA and actively involved in the decision-making process.

(Satoshi Hirahara)

References

- 1) Larson EB, et al: Survival after Initial Diagnosis of Alzheimer Disease. *Ann Intern Med* 140(7): 501-509, 2004.
- 2) Karlawish JH, et al: A Consensus-Based Approach to providing palliative care to patients who lack decision making capacity. *Ann Intern Med* 130(10): 835-840, 1999.

7. Motor Organ Dysfunctions (Orthopedic Diseases)

Most elderly people have some orthopedic diseases. As these diseases are not life-threatening and their major symptom is pain, treatment with nonsteroidal anti-inflammatory drugs (NSAIDs) is often continued without careful consideration. In this article, points in disease management when non-specialist physicians treat these patients in home-care settings will be explained by symptom type.

Basic Knowledge on Orthopedic Diseases

Orthopedics is a surgical specialty treating diseases of motor organs including bones, joints, and muscles and also spine, spinal nerves, and peripheral nerves. Patients are primarily elderly people except for congenital disorders, traffic injuries, and sports injuries. Aging and physical motor dysfunction are closely related.

The number of elderly patients in the field of orthopedics is estimated at about 15 million or 20 million, so most elderly people have some orthopedic diseases (**Table 1**).

Many of these diseases are not fatal; however, a main reason for seeking medical care is pain except for trauma. Major complaints other than pain are dysfunctions, such as inability to walk or move due to paralysis or numbness, and deformities, such as crooked joints. Therefore, how to manage pain is the point in treating patients at home.

Although X-ray examination is an important ancillary test in the diagnosis, it is not fully available in home-care settings. Thus, it is important to have criteria for judging whether X-ray examination is necessary or specialist's opinion should be sought.

Most patients are treated by medication; however, lifestyle regimens are highly useful. Instead of disease concepts (refer to textbooks), some basic orthopedic knowledge required in treating elderly patients at home will be stated in the following sections, with a focus on symptoms.

Complaints and Symptoms of Orthopedic Diseases

A. Joint Pain

It is critical to assess when pain is felt at rest or during exercise or the pain becomes worse or better in a particular daily life behavior or position. If the pain is felt at rest, it often indicates serious conditions, and diseases of organs other than the motor system must be suspected. When patients have local pain at rest, conduct a blood test to check the inflammatory response, including blood sedimentation rate and WBC count, with the possibility of tumors and infections in mind. If fever is accompanied, medical disorders rather than joint pain are suspected.

Pain is difficult to measure objectively. In case of joint pain, compare the range of motion to that of the healthy joint and assess the severity of the disease on the basis of the degree of limitation and the local inflammatory signs such as swelling and warmth. If there are no clear differences, the case can be considered to be mild.

The pain of acute inflammation usually reduces in three to several days. When the symptom is not relieved in several days after administering nonsteroidal anti-inflammatory drugs (NSAIDs), the patients should be referred to orthopedic specialist including X-ray examination.

Table 1. Diseases Relatively Frequently Seen in Home-care Settings

Around the hand joint	CM arthritis, Trigger finger, De Quervain's tenosynovitis, Ingrown toenails, Carpal-tunnel syndrome (Median nerve palsy)
Around the elbow joint	Osteoarthritis of the elbow (Hydros), Olecranon bursitis, Medial humeral epicondylitis, Lateral humeral epicondylitis (Tennis elbow)
Around the shoulder joint	Shoulder peri-arthritis (so-called frozen shoulder), Shoulder arthropathy (Hydros)
Hip joint	Hip osteoarthritis, Calcific peri-arthritis of the hip
Knee joint	Knee osteoarthritis, Ligament injury (Medial collateral ligament injury, Anterior/ Posterior cruciate ligament injury), meniscus injury, Knee hydros
Ankle joint, foot	Ankle osteoarthritis (Traumatic arthritis), Bursitis of lateral malleolus, Hallux valgus, Flatfoot/splay foot disorders
Spinal column	Degenerative cervical spondylosis, Cervical spondylotic myelopathy, Cervical spondylotic radiculopathy, Thoracolumbar spine compression fracture, Degenerative lumbar spondylolisthesis, Spondylolytic spondylolisthesis, Osteoporosis

B. Neuralgia and Limb Pain

When nerve pain radiates into the upper or lower extremities, the cause is often the deformation of the cervical spine for the former (cervical spondylotic radiculopathy) and the deformation of lumbar spine for the latter (lumbar spondylosis, radicular sciatica). Determine whether the paralysis is of central (spinal) or peripheral (cauda equina) origin on the basis of the degree of motor weakness and anesthesia or tendon reflex. Many cases are unilateral. If the patients have intensive pain that is difficult to diagnose, observe for several days with the possibility of herpes zoster in mind.

Numbness and pain in both lower limbs may indicate lumbar spinal canal stenosis or degenerative lumbar spondylolisthesis. Intermittent claudication, however, is difficult to confirm because most patients rarely walk for long periods of time. Circulatory disturbances, such as deep-vein thrombosis (DVT) or critical limb ischemia (CLI), often cause the symptoms. CLI can easily be excluded by palpating the dorsal artery of the foot.

C. Lumbar Backache

Lumbar pain does not indicate serious illnesses if the mobility of the lumbar spine remains. The association between vertebral deformity and pain is not always clarified with X-rays. When vertebral compression fractures caused by unrecognizable minimal trauma progress, lumbar backache continues for two to three months. Diagnosis can be made by observing the clinical course, if experienced before, and X-ray examination should be conducted. As elderly people with severe kyphosis, in which the thorax touches the pelvis, are unable to wear a corset, use suppositories like diclofenac sodium (Voltaren SUPPO®) and calcitonin injections for the treatment of intensive pain during the acute phase. Unfortunately, however, drug treatment efficacy is not promising in osteoporosis.

The important point is to control the pain and make the patients leave the bed as soon as possible. Some home care physicians have doubt that compression fractures may compress the spinal cord if the patients get out of the bed; however, it is unlikely that the posterior elements of the spinal column will be damaged by minimal pressure and result in bursting fracture. If spinal paralysis is observed, metastasis of malignant tumors to the vertebrae should be suspected.

Irradiating pain in the left shoulder is sometimes recognized in acute myocardial infarction, and it may be misdiagnosed as orthopedic diseases. It can be differentiated by the followings: the pain is felt at rest and accompanies dyspnea. Also, lumbar pain due to urinary tract calculi is often treated as lumbar spondylolysis. A urinary test should be used without hesitation because it can be relatively easily conducted at home.

Treatment at Home

A. Drug Therapy for Pain

Although NSAIDs are commonly used, caution must be paid when giving these drugs for a long time to elderly patients with body weight of 40 kg or lower. The author does not prefer the use of long half-life drugs that are administered once daily. Even if a drug is usually administered three times daily, it is often sufficiently effective in the once daily administration. Safety of long-marketed drugs, such as aspirin, paracetamol (Calonal[®], Anhiba[®], Alpiny[®]), indomethacin (Indomecine[®]), and diclofenac sodium (Voltaren[®]) is highly reliable considering the history of NSAIDs; however, attention to gastric mucosal lesions or renal damage are still needed. Acetaminophen is not categorized as an NSAID, but it is a safe analgesic agent. It can be used up to the maximum dose of 4,000 mg in patients with no hepatic disorder and 3,000 mg with hepatic disorder. Prepare several types of preparations with different routes of administration, including prodrugs and suppositories, and use the one you are most familiar with.

The incidence of gastric mucosal lesions induced by Voltaren[®] is high at around 20%. It has been said that the incidence is reduced to around a half of that with COX-2 selective inhibitors and decreases further to a half of that when concurrently used with PPI.

Most of these gastric mucosal lesions, a serious adverse reaction, are asymptomatic until the lesions start bleeding. Do not forget to check progression of anemia and fecal occult blood in a long administration regimen. Even in the use of suppositories, caution is still required because similar adverse reactions can be induced if the blood concentration rises.

When patients have hypochondriac complaints, the author preferentially uses vitamin preparations that have no definite pain-relieving effect because the administration is estimated to last long. Topical preparations, such as poultices, rarely induce adverse reactions. Though contact dermatitis is occasionally caused, it can easily be treated by discontinuing the preparations and applying steroids. As to whether hot or cold poultices should be used, use the one that is more comfortable for the patients. As there is no physical heat transfer, “hot” or “cold” does not matter.

B. Treatments Other Than the Administration of Analgesics

As mentioned before, because pain is the major complaint, some orthopedic diseases are treated with systemic NSAIDs regardless of locations of pain, even for toe pain. However, there are various effective treatments in addition to the drug therapy.

It has been known that muscle and nerve pain can be largely affected by the weather and environment, including temperature, humidity, and atmospheric pressure. Particularly for muscle pain, bathing is recommended since the pain is relieved with thermal therapy (both wet and dry). If bathing makes the pain worse, the pain may be caused by acute inflammation. Assessing changes in the symptoms caused by thermal therapy may be of help in making the diagnosis.

There is no effective treatment for the pain due to joint contracture except for exercise therapy. In home-care settings, however, simple physical therapy is available using hot packs warmed by a microwave oven.

C. Local Fixation

External fixation using a plaster cast is not only for treating fractures but also an effective treatment aiming to immobilize the affected parts. Braces or corsets effectively relieve pain by

immobilizing the affected sites. Simple fixation with bandages or supporters often can mitigate the symptoms.

D. Injections for Pain Relief (including blocks)

The procedure in which local anesthetic agents are injected into local tender points is called “trigger point injections” and is distinguished from muscle injections in claiming health insurance. The injections are performed in the tender points in the paraspinal muscles or trapezius muscles to treat lumbar pain or stiff shoulders. Concurrent use of dexamethasone and local anesthetic agents is common in the injections into the tendon sheath.

Injections of sodium hyaluronate (Suvenyl[®] and Artz[®]) into the joints must be performed with utmost caution, for instance, adequate sterilization, to avoid infection. If patients have purulent arthritis as a complication, it makes the treatment much more difficult. When injecting into the knee joint, a safe and easy way is to puncture the needle into the site around two fingerbreadth lateral to the upper edge of the patella with the knee slightly bent.

Injections in the sheath of the long head of the biceps have been also approved for patients with shoulder peri-arthritis.

Whether it is appropriate to use sacral block at home should be determined on the basis of the skill and experience of the physician. Pain in orthopedic diseases generally occurs with exercise. Since inactive elderly patients receiving home medical care are basically in the resting state, epidural block is seldom applied except for cancer pain.

E. Arthrocentesis and Others

If there is sudden swelling in the joint and it feels soft and flabby, it may be the onset of hydrarthrosis. Puncture of the joint to withdraw exudation helps in differentiating rheumatoid arthritis or pseudogout. Therefore, diagnostic significance should be enhanced when obtaining patients’ informed consent to arthrocentesis. In cases of protracted inflammation, however, hydrarthrosis often recurs after arthrocentesis, and multiple punctures are required. Do not expect that hydrarthrosis can be easily treated with arthrocentesis.

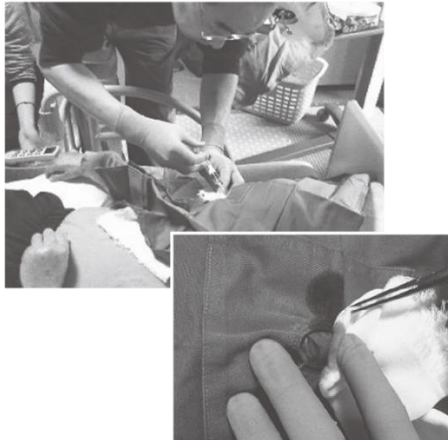
When performing arthrocentesis, strictly follow the basic procedure and perform disinfection. The procedure must be carried out with great care though it has less risk of infection compared to injecting preparations.

Other diseases requiring arthrocentesis in elderly patients in home-care settings includes ganglion cyst, Baker’s cyst (the back of the knee), synovial cyst, and subcutaneous hematoma due to trauma. As many patients receive antiplatelet therapy, cessation of the drugs may be instructed depending on the degree of the invasive procedure. As well as in cases of arthrocentesis, utmost caution to avoid infection is required.

F. Surgical Procedures Including Incision

Incision and drainage are necessary in cases of infectious atheroma or felon (infected ingrown toenail). Antimicrobial agents can be effective in cellulitis. Abscesses require immediate surgical treatment. Considering the in-home setting, a cross-shaped incision should be chosen. When placing a gauze drain after the treatment, consideration should be given to the postoperative care performed by home care nurses. Drugs with bleeding tendency must be discontinued in advance.

Reference: Incision and Suture in Home-care Settings



Important Diseases in the Home Medical Care

A. Locomotive Syndrome

This is a recently proposed disease concept as well as metabolic syndrome. The syndrome is treated with an aim to improve QOL, comprehensively considering various bone and joint diseases leading to loss of motor function during aging as motor disabilities instead of mere diseases. For instance, unsteady walking due to spine deformity caused by vertebral compression fracture or knee osteoarthritis can be improved by muscle-strengthening exercises. In addition, fracture risk can be reduced by fall prevention. In other words, this is the concept of preventive care.

B. Polymyalgia Rheumatica (PMR)

The reason of taking up this particular disease is that the author has treated many patients in home-care settings who had become bedridden without receiving the correct diagnosis (**Table 2**). Difficulties in making the correct diagnosis may be that due to a complication of dementia, patients are unable to complain in a reliable manner or appropriately answer the physician's questions. To deal with these difficulties, addition of erythrocyte sedimentation rate test (ESR) might be useful in cases of vague pain with unclear complaints and unidentified location and reduced activities. Histological diagnosis may not be necessary. As patients with this disease respond dramatically to steroid treatment, steroids can be used as a diagnostic therapy. Refer to textbooks for the recommended doses and cautions in using steroid drugs, as sufficient improvement is often observed with small doses. When improvement is not sufficient, other diseases should always be suspected.

C. Crowned Dens Syndrome (CDS)

This is a lesser-known disease since its disease concept has been established relatively recently. It begins with acute pain in the cervical vertebrae. The author decided to take up the disease here because the diagnosis is difficult in some patients. On the basis of their shape, the first cervical vertebra is called atlas vertebra and the second vertebra is called axis vertebra. The first vertebra is rotating around the axis of dens. In CT images, calcareous deposits around the dens appear like a crown. It is a type of so-called crystal-induced arthritis. It has been reported that colchicine and steroids are effective, although NSAIDs improve the symptoms in many cases.

(Hideki Ohta)

Table 2. Diagnostic Criteria for Polymyalgia Rheumatica

1. Bilateral shoulder pain and/or stiffness
2. Duration of onset of illness ≤ 2 weeks
3. Initial ESR ≥ 40 mm/hour
4. Morning stiffness ≥ 1 hour
5. Age ≥ 65 years
6. Depression and/or weight loss
7. Bilateral upper arm tenderness

When three out of the above seven criteria are met, or at least one and clinical or histopathological evidence of temporal arteritis coexist, it can be diagnosed as "probable PMR."

8. Lower Urinary tract dysfunction

Lower urinary tract dysfunction is common in elderly people in home-care settings, and their QOL is affected by the disorder. Urinalysis and residual urine measurement are simple and useful in diagnosing urinary disturbance. In this article, points in treatment of pollakiuria, urinary incontinence, and difficulty in urination/urinary retention will be explained by symptom profile for general physicians.

Pollakiuria

Frequent urination is a commonly seen symptom. Mobile patients often fall and fracture bones while trying to go to the bathroom. In bedridden patients, it increases the burden of caregivers.

Table 1. Drugs That Can Cause Lower Urinary Tract Symptoms

Drugs that can induce voiding symptoms	Drugs that can induce storage symptoms
<ul style="list-style-type: none"> • Opioids • Muscle relaxants • Vinca alkaloid drugs • Therapeutic drugs for pollakiuria, urinary incontinence, overactive bladder • Anticonvulsant drugs • Therapeutic drugs for peptic ulcers • Antiarrhythmic drugs • Antianxiety drugs • Tricyclic antidepressants • Antiparkinson drug • Antivertigo drugs, drugs for Ménière's disease • Centrally acting muscle relaxants • Bronchodilators • All in one cold and flu capsules • Drugs for hypotension • Antiobesity drugs 	<ul style="list-style-type: none"> • Antianxiety drugs • Centrally acting muscle relaxants • Anticancer agents • Alzheimer-type dementia drugs • Antiallergic drugs • Alpha-adrenergic blocking agent • Antianginal drugs • Cholinergic drugs

(Taken from "Practice Guideline for Lower Urinary Tract Symptoms in Women", 55, 2013, edited by the Practice Guideline for Lower Urinary Tract Symptoms in Women Preparation Committee, the Japanese Continence Society)

To make a diagnosis, careful history taking of symptoms and a urinalysis for hematuria and urinary tract infection should be performed. Examination of drugs, which may cause dysuria, should also be considered (**Table 1**). Perform residual urine measurement using ultrasonography to exclude overflow incontinence. The residual urine volume can be obtained after examining the postvoiding bladder with abdominal ultrasound using the ellipsoid approximation: Residual urine (mL) = Minor axis (cm) × Major axis (cm) × Anteroposterior diameter (cm) × 0.5. If possible, measure the prostate volume in men to exclude benign prostatic hyperplasia. When ultrasound is not available, measure the residual urine using urethral catheterization. Polyuria, bladder storage dysfunction, and sleep disorders are some of the factors that cause pollakiuria. A voiding diary, if possible, is a useful tool in determining whether it is polyuria or storage dysfunction. In home-care settings, however, valid information is difficult to obtain because of the reduced cognitive abilities of the patients or additional burdens on the caregivers. In patients who are difficult to evaluate, treatment should be started with α_1 -blockers following the treatment

protocol of benign prostatic hyperplasia if these patients are elderly men with a large volume of residual urine (≥ 150 mL) or dominant voiding symptoms (weakstream, intermittency, hesitancy, straining, and splitting). In contrast, the use of anticholinergic drugs or β_3 stimulants should be considered in women and patients with a small volume of residual urine (≤ 50 mL) or dominant storage symptoms (sense of urgency and urge urinary incontinence), following the treatment protocol for overactive bladder. In patients with dementia, dementia itself causes overactive bladder. As anticholinergic drugs can worsen dementia, treatment with these drugs should not be continued for a long period. Re-evaluation must be made around two weeks after the commencement; then carefully determine whether to continue or discontinue on the basis of the result.

Urinary Incontinence

Urinary incontinence can be categorized into the following four types: stress type, urge type, overflow type, and functional type (**Table 2**). A diagnosis should be made on the basis of careful history taking, physical findings, complications, and medical history.

Table 2. Categorization and Treatment of Incontinence

Categorization of incontinence	Clinical condition	Cause	Treatment
Stress incontinence	Leakage during coughing or sneezing. Leakage when abdominal pressure rises during moving. Usually with no desire to void when incontinence occurs. No or small volume of residual urine.	Flaccidity of the pelvic floor muscles due to aging or past childbirth. Constipation/obesity is also exacerbating factors.	Guidance for exercise to strengthen the pelvic floor muscles. Electrical stimulation therapy. Surgery β_2 stimulants
Urge incontinence	Incontinence occurs with sudden strong desire to void. Unable to hold urine, leakage before reaching the bathroom. Induced by the sight of water.	Overactive bladder. Neurological diseases inducing detrusor overactivity such as cerebrovascular disorder, multiple sclerosis, and Parkinson's disease.	Anticholinergic drugs β_3 stimulants Storage training
Overflow incontinence	Practically being in the state of urinary retention and urine flows over the bladder. Incontinence disappears after urethral catheterization.	Lower urinary tract obstruction such as benign prostatic hypertrophy. Peripheral nerve disorder due to diabetes, pelvic surgery. Neuropathy due to spine disorder.	α_1 -blockers Intermittent self-catheterization Catheter placement Surgery
Functional incontinence	No problem with the urinary function but unable to use toilet due to impaired motor function or dementia.	Impaired mobility due to motor dysfunction. Motor paralysis due to cerebrovascular disorder or neurological diseases. Dementia.	Improvement of environment for the impaired mobility and prompted voiding program for dementia.

Stress urinary incontinence is frequently seen in elderly women. Incontinence occurs when abdominal pressure rises, for instance, during coughing or sneezing. Flaccidity of the pelvic floor muscles due to aging or past childbirth is the cause of the symptom. Lifestyle guidance including control of constipation, improvement of obesity, and clothing and exercises to strengthen the pelvic floor muscle should be provided. Surgical procedures should be considered on the basis of the patients' wish and clinical conditions. Urge urinary incontinence is a condition where

incontinence occurs with strong desire to void, represented by overactive bladder. The treatment is the same as for the aforementioned pollakiuria. Clinical conditions of overflow incontinence are largely different from other types; thus, an exclusion diagnosis is required in the first place. The diagnosis of overflow incontinence can be easily made if the residual urine volume is significantly large and no incontinence occurs after urethral catheterization. The clinical conditions are almost the same as those in ischuria; therefore, the same treatment as that for urinary retention and urination difficulty, which is described below, can be applied. Functional incontinence is caused by decreased motor function or dementia even if the patients' urinary function is normal. In cases where the aforementioned types coexist, applicable treatments should also be concurrently used. Preparing an appropriate environment is effective for patients with impaired motor function, and prompted voiding (a behavioral therapy. Caregivers ask the patients if they have any desire or intention to urinate, and the patients provide the answer. When the patients are able to urinate without incontinence, caregivers praise them and prompt them to voluntarily communicate their desire to urinate) is useful for patients with dementia.¹⁾

Table 3. Indication of Urethral Catheter Placement in the Home-care Settings

<p>1. Urinary retention or similar clinical condition (overflow incontinence/significantly large volume of residual urine) Lower urinary tract obstruction such as prostate diseases Neurogenic bladder due to cerebrovascular disorders/spinal cord injuries/neurological diseases</p> <p>2. Prevention of urine contamination due to decubitus Remove quickly when the primary disease improves</p> <p>3. In bedridden or dementia patients when other urinary tract management methods are difficult to implement. As this is a relative indication, fully study other options before the implementation.</p>
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(Taken from *Super General Practitioner All about Home Medical Care*, Edited by Satoshi Hirahara, Published by Nakayama Shoten 126, 2014)

Urinary Difficulty/Urinary retention

Many elderly men have diseases related to lower urinary tract obstruction such as benign prostatic hypertrophy. Severe constipation also causes the symptoms in some cases. Therefore, a urinalysis and residual urine measurement are essential, and if possible, the prostate volume should be measured using ultrasound. PSA should be also measured to exclude prostate cancer when needed (a long survival period is expected). Consider the use of α 1-blockers in patients with no urinary retention and a small volume of residual urine. Consultation with urologists for possible surgery is necessary in cases with large prostates (in general, ≥ 30 cm³) and intense symptoms. Administration of 5- α -reductase inhibitors is also effective in patients with no indication of surgery. Catheter placement (**Table 3**) and intermittent catheterization programs should be considered for patients with no indication of surgery who have urinary retention and a large volume of residual urine.

(Shigeru Onozawa and Hironori Oyama)

References

- 1) Wakako Sato: The study of care system using prompted voiding (PV) for treatment of urinary incontinence in elderly individuals with dementia. Report of the Grant-in-Aid for Scientific Research by the Ministry of Education, Culture, Sports, Science and Technology, 57, 2009.

9. Bowel Problems

Digestive symptoms such as constipation and diarrhea are frequently seen in home-care settings, and management of defecation is an inevitable task for home care physicians. Whether the symptoms should be treated or not and, if yes, which treatment method should be used need to be determined considering the level of care that can be provided/dermatological states in addition to the symptoms. In this article, treatments for functional constipation and noninfectious diarrhea will be mainly described.

Views on Defecation

Treatment methods for constipation and diarrhea vary depending on the patients' skin conditions including the level of decubitus and care that can be provided. We think cases where "feces are retained in the intestine, accompanied by abdominal pain," and "there is pain on defecation due to hard feces" need to be treated. We do not treat cases with reduced number of defecations or reduced volume of feces alone. Likewise, we do not treat diarrhea with symptoms of "soft feces/watery stool" alone, unless "pain on defecation," "skin trouble around the anus due to watery feces," "high risk of infection to decubitus," and "heavy burden on caregivers due to frequent diaper change" are recognized.

How to Handle Constipation

Many family members of the patients tend to think that "a less frequent number of defecation/less fecal volume" means constipation. First, what condition is thought to be constipation that is necessary to treat should be explained to caregivers including families and home visit nurses. Particularly in patients receiving tube feeding, daily fecal volume sometimes decreases to around 40 g (usually 250 g/day). We need to make them understand that even if the frequency and volume of defecation decrease, it does not mean that "feces are retained in the intestine," since there is only small amount of feces.

It is also necessary to exclude the possibility of organic lesions, and to confirm that constipation is not induced by systemic diseases such as hypothyroidism or anticholinergic drugs as an adverse reaction.

< Treatment Policy >

a. Diet therapy

Instructions to eat diets rich in fiber and sufficient water should be given. We usually try on different types of enteral nutrition formulas nutrients or the concurrent use of other forms of nutrient in patients receiving tube feeding.

b. Drug therapy

Patients may have pain when there is no defecation for two to four days, though the defecation frequency differs widely between individuals. In that case, purgatives are often used. It is also useful to ask caregivers to record the patients' defecation cycle using a calendar. When using purgatives, the following points should be considered:

(1) Adjust the hardness of feces

In cases where hard feces are observed, the use of saline purgatives such as magnesium oxide (Maglax®) is effective to soften the feces. Softened feces moves faster in the intestine and a possible increase in the frequency of defecation is expected. Starting with saline purgatives is

recommended unless otherwise the patients have soft feces. When the saline purgatives fail to improve the symptom, consider using lubiprostone (Amitiza®), which improves the bowel movement by promoting water secretion into the intestine.

(2) Move the feces

In patients with abdominal bloating and poor bowel peristalsis, and when no defecation is observed after performing enema or disimpaction, irritant purgatives such as sennoside (Pursennid®) and sodium picosulfate (Laxoberon®) should be used. These irritant purgatives, however, are habit forming and often resulted in a dose increase. Therefore, other drugs (including pantethine (Pantosin®), mosapride citrate hydrate (Gasmotin®), and domperidone (Nauzelin®)) should be used concurrently, and continuous use should be avoided if possible.

When these treatments do not improve defecation, the following methods need to be taken because the patients' evacuation ability may be decreased due to the lack of urge to defecate or straining.

(3) Cause an urge to defecate

Sodium bicarbonate/anhydrous monobasic sodium phosphate (New Lecicarbon®) suppository (sodium hydrogen carbonate preparation) induces defecation by generating carbon dioxide gas in the rectum and causing colorectal distention. bisacodyl (Teleminsoft®) suppository also irritates the mucous membranes in the colon and increases bowel peristalsis, as well as causes defecation reflex by acting on the rectal mucosa.

(4) Put stress

In glycerin enema, glycerin injected into the colon increases bowel peristalsis with irritation by absorbing moisture. At the same time, it softens and moisturizes the feces, making defecation easier. Disimpaction should be used when enema does not cause defecation.

< When care that can provided is not sufficient >

In families where irregular defecation management is too difficult, care plans should be built so that the patients can defecate once to three times per week by enema or disimpaction performed by home visiting nurses. In that case, adjust the dose of saline purgatives to prevent too soft stools and administer sodium picosulfate hydrate (Laxoberon®) on the previous day of the visit before going to bed. If possible, use sodium bicarbonate/anhydrous monobasic sodium phosphate (New Lecicarbon®) suppository 30 minutes before the visit. Home visiting nurses take care of defecation management including enema and disimpaction.

How to Handle Diarrhea

First, organic lesions and inflammatory or drug-induced diarrhea should be excluded based on the patients' medical history, comorbidities, and physical findings. Diarrhea associated with malabsorption due to dyspepsia is commonly seen in elderly patients. Even in patients with soft stools, if sufficient care is available and there is no abdominal pain or skin trouble around the anus, treatment is unlikely needed. In contrast to patients with constipation, those with diarrhea may result in dehydration or electrolyte disturbances. Therefore, treatment policies should be determined based on the understanding of systemic conditions. Particular caution is required for elderly patients because they are easily dehydrated.

< Treatment policy >

Diets or enteral nutrition formulas should be reexamined in cases of functional diarrhea or digestion and absorption problems. Fasting, intake of water only, and easily digestible food are instructed according to the severity of the symptoms. For the intake of water, sports drinks are recommended to correct electrolyte abnormalities. Drip infusion is often needed when restricting the diet.

Many patients with mild symptoms are treated with lactobacillus preparations alone such as *Lactobacillus bifidus* (Biofermin[®]) and observed without further treatment. In cases where care ability is not adequate and frequent diaper change is difficult, loperamide hydrochloride (Lopemin[®]) should be used concurrently.

How to Handle Fecal Incontinence

Elderly people are prone to passive fecal incontinence (patients have no urge to defecate and have incontinence without noticing) due to functional decline in the internal anal sphincter. Fecal incontinence also occurs when a large amount of stools accumulated in the colon leak out.

< Treatment policy >

If there are organic causes such as inflammatory enteropathies, rectal prolapse, colorectal cancer, anal sphincter injuries, these causes should be treated first. Fecal incontinence due to functional decline in the internal anal sphincter often can successfully be treated by improving soft stools [adjusting purgatives, or with oral administration of polycarbophil calcium (Colonel[®]), loperamide hydrochloride (Lopemin[®])]. Passive incontinence can be improved by regularly emptying the colon using sodium bicarbonate • anhydrous monobasic sodium phosphate (New Lecicarbon[®]) suppository, enema, or disimpaction. When no improvement is obtained with these treatments, conservative therapies including biofeedback therapy at specialized facilities or retrograde continence enema should be considered as well as surgical therapy such as sacral nerve stimulation, anal sphincter reconstruction, and antegrade continence enema.

(Hideki Ito)

10. Decubitus

Various types of decubitus are seen in home-care settings. The decubitus are mainly taken care by home visiting nurses; however, physicians' cooperation is indispensable. In this article, main points in handling of decubitus will be described.

How Decubitus Form

Decubitus are called pressure ulcers. Skin problems are caused by external forces such as compression. It has been pointed out in recent researches that misalignment, tension, and shear are involved in forming decubitus. Also, decubitus formation means that the patients' resistance and care environment are not well balanced. When decubitus formed in residential patients, care environments should be reviewed in addition to the symptoms of the patients.

Patients with Higher Risk of Decubitus

Preventive intervention for patients with higher risk of decubitus is critical because a long period of time, large amount of effort and cost will be required for the treatment if decubitus are formed.

Ohura et al.¹⁾ have developed a scale focusing on the four points: self-sustainable ability to move unassisted, morbid bony prominence, edema, and articular contracture. Sanada et al.²⁾ have introduced Braden scale, which has the following subscales: sensory perception, skin moisture, activity, mobility, nutritional status, friction and shear. In the Clinical Protocol for Pressure Ulcer Management prepared by the Ministry of Health, Labour and Welfare (Annex Form 5), the following risk factors are mentioned: basic motor ability (position change on the bed, holding the sitting position), morbid bony prominence, edema, joint contracture, poor nutrition, wet skin.

In other words, many patients such as those who are bedridden and unable to move, with protrusion of the sacral bone or other bones, joint contractures, poor nutritional status, and continuously wet skin or wounds are at high risk of pressure ulcers. For these patients, it is required to take all possible measures to avoid decubitus, such as using body pressure redistributing devices before developing pressure ulcers.

Evaluation of Wounds

An important point is that the treatment should be determined after correctly evaluating the wounds. The Japan Society of Pressure Ulcers published DESIGN as a new pressure ulcer assessment tool in 2002, and also DESIGN-R in 2008 as a follow-up tool (**Table**). In this tool, all pressure ulcers are assessed for the following points: D (depth), E (exudate), S (size), I (inflammation/infection), G (granulation tissue), N (necrotic tissue). When pockets are formed, P (Pocket forming) should be added.

Deep pressure ulcers take the following clinical course to healing: acute stage (formation stage), inflammation stage, granulation tissue formation stage, and skin formation stage. These stages correspond to the categorization by the colors black, yellow, red, and white that had been frequently used. However, in such categorization, handling of pressure ulcers in the transient states between the stages was dependent on subjective observation. Thus it was decided that standardized descriptions of pressure ulcers should be used based on DESIGN instead of the categorization by disease stage. Using this DESIGN categorization, even shallow ulcers can be described without any problem.

Treatment of Pressure Ulcers

A. Basic Treatment Policy

Formation of decubitus means that the patients' state and the method and amount of care are not well balanced. The most important strategy in treating pressure ulcers is to remove the causes and recover the balance.

a. Treatable ulcers or not

Most deep pressure ulcers in patients in the terminal stage of cancer do not result in cure. Treatment of the ulcers in patients who are unable to turn over in bed due to senility is also difficult. Home care physicians are required to make a decision to treat or not to treat.

b. As far as in the treatable range

Home care patients and their families have various problems under different circumstances in addition to diseases. There can be improvable and unimprovable areas in the patients' states, care by the families, economical issues, and nursing or caring interventions. In order to solve the problems, we should do what is possible one at a time.

B. Use of Pressure Redistribution Devices (Mattresses)

The use of mattresses shows promising evidence among other preventive measures. Pressure redistribution devices have roughly four categories.

Various materials are used for the pressure redistribution mattresses including urethane, gel, water, and air. The point is, however, whether the softness of the mattress can be changed or not (variable type or static type), and whether it is easy for the patients to take a sitting position.

Variable types are mostly air-mattresses and have an automatic adjustment function. Urethane is commonly used for static types, but hybrid types of gel and air have been increasing recently.

The function of balancing the body pressure is better in the variable type, and thicker mattresses. When the function is too strong, however, patients are "buried" in the mattress and less able to move by themselves, such as rolling over on the bed. Influence on rehabilitation should be taken into consideration. Thus, selection of a suitable mattress should be made based on whether it allows patients to roll over and whether the head of the bed is raised or not (**Figure**). Recently, air mattresses are increasingly used even in patients undergoing rehabilitation because some of these mattresses use urethane at their edges and are stable for sitting.

Thicker mattresses are needed as the head of the bed is raised higher. Each patient's lifestyle should be reviewed and also consultation with a guidance officer for welfare aids should be sought.

Table. DESIGN-R for Assessment of the Clinical Course of Pressure Ulcers

Depth: This should be measured at the deepest point of the wound. If the wound becomes shallower, the decreased depth should be reflected in the assessment.					
d	0	No particular skin lesion and no redness	D	3	Lesion extends into the subcutaneous tissue
	1	Persistent redness		4	Lesion extends exceeding the subcutaneous tissue
	2	Lesion extends into dermis		5	Lesion extends into the articular or body cavity
				U	It is impossible to measure the depth
Exudate					
e	0	None	E	6	Heavy: requires dressing change more than twice a day
	1	Slight: does not require daily dressing change			
	3	Moderate: requires daily dressing change			
Size: Measure the area of a skin injury [longest wound length (cm) × the longest wound width perpendicular to this axis (cm)].*2					
s	0	None	S	15	100 or larger
	3	Smaller than 4			
	6	4 or larger but smaller than 16			
	8	16 or larger but smaller than 36			
	9	36 or larger but smaller than 64			
	12	64 or larger but smaller than 100			
Inflammation/Infection					
i	0	None	I	3	Clear signs of local infection (e.g., inflammation, pus and foul smell)
	1	Signs of local inflammation (fever, redness, swelling, and pain)		9	Systemic impact, such as fever
Granulation					
g	0	Granulation cannot be assessed because the wound is healed or too shallow	G	4	Healthy granulation tissue occupies 10% or more, but less than 50%
	1	Healthy granulation tissue occupies 90% or more		5	Healthy granulation tissue occupies less than 10%
	3	Healthy granulation tissue occupies 50% or more, but less than 90%		6	No healthy granulation tissue exists
Necrotic tissue: when necrotic and non-necrotic tissues are mixed, the dominating condition should be used for assessment					
n	0	None	N	3	Soft necrotic tissue exists
				6	Hard and thick necrotic tissue is attached to the wound
Pocket: the area obtained by subtracting the ulcer area from the entire pocket (including the ulcer) [major axis (cm) × minor axis *1 (cm)] in the determined position					
p	0	None	P	6	Smaller than 4
				9	4 or larger, but smaller than 16
				12	16 or larger, but smaller than 36
				24	36 or larger

*1: “Minor axis” is the longest wound measurement perpendicular to the longest wound length.

*2: Continued redness should be assessed according to skin injury.

(Taken from the Japanese Society of Pressure Ulcers Website: <http://www.jspu.org/jpn/info/design.html>)

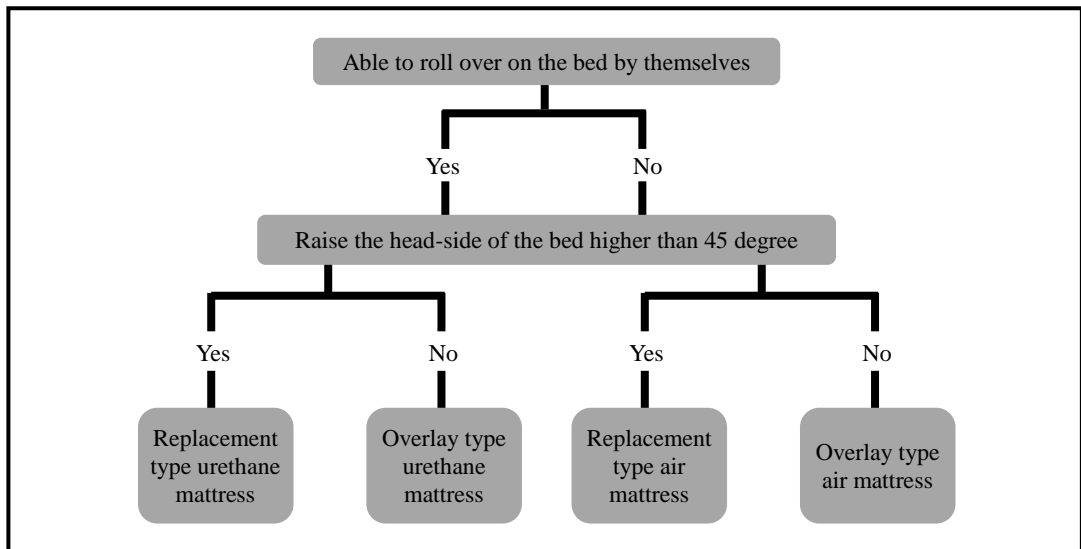
C. Nutritional Intervention

Most residential patients with pressure ulcers have malnutrition. Tube feeding should be considered in patients with no gastrointestinal absorption problem. When making decisions, the state and intension of the patients, wishes of the families need to be taken into consideration.

Nutritional balance has to be re-examined for efficient oral intake. Intake of 30 kcal/kg is said to be required for carbohydrates. If the serum albumin level is 2.5 g/dL or lower, consider ways to supplement protein. Trace elements such as zinc and copper are also necessary as well as vitamin C. However, it is not easy for patients with limited oral intake to take necessary nutrients through meals alone. In such cases, concurrently use appropriate dietary supplements according to the purpose including semi-solid nutrients such as Ensure liquid® and Racol® or ENEVO®, which contains more trace elements and is easily absorbed though low nutrients or V CRESC α®.

Oral care is also important in patients with swallowing problems. Effective oral care can reduce aspiration and choking, thus increase the amount of food intake.

Figure. How to Choose the Best Pressure Redistribution Device (Mattress)



D. Local Therapy

a. Basic strategy in local therapy

Three basic strategies are “keeping the wounds in a moist environment,” “removal of exudate and necrotic matters,” and “cleaning rather than sterilization.”

It has already been reported in the “Guideline for Prevention and Management of Pressure Ulcers” in 1998 that wound healing is accelerated by keeping the wounds moist, not dry, and delayed by sterilization. When being dried, the wounds will not be healed until an appropriate moist environment is created under the dried crusts. Surface cells are dried out and necrotized, making the wounds deeper.

b. The pros and cons of antiseptic drugs

Basically, antiseptics damage tissues. Avoiding the use of antiseptics has already become a general rule in pressure ulcer treatment aiming to regenerate tissues as much as possible.

Also, when directly applying to the wounds for a short period of time, the antimicrobial drugs do not fully penetrate into the deep layer of the wounds against the exudate. Local infection treatment such as debridement or drainage should be considered as well as systemic administration of antimicrobial drugs if the wounds fester and the patients develop fever.

c. Types and use of treatment materials

(1) Wound dressing (dressing materials)

Since the 2012 revision of medical service fees, wound dressings have been allowed to use for more than three weeks in home-care settings for deep pressure ulcers that extend to dermis.

(a) Polyurethane film

This is a thin plastic film. Sterilized films are used to fix the IVH; however, unsterilized films can be used for pressure ulcers because no sterilization is needed. Simply applying the film to the wound is effective in stage I ulcers. The films are used also for deeper stage ulcers as a secondary dressing material.

(b) Hydrocolloid dressing

One of the most commonly used dressing materials. Recently, however, the use of hydrocolloid for deep ulcers is decreasing because it hampers wound surface observation during the use, and it generates odiferous pus-like dissolved materials, making bed sheets or underwear dirty. On the other hand, it is commonly used for shallow pressure ulcers. Hydrocolloid is not suitable in the stages of heavy exudate, to infection wounds, and black phase ulcers.

(c) Alginate dressing

This dressing has hemostatic and infection inhibitory actions in addition to exudate absorbing action and is cotton-like in appearance. Alginate dressing is mainly used for hemostatic purposes; however, this dressing needs secondary dressings. Kaltostat[®], Sorbsan[®], etc. are included in this category.

(d) Polyurethane foam

Due to its high absorption and three-layer structure, this dressing leaves no residuals on the wounds, prevents external infections and contaminations, keeps an appropriate moist environment, and is well cushioned. This dressing does not autolyze. Recent widely used are the ones with antimicrobial action, containing Ag. Products using silicone gels on the patching surface can be re-attached to the wounds after being detached to check the wounds. Hydrosite Gentle Ag[®], Aquacell Ag Foam[®], Hydrosite Life[®], etc. are included in this category.

(e) Open wet dressing therapy³⁾

This is a method proposed by Toriyabe. Paper diapers wrapped with perforated polyethylene are used as a dressing to treat pressure ulcers. This is almost similar to therapeutic dressings in terms of keeping the wounds moist, absorbing excessive exudate from the wounds, and preventing adhesion of the wound and the dressing. This dressing is marketed as Moiskin Pads[®].

(2) External preparation

(a) Topical products for infection inhibition

Sulfadiazine silver (Geben Cream[®]) is unlikely to develop drug-resistant strains and is effective against fungi. This cream is suitable for treatment of dried wounds since its moisture content is relatively high.

Iodine sugar should be used for treatment of infected wounds or wounds at risk of infection. Put a sufficient amount on a thin gauze and apply it to the wounds. After that, apply a secondary dressing using polyurethane film as it easily becomes sticky and melts at body temperature.

(b) Drugs to promote epithelialization and granulation

Trafermin (Fiblast Spray[®]), a fibroblast proliferation-stimulating factor, can be used in the phase of granulation. This spray promotes granulation and epithelialization. When no improvement is obtained, caution must be required to avoid long-term use as this is an expensive drug. It has been reported that aluminum chlorohydroxyallantoinate (Isalopan[®]) and tretinoin tocoferil (Olcenon Ointment[®]) promote granulation.⁴⁾ In addition, there are some preparations to

promote skin formation, such as bucladesine sodium (Actosin Ointment[®]) and alprostadil alfadex (Prostandin Ointment[®]).

Handling of Pockets

Deep pressure ulcers often form pockets. The healing often takes time since exudate and necrotic matters are trapped within these pockets. Frequent cleaning is required in the first place. The aforementioned Fiblast Spray[®] should be concurrently used (it helps to fill the pockets with granulation tissue, and the pockets may disappear). Also in some cases, these pockets are laid open with local anesthesia to promote removal of necrotic matters.

It has been reported that the healing was accelerated by providing negative pressure to the wounds using vacuum-assisted closure therapy; however, it is difficult to perform at home in the medical service fee system.

(Hiroshi Suzuki)

References

- 1) 大浦武彦：褥瘡のトータルケア。メディカルトリビューン，22，2003。Takehiko Ohura: *Total Care of Pressure Ulcers*, Medical Tribune, 22, 2003
- 2) 真田弘美：褥瘡発生を予測する。褥瘡の予防・治療ガイドライン付録 / 褥瘡予防・治療指針策定のための研究報告書。照林社，9，1998。Hiromi Sanada: Prediction of pressure ulcers. Annex to the pressure ulcer prevention and treatment guideline/Study report for the development of the pressure ulcer prevention and treatment guideline. Shorinsha, 9, 1998.
- 3) 鳥谷部俊一：これでわかった褥瘡のラップ療法 一部位別処置事例集。三輪書店，2007。Shunichi Toriyabe: Understand the Wrapping Therapy of Pressure Ulcers—Case studies by site. MIWA-SHOTEN, 2007.

II. Acute-phase Issues in Home Medical Care

1. Pneumonia

With the arrival of a super-graying society, pneumonia has become the third leading cause of death among Japanese people, surpassing stroke. Clinical Practice Guidelines for Nursing- and Healthcare-associated Pneumonia (NHCAP)¹⁾ was prepared in 2011. Most cases seen in home care patients are NHCAP with underlying aspiration pneumonia. Among acute diseases accompanied by fever in elderly residential patients, pneumonia occupies the largest part²⁾ (45.0%), tends to increase in severity, often becomes fatal. It is an important disease for home care physicians.

Pathogenesis of Pneumonia in Elderly Residential Patients

The true character of pneumonia in elderly residential patients is aspiration pneumonia due to silent aspiration with no clear aspiration episode. The main underlying cause is stroke. One third of patients with a history of stroke develop pneumonia. In particular, lacunar infarction in the basal ganglia region that is commonly seen in Japanese people, results in a higher rate of aspiration pneumonia.³⁾ This is because dopamine metabolism is impaired due to the infarction in the basal ganglia, the ganglionic substance P of the pneumogastric and glossopharyngeal nerves is reduced and thus swallowing and cough reflexes are disturbed. The decrease in the swallowing reflex due to the impaired dopamine metabolism is observed in patients with Alzheimer's type dementia or Parkinson's disease.

Pneumonia is developed when the patients' ability to defend against infection is reduced such as airway clearance, or the patients have a compromised systemic condition, nutritional status and immune function, or aspirate many pathogens at a time in addition to these diseases.

Diagnosis of Pneumonia in Home-care Settings

Typical symptoms of pneumonia such as coughs and sputum are not frequently observed in elderly patients with pneumonia. Instead, atypical symptoms including "somehow out of sorts," "impaired appetite," "delirium," "standing and walking difficulty," and "incontinence" are observed. Although afebrile pneumonia was said to be common in elderly people, most cases are accompanied by fever. When vague symptoms expressed as "somehow" and continuous fever are observed, pneumonia should primarily be suspected.

In some elderly patients with aspiration pneumonia, continuous rales including rhonchi, wheeze, and squeaky sound are demonstrated in addition to coarse crackles in physical examinations. There are no specific findings on auscultation; however, usually large discontinuous rales are heard from the beginning of inspiration at the onset of pneumonia. Discontinuous rales are heard at the lesions in the later phase of inspiration during recovery, and the sound becomes less audible according to the degree of recovery.

Leukocyte classification must be conducted to check a left shift because an increase in WBC count is not always observed in elderly patients with pneumonia. CRP levels can be used for rapid diagnosis and measured easily. When high levels are measured, further examinations should carefully be continued as bacterial infection is strongly suspected. Also, CRP levels can be used as a treatment index by tracking the changes over time. However, CRP values right after the onset, especially those on Disease Day 1 should not be used for the evaluation because the production of CRP in the liver begins four to six hours after the onset of inflammation. CRP levels will increase two fold every eight hours and reach the peak in 24 to 48 hours.

In elderly patients with pneumonia, empiric therapy should be preferentially selected since the bacteriological examination of sputum provides only a limited result. The positivity rate in blood cultures is also low. Thus there is no need to routinize blood cultures for community-acquired pneumonia with no complication. On the other hand, urinary antigens of pneumococcus increase from the early stage of the disease; it can be measured right after making the diagnosis.

Measurement of percutaneous oxygen saturation (SpO₂) is important to decide whether hospitalization is needed or not. Arterial blood should be taken when SpO₂ measurement is not available.

Chest radiography is legally possible in home-care settings. Caution must be required that in elderly patients, it is impossible to determine the severity of pneumonia based only on the size of infiltrative shadows because when these patients have dehydration, shadows are not always recognized. Also there are scanning problems such as anteroposterior views or incomplete breath holding. Do not excessively trust X-rays in making the diagnosis of pneumonia. Purposes of chest radiography in home-care settings are mainly to confirm pneumonitis, differentiate tuberculosis, and examine a complication of lung cancer. As protective measures against stray radiation in home-care settings, instructions need to be given to family members that they should stay away for more than 3 m and, if possible, evacuate behind clay walls.

Hospitalization Criteria

NHCAP Guideline categorizes the treatment as follows: A (Patients for whom outpatient treatment is appropriate), B (Patients who are determined to require inpatient treatment and have no risk factors for involvement by drug-resistant pathogens), C (Patients who are determined to require inpatient treatment and have a risk of involvement by drug-resistant pathogens), D (Patients whose condition is considered severe enough to require intensive care in an intensive care unit [ICU] or mechanical ventilation, or both) (**Figure**). However, decision on hospitalization should be comprehensively made by physicians based not only on the severity, but also on wishes of the patients and families, restrictions on home care services and care ability.

Prevention of Pneumonia

Pneumonia in elderly people is caused by structural problems. Antimicrobial agents cannot prevent death from pneumonia in elderly people. Comprehensive preventive care is more important than the use of antimicrobial agents for managing pneumonia in elderly people.

A. Detection of and Preventive Measures against Aspiration

Preventive measures should be taken for patients with basal ganglia infarction since they are at higher risk of aspiration pneumonia.

When it is difficult to perform video fluoroscopy (VF) or video endoscopy (VE), bedside assessment helps to make an assessment. Simple swallowing provocation test (S-SPT) is most effective (refer to pages 77–78).

B. Prevention of Stroke

Prevention of stroke plays an important role in preventing pneumonia in elderly people in home-care settings. Prevention of dehydration and the use of antiplatelets and anticoagulants are effective in preventing the recurrence of stroke.

C. Oral Care

In elderly patients receiving home care, infecting bacteria are intraoral indigenous bacteria. Therefore, infection can directly be prevented by reducing the number of bacteria aspirated. The incidence of pneumonia in elderly people can be markedly reduced by providing complete oral care.¹⁾ In particular, oral care before bedtime is most effective in preventing pneumonia as silent aspiration often occurs during sleep at night. Sleep in Fowler's position is also effective in preventing reflux of stomach content, reducing silent aspiration and preventing pneumonia.

D. Drug Therapy

It has been considered that ACE inhibitors (one-half of the usual dose) and amantadine hydrochloride are effective in preventing aspiration pneumonia in elderly people by increasing the substance P level in the laryngopharynx and promoting swallowing and coughing reflexes. However, in completely bedridden patients, no clear evidence has been reported. On the contrary, it has been said that the easy use of antitussive drugs for chronic coughing can increase aspiration.

E. Improvement of Malnutrition

Patients in malnutrition status are prone to develop diseases and slower in recovery due to compromised immune function. It is estimated that 30% to 40% of residential patients are in malfunction status. Nutrition formula should be carefully considered based on nutritional evaluation for every patient.

F. Treatment of Underlying Diseases

Underlying diseases such as diabetes should be fully managed.

G. Vaccination

Cellular immunity is reduced in elderly patients; however, humoral immunity is maintained. Thus influenza and pneumococcal vaccination are effective.

H. Management of Tube Feeding

Nasogastric tube feeding in bedridden patients clearly increases the frequency of pneumonia. Also some patients with PEG develop refractory pneumonia due to reflux of nutrients. Slowing the feeding rate or administration of Rikkunshito may be effective in these cases. When there are frequent refluxes even after taking these measures, the use of half-solid nutrients can reduce the frequency.

Treatment of Pneumonia

A. Perspectives from Empiric Therapy

Infecting bacteria assumed in NHCAP when there is no risk of drug-resistant pathogens are pneumococcus, MSSA, gram-negative enterobacteria (*Klebsiella*, *Escherichia coli*), *Hemophilus influenzae*, intra-oral streptococcus, and atypical pathogens (particularly *Chlamydophila* spp). While drug-resistant strains are isolated in around 20% of the patients, the frequency varies by region and institution. In addition to these bacteria, *P. aeruginosa*, MRSA, *Acinetobacter* spp, ESBL-producing enterobacteria are also assumed in patients at risk of drug-resistant pathogens, such as the use of broad spectrum antibacterial agents within the past three months or tube feeding.

Unlike in cases of community-acquired pneumonia, there is no need to suspect atypical pneumonia such as *M. pneumoniae* in patients with NHCAP. However, *C. pneumoniae* can be an infecting bacterium in elderly patients causing a mixed infection with other bacteria.

B. Practical Treatment

An appropriate treatment method for residential patients with pneumonia should be chosen comprehensively considering the risk of involvement of drug-resistant pathogens, available

home care services, physical conditions of the patients including swallowing ability and renal function.

Internal antimicrobial agents should be used for Treatment category A, where patients have no history of pneumonia within the past three months and tube feeding, no overt aspiration and with adequate oral intake. Penicillin-based agents or new quinolones are recommended, however, the length of these drugs is generally 10 mm or longer. Garenoxacin (Geninax[®]) and levofloxacin hydrate (Levofloxacin[®]) granular tablets are relatively small and easy to take for elderly patients with swallowing problems to take.

For patients with limited oral intake and no history of using broad spectrum antibacterial agents within the past three months or tube feeding (Treatment category B), single daily intravenous administration or drip of antimicrobial agents should be chosen. Ceftriaxone: CTRX (Rocephin[®]) has long half-life. It can be effective with single daily administration and used in residential patients with renal disorders. LVFX injection can be administered once daily, by intravenous drip infusion. As these agents are not effective against anaerobes, administration of ampicillin–sulbactam; SBT/ABPC (Unasyn-S[®]) twice daily should be considered when the involvement of anaerobes is suspected.

For patients in Treatment category C, where risk factors of drug-resistant pathogens (history of using broad spectrum antibacterial agents within the past three months or tube feeding) exist, broad spectrum antibacterial agents effective for drug-resistant strains should be used from the beginning. Treatment at home is possible if twice daily injections are possible.

Antipseudomonal cepheps including CFPM (Maxipime[®]) or CPR (Broact[®]) should be used by intravenous administration twice daily. As these drugs have limited effect on anaerobes, clindamycin; CLD (Dalacin[®]) should be used in combination, or antipseudomonal carbapenem should be chosen from the beginning if necessary.

For whom securing intravenous lines is difficult, intramuscular injection of imipenem hydrate/cilastatin sodium (Tienam[®]) twice daily or subcutaneous transfusion of CTRX or CFPM may be considered.

When providing treatment aiming to cure patients in Treatment category D, where intensive care including mechanical ventilation is needed, it should be performed in the hospital setting.

C. Handling of Refractory Pneumonia

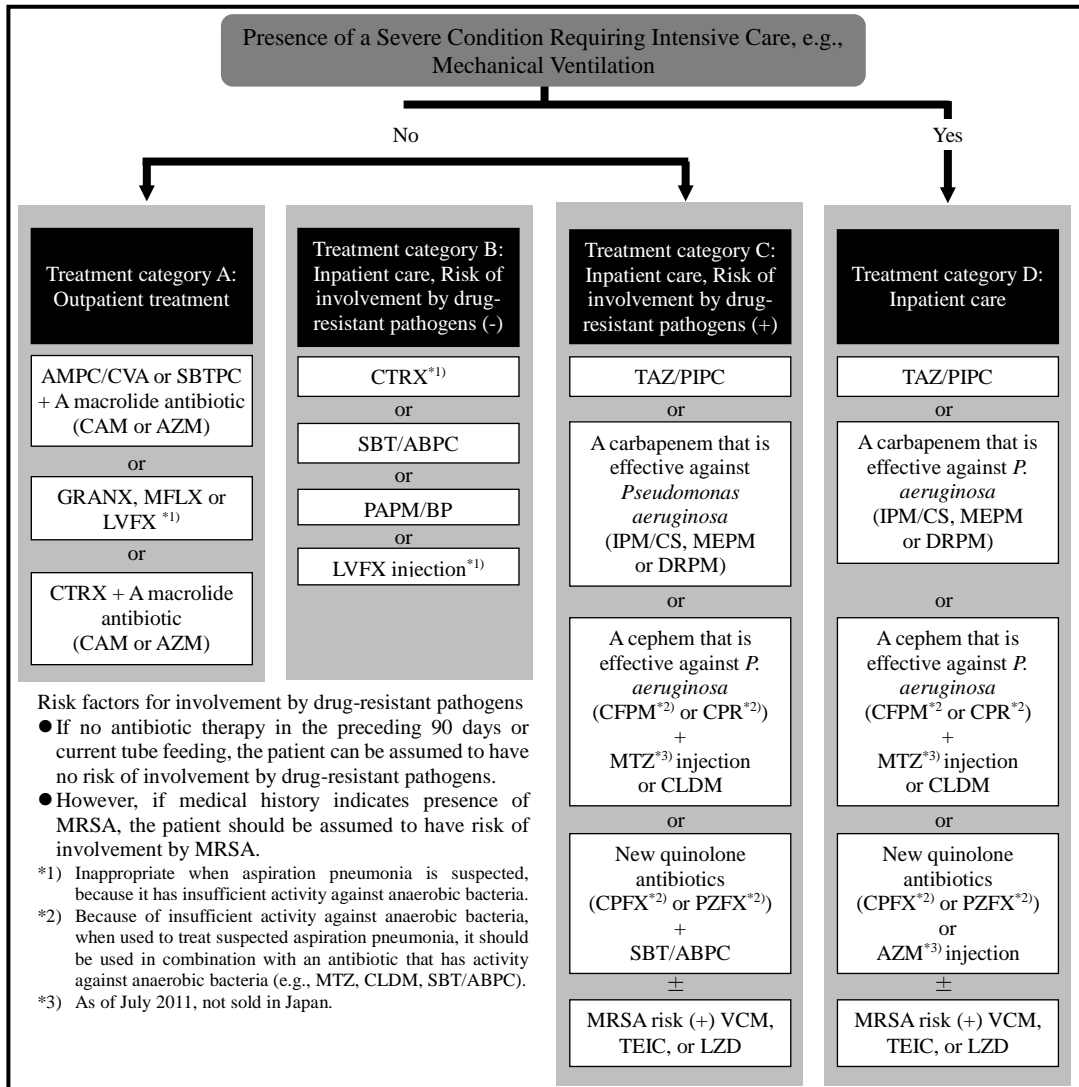
When patients show no response to these empiric therapies and infecting bacteria are not identified or have a relapse of pneumonia after responding to these therapies, consider the possibility of continuous aspiration (silent), infection with drug-resistance strains (MRSA, multi-drug resistant *P. aeruginosa*), infection with acid-fast bacteria or fungi, obstructive pneumonia or tumor fever due to lung cancer, pneumonia hypersensitivity or BOOP, and interstitial pneumonia.

In order to differentiate these possibilities, portable radiography, blood tests (nutritional status assessment, tumor marker, KL-6, β -D-glucan, and QFT) and sputum tests (general bacterial culture and acid-fast bacteria smear, culture, and PCR) are required. If possible, plain CT scanning can be of great help in making the diagnosis. However, hospitalization is preferable.

Limitations in the Treatment of Elderly Patients with Pneumonia

Pneumonia in elderly people in home-care settings is clearly different from community-acquired pneumonia in the aspect that it is not necessarily caused by pathogens but is developed as a systemic disease of their hosts. When the condition of an individual host becomes irreversible, pneumonia is no longer curable. It is true that pneumonia in elderly residential patients is not always treatable. Even for experienced home care physicians, it is not easy to assess how much improvement can be expected and determine the right moment to start palliative care.

Figure. Algorithm of Pneumonia Treatment



AMPC/CVA: amoxicillin/clavulanic acid; SBTPC: sultamicillin; CAM: clarithromycin; AZM: azithromycin; GRNX: garenoxacin; MFLX: moxifloxacin; LVFX: levofloxacin; CTRX: ceftriaxone; SBT/ABPC: sulbactam/ampicillin; PAPM/BP: panipenem/betamipron; TAZ/PIPC: tazobactam/piperacillin; IPM/CS: imipenem/cilastatin; MEPM: meropenem; DRPM: doripenem; CFPM: cefepim; CPR: ceftiprome; MTZ: metronidazole; CLDM: clindamycin; CPF^{*}: ciprofloxacin; PZF^{*}: pazufloxacin; VCM: vancomycin; TEIC: teicoplanin; LZD: linezolid.
Taken from References 1).

(Satoshi Hirahara)

References

- 1) 日本呼吸器学会：医療・介護関連肺炎（NHCA）診療ガイドライン。2011。The Japanese Respiratory Society: Clinical Practice Guidelines for Nursing- and Healthcare-associated Pneumonia (NHCA) 2011.
- 2) Yokobayashi K, et al: Prospective cohort study of fever incidence and risk in elderly persons living at home. BMJ Open 2014, e004998.
- 3) Nakagawa T, et al: High incidence of pneumonia in elderly patients with basal ganglia infarction. Archives of Internal Medicine 157(3): 321-324, 1997.
- 4) Yoneyama T, et al: Oral care and pneumonia. Lancet 354: 515, 1999.

2. Dehydration and Electrolyte Management

Patients receiving home medical care are often unable to complain about their symptoms. Even when their clinical condition appears stable, they can easily develop dehydration or an electrolyte abnormality, by heat stroke during the summer season or because of heaters, unbalanced fluid intake, or excretory disorders. It is important to make decisions considering the patients' situation, histories, and physiological findings based on the understanding of the clinical condition.

Dehydration Assessment

In home-care settings, medical workers are able to witness and understand the patients' living environment. It is more important than any examinations for us to observe the patients' circumstances, including diet and fluid intake status, relationship with their family, personality, and air-conditioning system. On the other hand, it is often difficult to quickly conduct various examinations that are generally useful in making a diagnosis. Thus, available examinations need to be combined in an effective manner. Symptoms alone are not sufficient for diagnosing electrolyte abnormality. Blood tests are needed to make the diagnosis; however, we do not have time to outsource the tests to external laboratories. It is recommended to bring a portable type blood gas analyzer to the patients' home to examine venous blood, as many of the analyzers are capable of analyzing electrolytes (refer to pages 38–42). For examining the water balance, in the body at home, observation of the IVC, heart, and urinary system using ultrasonography devices is useful.

It is relatively difficult to figure out an appropriate water balance for elderly patients, because the fluid allowance widely varies by patient, depending on the underlying diseases and living environment. Indoor heat stroke is commonly observed in elderly people (**Figure**). It is necessary to decide criteria for water balance using the most stable status as the benchmark.

Figure. Categorization Recommended by the Japanese Association for Acute Medicine, “Committee on Heatstroke”

	Symptom	Severity	Treatment
Stage I (First-aid treatment and observation)	Vertigo, dizziness on standing up, slight yawn, Drenching sweats, muscle pain, Stiffness of the muscle (cramps in the calves), no impairment of consciousness (JCS = 0)		Usually treatable at site → rest in a cool place, cooling the body surface, oral intake of water and sodium.
Stage II (Refer to medical institutions)	Headaches, Vomiting, Malaise, Feeling of weakness, Concentration/ judgement impaired (JCS ≤1)		Treatment at medical institution is required → Body temperature management, rest, intake of sufficient amount of water and sodium (by drip infusion when oral intake is difficult)
Stage III (Hospitalization)	Either one of the following three: (C) Central nervous symptoms (impairment of consciousness JCS ≥2, cerebellar symptoms, seizures) (H/K) Hepatic/ renal dysfunction (hepatic or renal disorders requiring hospitalized observation, hospitalized treatment) (D) Coagulopathy (The diagnostic criteria of acute DIC [the Japanese Association of Acute Medicine] are met)→Severer in the stage III		Hospitalized treatment (intensive treatment in some cases) is required → body temperature management (cooling of the inside of the body, vascular hypothermia in addition to cooling of the body surface), breathing, circulatory management, DIC treatment

First-aid treatment and observation are sufficient only when Stage I symptoms are showing gradual improvement.

Immediately transfer the patient to the hospital when Stage II symptoms are observed or Stage I symptoms are not improved. (Judged by people around the patient)

Whether the symptoms are Stage III or not will be determined by emergency staff or hospital staff after hospitalization.

(Revised from the Japanese Association for Acute Medicine: Clinical Practice of Heatstroke 2015)

Electrolyte Abnormality

(1) NaCl

Hypnatremia is commonly seen in patients in home-care settings. The causes include insufficient salt intake, chronic hyperglycemia, heat stroke, diuretic agents, and excessive water intake. Because of the lower levels of NaCl contained in the nutrients of many tube feedings, particular caution is required for patients receiving only tube feeding. Hypernatremia is caused by insufficient water intake, excessive intake of salt, endocrine abnormality, and administration of excess extracellular fluid.

Abnormal levels of Na are often accompanied by fever. Particularly in cases of fever with no inflammation, Na abnormality should be suspected. In any case, estimating the possible cause by obtaining information on medical history and understanding the systemic condition of the patients by physical examination are critical. Methods to correct Na levels are the same as in outpatient and hospitalized treatments. However, abnormal blood Na levels are often caused by problems in the living environment or some pathological conditions. Therefore, simple transfusions to correct the levels are not sufficient from the perspective of home medical care. In cases of large amount of vomiting or upper gastrointestinal tract drainage, correction by saline transfusions is needed as hypochloremic alkalosis is likely caused. Patients with diabetes insipidus sometimes demonstrate abnormal blood Na levels with no causal condition or disease. In such cases, intake of salt should be encouraged and NaCl should be orally administered.

(2) K

Hypokalemia is likely caused by dehydration due to diarrhea, diuretic agents, and insufficient K intake. Treatment may include correction of K levels after removing these causes; however, monitoring with frequent blood drawing is not easy in home-care settings. Correction of the level needs to be carefully performed. Observations may be recommended and could be sufficient if the symptoms are mild.

Hyperkalemia is caused by renal failure, gastrointestinal bleeding, and, in rare cases, by excessive intake of K due to transfusions or drugs. If hyperkalemia is severe, immediate correction using transfusions containing no K and diuretics is required. If effective correction is difficult, emergency transportation to the hospital should be considered. In cases of gastrointestinal bleeding without hematemesis and melena, gastrointestinal drainage with a stomach tube and purgatives is effective.

(3) Ca

Hypocalcemia is caused by endocrine disorders, drugs, vitamin D deficiency, pancreatitis, and renal dysfunction. In rare cases, it is caused by Mg deficiency and hyperphosphatemia. Hypocalcemia causes tetany in severe cases; however, it often causes no symptoms in mild cases. Administration of Ca preparations to patients with hypocalcemia is not effective, because 99% of human body Ca is in the bones and balanced by parathyroid hormones and vitamin D, together with PO₄.

Hypercalcemia is more likely caused by bone metastases of malignant tumors or PTH-like hormone-secreting tumors compared to endocrine disorders. In rare cases, it is caused by vitamin D intoxication, granulomatous diseases, or drugs. It cannot be evaluated using blood Ca values alone. The evaluation needs to be corrected by blood albumin levels.

Corrected Ca value (mg/dL)

= Measured Ca value (mg/dL) + {4.0 – blood albumin level (g/dL)}

Patients with high Ca values often demonstrate severe gastrointestinal and psychiatric symptoms accompanied by severe dehydration and acidosis. When acute psychiatric symptoms, gastrointestinal symptoms or dehydration are observed in patients with malignant tumors, a differential diagnosis must be made. In home-care settings, too, hypercalcemia requires immediate treatment. Delay in providing appropriate treatment could result in pain and often be fatal. First, administer adequate transfusion and furosemide, then steroids, bisphosphonates, or calcitonin preparations. In patients with hypercalcemia due to bone tumors including metastatic tumors, caution needs to be required for pathological fractures.

(Keigo Yasukawa)

3. Falls and Fractures

Elderly people are more prone to fractures, even in conditions of mild trauma, such as falls. It is important to prevent them from being bedridden by preventing trauma, such as falls, and providing appropriate treatments that do not immediately restrict their mobility. However, standard therapies are not always appropriate in some cases of pathological fracture. As being called “pathological,” it is different from ordinary fractures and caused by external forces that are usually too weak to fracture the bones. This article presents particularities in diagnosis and treatment of fractures in fragile elderly patients in need of care.

Prevention of Fractures

According to a survey of bedridden patients, they were often rendered bedridden because of fractures. Some have problems in their treatment course, such as inability to cooperate in the treatment due to dementia, or to start the postoperative treatment due to paralysis from cerebrovascular diseases. In some cases, the disorder remains despite surgical treatments and results in bedridden status. It can be said that in fragile elderly people, preventing fractures leads to the prevention of being bedridden.

Many epidemiological surveys have been conducted on fractures in elderly people. Among them, the Tokyo Metropolitan Institute of Gerontology has reported an interesting finding. According to the report, risk factors for falls include the followings: women, slower walking speed, and history of falls (multiple falls in a short period of time). A severe trauma including fractures occurs in one in 10 falls.

Strengthening the lower-limb muscles is effective for preventing fractures. It will improve the speed and stability during walking, and make the postural reflexes quicker. As a result, people will be less prone to fall. In some researches, it has been reported that they were less likely to have fractures even if they fell. However, the subjects in these studies were elderly people living an independent life. Risk of fractures is higher in fragile elderly patients receiving home medical care. They easily break their bones even due to slipping on the floor while trying to move from the bed to wheelchair, or from the wheelchair to toilet seat.

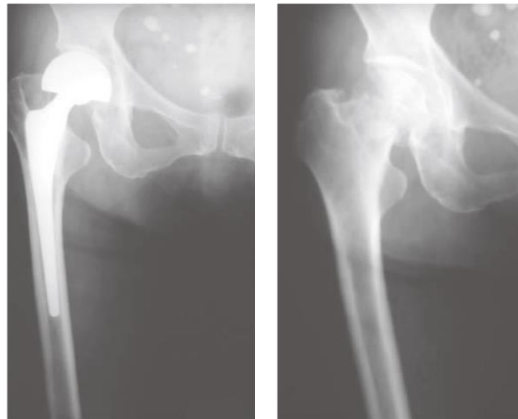
Drug therapy for osteoporosis is often thought to be effective in preventing fractures, though there has been no reliable data on the elderly aged 75 or over, and 85 or over in need of care.

Diagnosis of Fractures

Fractures should be suspected even in mild trauma, such as falls and falls on the bottom, when any motion limitation is observed in the limbs and there are localized swellings, inflammation and pain. Judging from the plain radiography immediately after the injury and making a correct diagnosis of compression fracture of the spine and fracture of the femoral neck, in which the neck is displaced into the bone head, are sometimes difficult even for experienced orthopedists (**Figure 1**). In some cases, fractures may not be detected at the time of injury. When symptoms like pain continue, these fractures are detected in X-ray images taken 2 or 3 weeks after the injury. Fractures will be clearer in the X-ray images over time. For instance, making the diagnosis of compression fracture of the spine becomes easier when the collapse begins.

Fractures should also be suspected when there is no clear mechanism of injury but patients suddenly stop walking, or complained pain during diaper changes. Malignant tumors sometimes are diagnosed, based on pathological fractures due to bone metastases.

Figure 1. Artificial Head Bone Replacement Operation (Left) and Overlooked Fracture of the Femoral Neck (Right)



Treatment of Fractures

Fractures can be conservatively treated as far as open fractures or bone dislocations are not involved. In general, the purpose of open treatment is to retrieve supporting function by anatomically reducing the fracture, and to shorten the period of rest after the surgery by achieving a stable internal fixation.

A. Fracture of the Femoral Neck

This is the first fracture to be suspected when elderly people fall. The site is anatomically prone to injury by a minor external force and takes time to achieve the bone union. Therefore, an artificial head bone replacement operation is recommended in medial femoral neck fractures. Experienced orthopedics can complete the operation in about 1 hour, and the patients can use a wheelchair in several postoperative days. Fixation with screws or intramedullary nails should be performed in patients with lateral or intertrochanteric fractures. In these cases, the bone union occurs faster compared to the medial femoral fractures. However, we do not think positive treatments of fractures are necessary in elderly patients receiving home care, as they are at higher risk in invasive treatments including anesthetics due to complications such as dementia or severe cardiac diseases. The bone union can be achieved in 2–3 months in most fractures. Although malunions are observed in many cases, these malunions do not result in substantial functional loss.

When it comes to the medial femoral neck fracture, even if the affected limb externally rotates and shortens, and then a false joint is formed, the patient can walk a short distance with support, with no strong pain. If the patient used a wheelchair before the injury, the ADL level can be maintained. Invasive treatments aiming at the anatomical reduction of the fractures do not have a significant meaning in patients who had walking difficulties before the injuries.

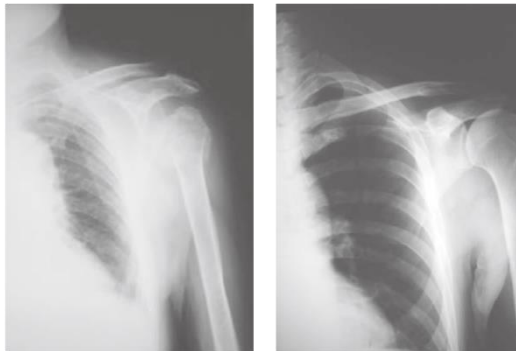
However, caution must be required for fat embolism syndrome, one of the severe complications of fractures for several days after the injury in bedridden patients. The syndrome is asymptomatic in most cases, but oxygen therapy may be needed in some cases.

B. Vertebral Compression Fracture

Vertebral compression fracture should be suspected first when the patients fall on the bottom. Textbooks say that it is generally treated by the external fixation of the trunk; however, we do not think that fracture treatment is necessary for fragile elderly patients. Instead, an effort should

be made to prevent the disuse syndrome by not restricting daily activities such as taking a bath or using a bathroom, avoiding too much bed rest with effective pain control.

Figure 2. Comparison of the Fractured Surgical Neck of the Humerus (Left) and Normal Humerus (Right)



C. Upper Limb Fractures

In addition to the abovementioned injuries, fractures of the surgical neck of the humerus (**Figure 2**) and wrist fractures are relatively common in elderly people. Most of these cases do not have indications for invasive treatments. In cases of humerus fracture, fixation with a sling should be used for about 3 weeks, and then pendulum exercises should be allowed as soon as possible. In cases of wrist fracture, the bone union can be expected by fixation of 4–6 weeks with a splint.

We have often experienced cases in which the patients develop anorexia resulting in dehydration or malnutrition due to nighttime restlessness or moodiness from uncomfortable plaster fixation. Although the fractures healed, the patients' QOL decreased in these cases. Physicians should be particularly careful in selecting an appropriate treatment of simple fractures in fragile elderly patients in need of care.

(Hideki Ohta)

4. Delirium

Delirium is a syndrome which is quite often seen in the home-care settings. Delirium is associated with a poor prognosis of physical diseases, increases the patients' and families' pain, and adversely affects decision making. It is an important task for home care workers to prevent and detect delirium, and make a quick intervention.

What is delirium?

Table 1 shows the diagnostic classification of delirium stated in the fifth edition of the *Diagnostic and Statistical Manual* of the American Psychiatric Association (DSM-5, 2013). In summary, delirium is described as “acute and fluctuating disturbances in awareness/cognition induced by physical diseases and intoxication.”

DSM-5 requires to identify whether the delirium is “acute (lasts for several hours or days)” or “continuous (lasts for several weeks or months),” “hyperactive,” “hypoactive,” or “mixed” type (**Table 2**) when making a diagnosis. In particular, caution is required for “hypoactive” delirium because it is often mistaken for depression or not recognized as delirium.

Although delirium is a separate syndrome from dementia, these two are often presented in combination, making the differentiation difficult. However, in some cases of delirium, severe underlying diseases are involved. Delirium often results in falls and fractures, too. It is always required to differentiate symptoms of dementia from delirium.

About 90% of cancer patients with only weeks to live are said to experience delirium. Of these delirium cases, it is difficult to improve “end-stage delirium,” which occurs 24–48 hours before death as a result of exacerbation of general condition. But it is supposedly possible to identify the cause of delirium in more than 90% of the patients expected to live about 6 months; thus it is therapeutically possible to treat.

Table 1. Diagnostic Criteria for Delirium (DSM-5)

- A. Disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and awareness (reduced orientation to the environment).
- B. The disturbance develops over a short period of time (usually a few hours to a few days), represents an acute change from baseline attention and awareness, and tends to fluctuate in severity during the course of a day.
- C. An additional disturbance in cognition (e.g., memory deficit, disorientation, language, visuospatial ability, or perception).
- D. The disturbances in Criteria A and C are not better explained by a pre-existing, established or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousal such as coma.
- E. There is evidence from the history, physical examination or laboratory findings that the disturbance is a direct physiological consequence of another medical condition, substance intoxication or withdrawal (i.e., due to a drug of abuse or to a medication), or exposure to a toxin, or is due to multiple etiologies.

Table 2. Classification of Delirium

Hyperactive delirium	Hypoactive delirium	Mixed delirium
Increased motor activity Loss of activity control Restlessness Wandering	Decreased motor activity/speed Reduced situational awareness Decreased speech Lethargy Hypoarousal, social withdrawal	These two symptoms are mixed in a day

Factors and Treatment of Delirium

Table 3 shows developing factors of delirium summarized based on the classification by Lipowski.¹⁾ As shown, the cause of delirium is multifactorial and difficult to differentiate. However, treatment and removal of the factors are needed in the definitive treatment and prevention of delirium. Treatment steps will be described in the followings.²⁾

Table 3. Development Factors for Delirium

<p>Direct factors: Factors which can cause delirium singularly</p> <ol style="list-style-type: none">(1) Intake of substances that act on the central nervous system (pharmaceutical products such as anticholinergic drugs/benzodiazepine anxiolytic/hypnotic drugs/steroid/opioid drugs, alcohol, stimulant drugs)(2) Withdrawal from addictive drugs(3) Central neurological diseases (cerebrovascular disorders, head injuries, cerebral tumors, infections)(4) Systemic diseases (sepsis, metabolic diseases including blood sugar abnormality/electrolyte abnormality/renal failure/hepatic failure/vitamin deficiency, endocrine diseases, circulatory diseases including myocardial infarction/heart failure, respiratory failure, hematological disorders including anemia/DIC, severe injuries and burns, malignant tumors)
<p>Facilitating factors: Factors which do not cause delirium alone but can cause in combination with other factors</p> <ol style="list-style-type: none">(1) Physical factors (pain, constipation, ischuria, dehydration, placement of drains, body restraints, impaired vision/ hearing)(2) Psychiatric factors (depression, anxiety)(3) Environmental change (hospitalization, relocation, luminous environment, noise)(4) Sleep disorders (insomnia, sleep rhythm disorders)
<p>Predisposing factors: Factors which can lead to delirium Age, cognitive disturbances, severe physical diseases, histories of head injury, histories of delirium, excessive consumption of alcohol</p>

A. Measures against Physical Factors

First, examine whether there is any “direct factor,” then “facilitating factor” involved. If yes, make an attempt to treat or remove these factors. Reviewing and reorganizing prescriptions is important, as delirium associated with the use of drugs is frequently seen. It is important to comprehensively and longitudinally understand the patients’ disease status, though information

necessary for diagnosis and available treatment methods are limited in home-care settings. Some patients may need to be treated in the hospital. As hospitalization is one of the “facilitating factors,” staying period in the hospital should be minimized, particularly for elderly patients with dementia, based on careful coordination with related institutes.

B. Environmental Coordination (Non-drug Therapy)

Environmental coordination should be carried out focusing on the “facilitating factors.” Effective coordination can be achieved when home care workers place themselves in the patients’ environment and also by careful collection of information on daily living and care programs. Prolonged delirium may result in hospitalization or giving up home care. On the other hand, though, we suppose that many home care workers have experienced cases in which treatment-resistant delirium lasted during the hospitalization was spontaneously resolved by returning home. In home-care settings, resolving anxieties or fatigue of the families or caregivers often reduces the patients’ anxieties or delirium. However, there are some patients who feel reassured in a palliative care ward, surrounded by professional workers ready to take care of them at any time.

As such, environmental coordination includes individual assessment of how people and environment surrounding the patients contribute to make them feel relieved, and providing options of places to stay. This assessment ability and how many options can be prepared are important as the core competence of the home care workers.

C. Drug Therapy

When sufficient improvement is not obtained with the abovementioned considerations and interventions, and the patients show severe psychomotor excitation, minimum drug therapy should be attempted.^{Note)} Do not consider adding new drugs until all the drugs used in the past are fully reviewed and reexamined. Preferably, therapy should start at one-half or one-fourth of the dosage indicated for adults and increase gradually. It should be decreased and discontinued as soon as improvement is recognized.

(Shiro Kitada)

References

- 1) Lipowski ZJ: Delirium: Acute confusional states. Oxford University Press, 1990.
- 2) 北田志郎：認知症患者に生じたせん妄や問題行動（BPSD）. In 日本家庭医療学会（編）：プライマリ・ケア救急，プリメド社，304-309，2007. Shiro Kitada: *Delirium and behavioral and psychological symptoms of dementia (BPSD) observed in patients with dementia*. Edited by the Japanese Academy of Family Medicine: Primary Care Emergency, PRIMED-SHA Co.,Ltd. 304-309, 2007.

Note) Tiapride is the only delirium treatment drug covered by the national insurance at the writing of this article. (According to the notification dated September 28, 2011 issued by the Director of Medical Economics Division, Health Insurance Bureau, Ministry of Health, Labour and Welfare, “Handling of unapproved indications of pharmaceutical products in the National Health Insurance program,” the four drugs, risperidone, haloperidol, quetiapine, and perospirone, are covered by the insurance if delirium is shown as the disease name. However, this notice does not approve the indication.) In addition, there have been reports on the use of antidepressants such as mianserin and trazodone, herbal preparations including Yi-Gan-San (抑肝散, Yokukansan), Gou-Teng-San (鈎藤散, Chotosan), and Huang-Lian-Jie-Du-Tang (黃連解毒湯, Orengedokuto). Indications must be carefully considered individually.

Chapter II References

I. Impaired Functioning and Home Medical Care

1. International Classification of Functioning, Disability, and Health and Rehabilitation
 - (1) 上田敏：ICF の理解と活用。萌文社，2013。 Satoshi Ueda: Understanding and utilization of ICF, Hobunsha Publishing Corporation, 2013.
 - (2) ICF コアセット 臨床実践のためのマニュアル。医歯薬出版，2015。 ICF Core Set -- Manual for clinical practice, Ishiyaku Pub. Inc., 2015.
2. Sarcopenia and Frailty
3. Dysphagia
4. Nutritional Assessment and Prescription
5. Dietary Support Needed in the Home Medical Care
6. Dementia
7. Motor Organ Dysfunctions (Orthopedic Diseases)
8. Dysuria
9. Bowel Problems
10. Decubitus

II. Acute-phase Issues in Home Medical Care

1. Pneumonia
 2. Dehydration and Electrolyte Management
 - (1) 曾我幸弘：看護・介護の現場で役立つ すぐ引ける救急辞典。成美堂出版，2007。
Yukihiro Soga: On the Spot Easy-to-Use First-Aid Dictionary, Seibido Publishing Co., Ltd., 2007
 - (2) 日本救急医学会：熱中症診療ガイドライン 2015。 Japanese Association for Acute Medicine, Clinical Practice Guideline for Heatstroke 2015
<http://www.jaam.jp/html/info/2015/pdf/info-20150413.pdf>
 3. Falls and Fractures
 4. Delirium
-

Chapter III.

Therapeutic Technique in Home-care Settings

When I started working in home-care settings, I found that there was so much I have to learn. Since textbooks these days do not provide the information that I wanted to know, I have been seeking answers through trial and error for more than 10 years along with the help of my patients and their families.

I had thought that the knowledge and treatment policies I accumulated these past years were not widely applicable because the knowledge and policies were based on my limited experience. Through exchange opportunities with other experienced home care physicians, I have found that the knowledge and treatment policies individually developed were in fact commonly applicable.

There are therapeutic techniques and knowledge unique to home care. In this chapter, the techniques and knowledge will be described with the hope that the information will be of some help to our readers in their daily work in home care services.

(Hiroshi Suzuki)

The Yuumi Memorial Foundation for Home Health Care website has a section providing a listing of medical facilities dedicated to home medical care.

Please contact our executive office if you are interested in signing up for the listing.

Note) The website only provides names with contact information of the physicians and medical facilities, which are not intended for recommendation.

1. How to Use Antimicrobial Drugs

Infections in elderly patients have two characteristics: the causes are often local disorders such as dysphagia and dysuria, and chronic complicated infections are common. Infections in elderly patients receiving home care are likely to increase in severity and often result in death. Therefore, antimicrobial drugs should be used appropriately.

Characteristics of Infections in Elderly Patients

Elderly people are not prone to viral infections except for influenza as their humoral immunity is maintained. Thus, influenza and pneumococcal vaccinations are effective in elderly patients. On the other hand, they are prone to infections with common bacteria, acid-fast bacilli, or fungi because their cellular immunity is reduced. Unlike hospitalized patients, fatal opportunistic infections caused by *Pneumocystis carinii*, *Cytomegalovirus*, or fungi are rarely seen in patients receiving home care.

Infections with common bacteria often occur in the respiratory organs, urinary organs, skin, hepatobiliary system, and gastrointestinal tracts. They include not only highly pathogenic bacteria such as *Staphylococcus aureus*, *Streptococcus pneumoniae*, and *Escherichia coli* but also low virulent bacteria such as *Enterococcus* spp. and *Pseudomonas aeruginosa*. In addition, polymicrobial infections are frequently observed.

With regard to infections with acid-fast bacilli, people who were infected with tubercle bacillus in the pre- and post-war periods developed pulmonary tuberculosis due to their aging and compromised immunity. Nontuberculous mycobacterial infection, one such quiet but intractable diseases, is common in elderly women and home-care settings.

Trichophyton spp. and *Candida* are often causative bacteria in skin infections with fungi. Aspergilloma is found in some cases and *Mycoplasma* is occasionally found in patients younger than 60 years. However, *Mycoplasma* rarely causes an infection in elderly patients receiving home care services. On the other hand, infections with *Chlamydomphila pneumoniae* can be found in elderly patients with other bacteria in mixed infections.

Cautions in Antimicrobial Administration to Elderly Patients

Serum half-life is often extended even in patients in their late 70s with normal serum creatinine levels. When determining dosages, one has to assume that the usual dose for younger people is the maximum dose for the elderly.

When administering penicillins or cepheims to patients with renal failure, the dosage interval should be extended. Reduced doses should be used when using carbapenems and aminoglycosides because these drugs have nephrotoxicity.

Hepatically metabolized drugs such as CTRX (Rocephin®), CPZ (Cefoperazone®), and CLDM (Dalacin S®) can be used at the usual dosage amount in patients with renal dysfunction.

When using carbapenems or new quinolones, caution has to be exercised for neurological symptoms including convulsion. Caution is also required because a diagnosis of pulmonary tuberculosis can be delayed due to the use of new quinolones.

Effective Use of Antimicrobials

It is difficult for home care physicians to visit the same patient multiple times in a day. Due to this limitation, antimicrobial agents need to be used in an effective way including:

- (1) Using oral medicines, when possible.
- (2) When using injection agents, use cephem drugs because they have a long serum half-life (refer to pages 118–120).
- (3) Reduce the number of administrations with a dosage interval of 12 to 24 hours for patients with impaired renal function.
- (4) Consider a combination of oral drugs and injection agents, or the use of suppositories.
- (5) Consider subcutaneous transfusion of Ceftriaxone or Cefepime when the intravenous route is not available.
- (6) Cooperate with home nursing care services (injection procedure).

Practical Use of Antimicrobials

A. Urinary Tract Infections

Residential patients often have complicated cystitis caused by underlying urinary tract diseases. The infecting bacteria are mainly drug-resistant strains such as *Serratia* spp, *P. aeruginosa*, *Enterococcus* spp. or *Candida*. Not many cases are caused by *E. coli*. Penicillin or new quinolone drugs should be administered orally. While penicillin-based tablets are big in size and need to be taken three times daily, new quinolones can be effective with once-daily administration because of their stronger antibacterial activity. However, caution must be exercised for ESBL-resistant strains when using new quinolones. If patients do not respond to new quinolones, the possibility of bacterial cystitis due to ESBL-resistant strains or fungi including *Candida* and stone formation should be considered. Complications of pyelonephritis, prostatitis, or epididymitis are highly likely when the patients with chronic cystitis develop high fever.

B. Skin/Soft Tissue Infections

Skin infections are usually caused by indigenous bacteria on the skin such as *S. aureus*, *S. epidermidis*, *S. pyogenes*, and *E. coli*. However, MRSA or *P. aeruginosa* are sometimes responsible. An incision and drainage should be performed if necessary. In patients with moderate to severe symptoms, antibiotic administration is required after bacterial cultivation.

Decubitus infection means the state that (1) “redness,” “warmth,” “swelling,” and “pain” are recognized around the wounds and (2) foul odor, pus collection, and systemic symptom of fever are observed. To treat the decubitus infection, systemic administration of antimicrobial drugs and surgical incision, drainage, and cleansing should be performed in parallel.

C. Bacterial Enteritis

Bowel rest should be maintained and transfusion is required to prevent dehydration. New quinolones and PIPC (Pentocillin[®]) or CTRX (Rocephin[®]) should be used as oral and injection preparations, respectively.

Even in home-care settings, *Clostridium difficile* (CD) enteritis can develop when broad spectrum antibacterial agents are used for a certain period of time to treat pneumonia or urinary tract infections. If CD enteritis is suspected, one should examine the CD toxin in addition to fecal bacterial culture, and administer metronidazole (Frazier[®]).

D. Cholecystitis and Cholangitis

Acute cholecystitis and suppurative cholangitis are mainly caused by *E. coli*, *Klebsiella* spp., and *Enterococcus* spp. Hepatically metabolized third-generation cephalosporins such as CTRX (Rocephin®) or CPZ (Cephobid®) are used in the treatment.

E. Catheter-Related Blood Stream Infection (CRBSI)

Among other CRBSIs, central venous catheter-related infections can lead to systemic blood infections and sometimes be fatal. These infections must be strictly prevented.

When the signs and symptoms of a suspected infection including fever, elevated WBC (left shift), increased CRP, or elevated blood sugar are observed in residential patients with TPN, a blood culture should be quickly performed. Three strains mainly (coagulase-negative *staphylococcus* [*Staphylococcus epidermidis*], *Staphylococcus aureus*, and *Candida*) represent about 70%–80% of the causative bacteria of these infections. When infections are confirmed, systemic administration of antimicrobials and removal of the catheter are the basis of the treatment. However, hospitalization is required because many residential patients using central venous catheters have a port, and highly fatal complications of cancer leading to blindness (in the case of *Candida*) can develop.

(Satoshi Hirahara)

2. Tracheostomy Management

Patients who underwent tracheostomy often receive post-surgery treatment at home. Therefore, home care physicians need to have basic knowledge about tracheostomy including how to select an appropriate tracheal cannula. This article mainly describes tracheostomy management and cannula selection. No detailed description about suctioning is included.

Indications and Complications of Tracheostomy

Tracheostomy is indicated for bilateral vocal cord paralysis, upper airway obstruction such as head and neck tumors, management of prolonged mechanical ventilation, difficulty in ventilation due to airway secretions, and aspiration. It is unlikely for home care physicians to make decisions on tracheostomy as the procedure is usually performed in hospitals.

One of the typical chronic complications is “intratracheal and tracheal stoma granulation tissue.” It tends to appear frequently when the first tracheal cartilage is damaged and causes bleeding or pain during cannula changes or tracheal stenosis. This tendency is stronger in younger patients. Granulation can be improved to some extent by carefully changing cannulas to not injure granulation tissue and selecting appropriate cannulas. It usually improves over time. However, using a softer cannula should be considered if no improvement is observed. Surgical procedures may be required when there are problems such as repeated bleeding, pain, and difficulties in inserting cannulas. In some cases, granulation occurs in the trachea due to repeated suctioning and causes bleeding. Types or fixation methods of cannula may be changed or ablation of granulation may be required in patients with repeated bleeding. Another serious complication is tracheo-innominate artery fistula. This complication is not frequently observed but can lead to massive bleeding and its prognosis is very poor.

Tracheostomy Management

A. During Cannula Changes

It has been reported that cannula changes are not necessary until a cuff breaks or the lumen narrows due to airway secretions. In home-care settings, cannulas are regularly changed because emergency responses are not always available. Cannulas are usually changed every two weeks at the beginning. The frequency should be adjusted from every week to four weeks depending on the degree of narrowing of the lumen. If narrowing is observed in a week, double-tube cannulas are used to prevent narrowing. Sterilization is not necessary when changing cannulas, and usually cleansing should be sufficient. Suction must be performed from the subglottic suction port before cannula changes.

B. Routine Management

We perform cleansing alone and do not routinely sterilize cannulas. If patients have leakage of airway secretions from the tracheal stoma or skin trouble due to direct contact with the cannula, we often place Y-cut gauze between the cannula and skin. When patients have viscid sputum and humidification is insufficient, we use a heat moisture exchanger or humidifier. A cannula with large volume cuff can reduce the amount of saliva flowing in the trachea. However, the leakage from the tracheal stoma increases, and new gauzes or suction from the subglottic space may be required more frequently. If it increases the burden on caregivers, we usually use continuous low pressure suction devices.

The cuff pressure needs to be checked by a cuff pressure adjuster about once daily when using a cuffed cannula. Postural changes can result in changes in the cuff pressure. We recommend the use of cannulas with automatic cuff pressure adjustment (Covidien Japan Inc./Lanz™ System). Recently, a new type of cannula with integrated cuff pressure indicator (Koken Co., Ltd./Koken Maisutah-Buresu®) has been introduced.

Types of Cannula and How to Choose the Correct One

Classification of cannulas that can be included in the medical fee calculation in home-care settings (a cannula is called an intratracheal disposable catheter for bedridden patients at home in the medical fee calculation system) is shown in the following **Table**.

Table. Types of Tracheostomy Tubes

Functional classification				Official price
General type	Cuffed tracheostomy tube	With subglottic suction port	Single cannula	¥4,460
			Double cannula	¥5,970
		Without subglottic suction port	Single cannula	¥3,730
			Double cannula	¥6,150
	Uncuffed tracheostomy tube			
Tracheal stoma retainer				¥6,100

A. Cuff

A cuff is used to prevent air leak in mechanical ventilation and aspiration of saliva or vomit. In patients with upper airway obstruction or those who underwent tracheostomy to drain the sputum, cuffless is required. For these patients, either a tracheal stoma retainer or a uncuffed tracheostomy tube can be used. We usually choose a tracheal stoma retainer (Koken Co., Ltd./Retina®) for patients with a good level of consciousness complaining about discomfort of cannulas and patients who may remove the tube by themselves. In other cases, a uncuffed tracheostomy tube is typically chosen as it is easier to insert.

B. Subglottic suction port

Suction from the subglottic space is performed to remove swallowed saliva or vomit and to prevent them from flowing into the trachea. It can also be used for vocalization with a steady-flow gas. In order to prevent aspiration associated with dysphagia, a cuffed tracheostomy tube with subglottic suction port should be selected. Gaps may be created between the cannula and trachea during swallowing or body movement besides cannula changes, and each time saliva flows into the trachea. Thus, this function is necessary to perform regular suctioning.

It has been reported in a research on patients with mechanical ventilation that the incidence of pneumonia was lower when performing the suction from subglottic space, even if there was no overt aspiration.¹⁾ Therefore, we usually select a cuffed tracheostomy tube in mechanical ventilation management. Some cannulas have suction holes at the tip. In some cases, these cannulas are used in a system in which secretions are continuously suctioned from the trachea in a fixed small amount using a pump.

C. Single-cannula and Double-cannula

Single-cannula types have the outer tube alone, and double-cannula types have the inner and outer cannulas. When using the double-cannula types, the inner cannula can be removed without

removing the outer cannula, thereby enabling checking of the degree of lumen narrowing and cleaning. This double-cannula type cannula should be chosen for patients with a large amount of airway secretions and the lumen narrowing tends to occur frequently.

There is no significant functional difference between tracheal stoma retainers and non-cuffed tracheostomy tubes. When selecting a cuffed cannula, we usually consider “the size of the cuff,” “the thickness of the cuff,” “whether the cuff pressure is adjustable or not,” and “price.” As a result, cannulas with a large amount and low pressure cuff (Covidien Japan Inc./Tracheosoft™ series) are used in our clinic. The most advantageous point in using a large amount and low pressure cuff is prevention of aspiration. Since the large amount cuff can maintain contact with the tracheal mucosa even under the low pressure, ischemia of the mucosa can also be prevented. The frequency of suctioning decreased in many patients with dysphagia who switched to the large amount cuff from the smaller one. This type of cuff is particularly effective in patients with saliva aspiration.

(Hideki Ito)

References

- 1) Smulders K, van der Hoeven H, Weers-Pothoff I, Vandenbroucke-Grauls C: A randomized clinical trial of intermittent subglottic secretion drainage in patients receiving mechanical ventilation. *Chest* 121(3): 858-862. 2002.

3. Home Mechanical Ventilation (HMV)

Home Mechanical Ventilation (HMV) is now positioned as a rehabilitation treatment or a palliative care for respiratory discomfort instead of a mere tool of disease management or life-sustaining treatment.

Multidisciplinary team should perform multidimensional and comprehensive respiratory care services. Technical aspects of HMV will mainly be described in this article. We need to have sufficient knowledge for advanced care planning (ACP).

Current Status of HMV

In the past, invasive positive pressure ventilation was performed in acute phases. However, many patients were unable to be extubated and moved to their home with tracheostomy positive pressure ventilation (TPPV). Recently, the number of these patients has decreased due to an increased use of noninvasive positive pressure ventilation (NPPV) in the acute phases. NPPV is rapidly replacing TPPV particularly in the treatment of respiratory and circulatory diseases.

Tracheostomy is postponed for the patients suffering from neuromuscular disease. Many muscular dystrophy patients on NPPV live throughout their lives without tracheostomy, but NPPV should start at an appropriate time, and they have to get airway clearance technic and keep the mobility of the thoracic cage. However, tracheostomy is inevitable in patients with rapidly progressing bulbar palsy who have difficulty in airway management and sputum drainage. Many neuromuscular disease patients can't visit a hospital and should be treated by home care physicians instead of neurologists in the phases of progressing respiratory failure. In fact, HMV for neuromuscular disease patients is managed mainly by home care physicians.¹⁾ Therefore, home care physicians must acquire proficiency in HMV.

Introduction of Mechanical Ventilation Therapy in the Chronic Phases

The first choice of Mechanical ventilation is NPPV for the patients without airway closure and unstable upper airway. We described the title as “mechanical ventilation therapy” because airway clearance is indispensable for successful NPPV in addition to titrate NPPV. Home care physicians must have sufficient knowledge to make ACP and not miss the right time to start therapy.

A. Patients with No Respiratory Muscle Paralysis

Patients with respiratory disease, circulatory diseases, severe sleep apnea syndrome, and obesity hypoventilation syndrome are included in those without respiratory muscle paralysis. However, we focus particularly on those with respiratory diseases. Patients with chronic obstructive pulmonary disease (COPD) or intractable bronchial asthma develop obstructive ventilatory impairments mainly due to airway lesions, but also present restrictive ventilatory impairments due to atrophy or fibrosis of respiratory muscles caused by accumulated fatigue. Restrictive ventilators impairments can be induced by tuberculosis sequelae, lung surgeries, thoracic deformation such as scoliosis and kyphosis, or in the end stage of lung fibrosis (refer to the guideline for the institutional criteria).

Generally, NPPV should be introduced in patients who have been repeatedly hospitalized with an acute exacerbation with hypercapnia to achieve a chronic stable condition. Firstly, daytime hypoxemia is discovered, these patients have alveolar hypoventilation during sleep at night before developing hypoxemia. Therefore, nighttime SpO₂ monitoring should be carried out. When patients continuously show SpO₂ <90% for five minutes or longer, or SpO₂ <90% was

observed in 10% or higher of the entire period, NPPV should be indicated.²⁾ If the decrease in SpO₂ caused by hypoventilation is supplemented with only oxygen, PaCO₂ will increase. We have to introduce ventilatory support, NPPV for these patients.

COPD patients are often treated by physicians not a pulmonologist without receiving clear diagnosis because COPD is a common disease and they have many comorbidities caused by smoking. For patients with a smoking history presenting respiratory discomfort, respiratory function tests should be proactively performed to make an appropriate respiratory intervention. Symptoms of COPD can be treated by inhalation drugs these past years. We have mentioned this because if home care physicians are aware of the possibility of COPD and make the correct diagnosis, it would be beneficial for many smokers in aging baby boomers.

B. Patients with Respiratory Muscle Paralysis^{1),2)}

Patients with neuromuscular diseases or spinal cord injuries develop restrictive ventilatory impairments due to respiratory muscle paralysis. When a decrease in vital capacity is observed (%VC < 60%), and they have chronic alveolar hypoventilation symptoms such as fatigue, breathlessness, morning headache, and malaise, then SpO₂ monitoring during sleep should be carried out when daytime SpO₂ <94% or PaCO₂ ≥45 Torr is observed. NPPV during sleep should be introduced when apnea hypopnea index (AHI) keeps to be ≥10/hours and a decrease of SpO₂ <92% occurs four times or more or is observed in 4% or higher in the whole sleeptime. Administration of oxygen alone should be avoided. At the same time, we prevent a decreased compliance of lungs and chest wall, and the ability of airway clearance. If the thorax does not expand when the lungs expand, patients develop peripheral atelectasis, their lung volume decreases, and they have restrictive ventilatory impairments. To prevent this deep inspiration to maximal inspiratory level (maximum insufflation capacity; MIC) should be exercised. Patients can take a maximal expiratory effort by stacking air with glossopharyngeal breathing or by three insufflations by a manual resuscitation bag without exhalation after a spontaneous maximal expiratory effort. It has been recommended to perform the exercise three times per day. The loss of the expiratory muscle strength results in inefficient spontaneous cough and the accumulation of secretion. To evaluate the cough force, cough peak flow (CPF). The flow rate of coughs is measured with a peak flow meter. If CPF <270 L/min, it is not sufficient for patients to cough up the secretions when they have upper respiratory inflammation or aspiration. Therefore, training is required for effective coughing. After a deep inspiration to maximal inspiratory level, cough support including pressing the patients' thorax or abdomen should be provided, or the use of mechanical insufflations-exsufflation (MI-E) can be attempted. With these respiratory therapies, the survival rate and QOL have clearly improved in patients with ALS and Duchenne-type muscular dystrophy.

TPPV is chosen in ALS patients with progressing bulbar palsy or multiple-system atrophy patients with vocal cord dysfunction or laryngeal dystonia, and prevent suffocation. Patients with TPPV also need respiratory care that lung expansion in order to prevent peripheral atelectasis and airway clearance technic to keep good compliance of lungs and chest wall.

Selection of a Device and Mode

A built-in battery type ventilator should be chosen particularly when the device is used for life support. There are volume control and pressure control ventilators. The pressure control type has a wider variety and can be adjusted more specifically. Traditionally, the pressure control type is preferably used in patients with respiratory diseases, while the volume control type is used in neuromuscular disease patients with a larger amount of airway secretions to prevent a decrease in the ventilation volume caused by narrowed airway lumen due to sputum. The volume control type ventilator has some advantages such as the use of several stacked tidal volumes for effective caught to put out of sputum. There are also closed- (expiration valve) and open-circuits

(expiration port) ventilators. The closed-circuit ventilator with expiration valve is used in neuromuscular disease patients with no intrapulmonary diseases. In these cases, the expiratory positive airway pressure (EPAP) is set at 0 to allow the support pressure (IPAP-EPAP) higher. If EPAP is not set at 0, air leaks when the patients open their mouths, which makes eating and speaking difficult. The pressure control type ventilator can also be used in patients with a large volume of airway secretions, increase airway resistance by sputum and tidal volume decrease. But in a newly developed mode, we set a target tidal volume and the lowest and highest values of inspiratory positive airway pressure (IPAP) in advance. IPAP will automatically rise and drop within the preset range to maintain the preset tidal volume during sleep hypoventilation. In neuromuscular patients, the same ventilator may be used: in volume control mode during the waking state and pressure control mode during sleep. In addition, the latest mode of Auto-EPAP has been developed to respond to airway obstruction that is found by oscillation of 1 cm H₂O at 5 Hz in the expiratory phase. If obstruction induces insufficient flow change, the ventilator determines increase EPAP within the preset range. However, the actual log data shows that EPAP does not increase effectively because oscillation is performed only at certain intervals. Although it seems hard to understand since the same mode is described differently depending on the ventilator and in English abbreviations, it is not so complicated once you understand the system.³⁾

Home Mechanical Ventilation Care

In summary, a principle in mechanical ventilator setting is to improve the patients' pathophysiology of respiratory failure and to provide sufficient ventilation support appropriate for their body size regardless of NPPV or TPPV. Observation points, how to check the ventilator and airway clearance details required to continue effective mechanical ventilation care at home will be described below. When you take care of mechanically ventilated patients in home-care settings, be sure to review these points.

A. Is It an Appropriate Setting?³⁾

Many patients develop secondary restrictive ventilatory impairment caused by insufficient settings of their ventilators. Particularly some patients have rapid shallow spontaneous breathings frequently under TPPV as the weaning setting, for example a very weak setting with respiratory rate 3/min, support pressure 3 cm H₂O. In these cases, fatigue, fibrosis, and atrophy were observed in the patients' respiratory muscles because they had to breathe more frequently to compensate for the insufficient ventilation support. Because they believe that spontaneous breathing must remain remain under TPPV and they must be prepared accidentally when the ventilator is removed. But except for patients with progressive diseases such as ALS, spontaneous breathing always resumes after removing the ventilator. Mechanical ventilation is required to support insufficient spontaneous breathing. If ventilatory support is weak, it makes the patients' weakened respiratory muscle work harder and causes further fatigue, fibrosis, and atrophy. The patients then develop secondary restrictive ventilator impairment. In patients with progressive diseases such as ALS, DMD, a weak setting is harmful as it may accelerate the progression of respiratory muscle paralysis. Therefore, mechanical dominant breathing without spontaneous breathing should be aimed.

Why is one pattern of ventilator settings almost all IPAP 8 cm H₂O and EPAP 4 cm H₂O, often repeated, and no titration performed performed? It must be carefully observed that tidal volume is sufficient or not and IPAP must be increased if it is not suitable for the patients' body size. In the patients with a rigid thorax, tidal volume must be gradually increased because these patients are unable to accept a large increase at a time. The respiratory rate should be set at the same level of their spontaneous breathing or slightly lower after increasing the tidal volume by raising IPAP. And the rigid thorax can get good mobility, which leads to higher IPAP and then the tidal volume appropriate for the patients' body size can be obtained. For patients with

intrapulmonary diseases, optimal EPAP should be set. As COPD patients have airflow limitation and develop dynamic pulmonary hyperinflation, EPAP appropriate for intrinsic PEEP (positive end expiratory pressure) needs to be set. We should titrate the setting that can improve the patients' pathophysiology and provide respiratory muscle rest. The setting to achieve mechanical dominant breathing without spontaneous breathing should be sought in the use of NPPV for the patients with not only paralytic respiratory failure but also non paralytic respiratory failure such as COPD.

Currently, advanced home mechanical ventilators are capable of showing waveforms from each breath of the patient on the graphic monitor similarly to ICU ventilator. In addition, The log data recording waveforms of pressure, flow, tidal volume and leaks can be downloaded and helps us to know the patients' condition and if the ventilator is effective or not. Mechanical dominant breathing can be distinguished from spontaneous triggered breathing. The analysis of log data during night-time sleep, which is the most important observation data, helps us titrate ventilator to the optimal setting.

B. Maintaining Airway Clearance and Thoracic and Lung Compliance

Ventilation with a constant tidal volume alone may develop peripheral atelectasis in neuromuscular disease patients with progressive respiratory paralysis. Thus, several times of deep breaths per hour when using ventilators with deep breathing mode should be set. If the mode is not available, the aforementioned deep inspiration to maximal inspiratory level or the use of MI-E should be considered. In many cases, these have never been considered before.

C. Can NPPV Be Continued? The Right Time to Perform Tracheostomy

It depends on whether sputum can be removed with MI-E. If not, tracheostomy is necessary for intratracheal suctioning. In ALS patients with bulbar paralysis, in multiple system atrophy patients with vocal cord dysfunction, or when airway management becomes difficult due to airway collapse caused by progression of laryngeal dystonia, tracheostomy is required.

Hospitalization and Reference to a Specialist

When the patient is referred from the hospital, be sure to request the physician in charge to admit the patients with acute exacerbation.

As acute exacerbation in COPD patients decrease their survival rate and respiratory function, it is required to achieve a chronic stable condition at home. The acute exacerbation can be prevented by early intervention including administration of steroids or antibiotics. Early intervention demands carefully observing activities of daily living and detecting unusual respiratory discomfort that is an early sign of acute exacerbation. However, hospitalization is required when lung hyperinflation is not improved in home-care settings, when high flow of oxygen is required, or sputum secretion is not controllable due to severe airway infection, when patients have strong anxiety, or further home care is impossible due to difficulty in oral intake.

Neuromuscular disease patients using NPPV should be hospitalized when cough is too small to put out sputum using MI-E for airway infection. Muscular dystrophy patients often present dilated cardiomyopathy. Vital prognosis of these patients has been improved by taking cardioprotective strategy focusing on ACE inhibitors and beta-blockers.⁴⁾ Referral to a specialist is necessary when the strategy is not available or the patients' heart failure exacerbates. As gastrointestinal function significantly decreases in these patients, daily bowel movement control should be started in the early stages. The control works as gastrointestinal rehabilitation.⁴⁾ Muscle defense is a sign of peritonitis, but it disappears in neuromuscular disease patients because of their atrophic abdominal muscles.⁴⁾ Hospitalization is also necessary when fasting is required in patients who develop acute gastric dilation.

Coordination to Support Patients

A. Neuromuscular Disease

Use of TPPV accompanies sufferings such as restrictions on activities, increased susceptibility to infection, and communication disturbances. After some patients get tracheostomy, they have refuse postural change and suffer contracture pain. It is critical for patients to change postures, not only supine position not only lateral position. Tools utilizing the remaining functions such as a switching device can be considered. Communication tools can also be developed utilizing the patients' voice recorded before the tracheostomy. ACP should be made through discussions among the team. Maximum effort should be exerted to minimize the burden on the families to continue home care.

B. Respiratory Disease

We are deeply concerned that many home care physicians are reluctant to take care of patients with respiratory failure. If home care physicians have sufficient knowledge and skills, many things can be done in home-care settings to improve survival rates and maintaining patients' QOL. Multidimensional and comprehensive respiratory care provided by multidisciplinary team should prevent acute exacerbation. The strongest prognostic factor for COPD patients is the amount of physical activity. Combined therapy of nutritional therapy and respiratory rehabilitation, especially exercise therapy is important to improve physical activity. Patients may perform rehabilitation and maintain physical activities during the daytime, and use NPPV with complete mechanical breathing at night for respiratory muscle rest. In patients with exercise limitation due to dynamic pulmonary hyperinflation, high-intensity exercises can be performed by using NPPV in a rehabilitation mode in which higher IPAP and EPAP are set.⁴⁾

Cooperation with Mechanical Ventilator Manufacturers

A detailed explanation should be provided to medical staff working in the area before introducing the mechanical ventilation therapy. In case of TPPV, it is necessary to determine how, when, and by whom the circuit should be replaced through prior discussions with the manufacturer. The manufactures also teach the NPPV patients and family members how to clean of the interface and circuit. Regularly analyzing the log data of the ventilator to check if the setting is appropriate is also required. All possible events such as emergency measures at the time of disaster should be included in the discussions.

(Yukako Takechi)

References

- 1) 日本神経治療学会治療指針作成委員会：標準的神経治療 重症神経難病の呼吸ケア・呼吸管理とリハビリテーション. 神経治療 30(2): 193-212, 2013. Japanese Society of Neurological Therapeutics, Treatment Guideline Preparation Committee: Standard Neurotherapeutics: Respiratory Care for Severe Intractable Neurological Diseases/Respiratory Management and Rehabilitation. *Neurotherapeutics* Vol. 30 (2): 193-212, 2013.
- 2) 日本呼吸器学会 NPPV ガイドライン作成委員会：NPPV（非侵襲的陽圧換気療法）ガイドライン改訂第2版. 南江堂, 2015. The Japanese Respiratory Society, NPPV Guideline Preparation Committee: *NPPV (Non-invasive Positive Pressure Ventilation) Guideline, Revised 2nd Edition*. Nankodo Co., Ltd., 2015
- 3) 武知由佳子：在宅人工呼吸療法. スーパー総合医 在宅医療のすべて, 中山書店, 298-307, 2014. Yukako Takechi: *Super General Practitioner: All about Home Care*, Nakayama Shoten, 298-307, 2014
- 4) 石川悠加 編：非侵襲的人工呼吸療法ケアマニュアル～神経筋疾患のための～第1版. 日本プランニングセンター, 2004. Yuka Ishikawa, ed.: *Non-invasive Mechanical Ventilation Care Manual-for Neuromuscular Diseases*, 1st Edition. Japan Planning Center, 2004
- 5) 武知由佳子：在宅療養支援診療所. 呼吸リハビリテーション最前線 身体活動性の向上とその実践, 医歯薬出版, 198-205, 2014. Yukako Takechi: Home care support clinics. *The Front Line of Respiratory Rehabilitation Improvement of Physical Activity and its Practice*. Ishiyaku Publishers, Inc., 198-205, 2014.

4. Tube Feeding

Tube feeding has rapidly become common because of the spread of percutaneous endoscopic gastrostomy (PEG). In the debate over the pros and cons of PEG in patients with advanced dementia, the use of PEG should be reviewed. However, it is undoubtedly an important tool for nutrition management. PEG management is an essential consideration in home medical care.

PEG Management

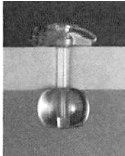
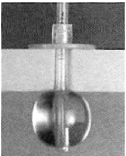
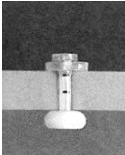
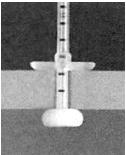
Currently known as gastric fistula, it is a gastric fistula with an endoscopically placed gastrostomy tube (PEG). Because PEG is a minimally invasive procedure and has few associated complications in addition to causing little discomfort after placement, it has rapidly become common in approximately the last 10 years.

A. Types of PEG Catheters (Figure)

PEG catheters are divided into 4 different types on the basis of “the method of gastropexy” and “the length of the catheter.”¹⁾

- (1) Bumper type: The structure whereby the stomach and abdominal walls are held by 2 discs. The disc in the stomach is called the “bumper” and the disc on the body surface is called the “stopper.”
- (2) Balloon type: The balloon is placed inside the stomach and inflated. Although this type of catheter is easier to replace than the bumper type catheter, it could fall out because of a spontaneous balloon rupture. The formation of the fistula is also weaker than in the bumper type catheter. If gastropexy is performed when placing PEG, the catheter can be changed at home without any major problems.
- (3) Button type: A type where the catheter does not appear on the body surface and only the button type clamp is seen.
- (4) Tube type: A type where a 40–50-cm catheter emerges out of the body surface. It is the mainstay of PEG catheters in recent years.

Figure. Types of Catheters

		Types based on the catheter length	
		Button type	Tube type
Types based on the gastropexy method	Balloon type		
	Bumper type		

From References 1)

B. Replacement of PEG Catheter

The frequency of catheter replacement is usually about once every 6 months for the bumper type and once every 2 months for the balloon type. If force is used during the replacement, it can lead to serious complications such as catheter dislocation into the abdominal cavity and peritonitis due to damage to the fistula.

The number of cases of replacement using endoscopy and fluoroscopy at hospitals or clinics has recently increased to avoid accidentally inserting into the abdominal cavity. With acceptance on this point, doctor fees were able to be calculated for medical service fees.

Therefore, if a PEG catheter is replaced at home, then using a portable endoscope while confirming the performance is the right way. However, there is a need for the replacement to be done at home. We describe here the procedure for gastrostomy catheter replacement at home.

- (1) The administration of tube feeding is discontinued immediately prior to the replacement. There is a method for confirming after replacement by injecting 50–100 mL of a dye such as indigo carmine and methylene blue.
- (2) The old PEG catheter is removed. There is a strong resistance when removing the bumper type catheter. Patients may complain of pain. Force used to pull it out could lead to a massive hemorrhage and damage to the fistula. Check the direction of the fistula carefully and apply a force straight in that direction. When it is just about ready to come out, pull it through the fistula slowly and gently; in such cases, the blood loss is often small.
When the balloon type catheter is removed, the balloon needs to be completely deflated. It does often not require tugging as in the bumper type catheter. However, because the old balloon does not change back into the original shape completely and thus the shape remains slightly expanded, there may be an unexpected strong resistance when removing. Check the direction of the fistula carefully when pulling, as with the bumper type catheter.
- (3) Lubricant (such as Xylocaine Jelly®) is applied around the fistula when a new catheter is inserted. Care should be taken with regard to the direction of the fistula, and do not use force when inserting.
- (4) Connect the syringe to the catheter and check the reflux of the gastric contents or the dye that was injected in advance. Check the systemic condition of the patient. Although a little bleeding may be observed, any special intervention is rarely needed.
- (5) Adjust the position of the stopper. It is placed about 1 cm from the abdominal wall. It is correct if there is no resistance when rotating the PEG catheter. A prompt coordination with medical teams is required in case of any problem and appropriate treatment should be given.
- (6) Confirm that the catheter is inserted in the stomach at this time using a portable endoscope if available.

If the catheter is replaced at home without endoscopy, the use of a balloon type catheter with guide wire (GB Gastrostomy Balloon Catheter®: NIPRO, Gastrostomy Clinical Kit®: CREATE MEDIC, etc.) is a safer method of replacement. Nevertheless, it is possible to shift the direction between the fistula and insertion, and caution should be exercised.

C. Late Complications after PEG Placement and Their Management

a. Problems that occur because of forceful placement in the gastric wall

In the early stage of gastrostomy insertion, stomach and abdominal walls are held by a stopper and bumper or balloon and are gently pressed because of the presence of fistula. However, the pressure is unnecessary after completion. The continuation of pressure causes various problems around the gastrostoma.

- (1) Buried bumper syndrome: A condition where the bumper burrows into the fistula. It is often found that feeding though the gastric fistula becomes impossible. Redness and effusions are

observed at the catheter insertion site, and sometimes, a part of the bumper emerges from the insertion site. In such cases, the catheter is removed under local anesthesia, and the gastric fistula is closed.

- (2) Development of granulation tissue around gastric fistula: If the bumper is forcefully placed, granulation tissue is formed and bleeding and effusion discharge occur. Loosening the bumper and applying steroid ointment often induces granulation tissue shrinkage.
- (3) Enlarging fistula diameter: If the catheter is placed at an angle against the fistula, the fistula diameter is enlarged and gastric juice may leak while feeding. The gastric juice can then cause problems to the skin around the fistula site. As a good practice, catheter placement with a small angle is effective. The effectiveness of decreasing the feed volume and solidifying the feeding formula using agar has also been reported.

b. Problems with catheter management

- (1) Yellow deposits inside catheter: When tube feeding continues for a while, yogurt-like deposits are formed inside most catheters. It causes blockage of the catheter and bacterial contamination. Fill vinegar diluted 10 times in the catheter overnight to prevent this.
- (2) Catheter falls out: Sometimes accidental removal may occur. Check the volume of water in the balloon once a week in case of the balloon type catheter.
Take immediate action in case of accidental removal because the fistula is immediately closed after the removal of the catheter. In such situations, cut the balloon from the end of the PEG catheter or the bumper with scissors and insert the remaining catheter in to the fistula temporarily and then secure using adhesive tape until nurses or physicians come.
- (3) Problems with catheter replacement: As previously mentioned, serious complications such as peritonitis may occur when replacing the catheter. It is a standard in recent years that the first replacement is performed by the physician who placed it at the hospital. It is strongly advised to check using portable endoscopy after replacement of the catheter at home afterward.

Nasogastric Tube

The advantage of a nasogastric tube is convenience of use. Feeding can be initiated soon after the insertion of a tube and discontinued when removed; therefore, this is a less invasive procedure. However, its disadvantage is that patients experience pain when changing and feel discomfort in pharynx and larynx, and it has a negative impact on swallowing. Choosing a nasogastric tube has increased due to a feeling of rejection in gastric fistula. The nasogastric tube at home should be managed but with full understanding.

A. Tube Selection

Although most tubes are made of vinyl chloride or polyvinyl chloride, polyurethane and silicone tubes are also available. The latter are soft and cause less discomfort to the pharynx. However, a stylet or sheath may be required for insertion because of lack of “stiffness” in the tube.

B. Complications of Nasogastric Tube Feeding and Their Prevention

Utmost attention should be paid to avoid incorrect insertion. Feeding through a tube that has been incorrectly inserted into the bronchus can lead to serious pneumonia. Insert correctly, and the most important consideration is to confirm whether it has been inserted into the stomach or not. As mentioned in Section “PEG,” there is a method to confirm the reflux of the gastric contents using a dye infusion. Caution should be exercised when confirming insertion by air sound only because it can be confused with that of inserting into the bronchus. Because inserting into the

bronchus is often observed in patients with decreased swallowing function, the procedure should be followed carefully.

Ulcer caused by tape around the nasal cavity is the second most common complication.

Percutaneous Transesophageal Gastro tubing

Percutaneous transesophageal gastro tubing (PTEG) is a procedure whereby a gastric tube is introduced from the esophagus into the stomach. The balloon attached to the catheter is inflated in the esophagus, and the inflated balloon is punctured under fluoroscopy. The guidewire is inserted into the esophagus, and then the gastric tube is inserted after inserting the introducer. Presently, it is not covered by the Japanese National Health Insurance system.

A. Indication and Contraindication of PTEG

The best indication of PTEG is basically for the patients with whom it is difficult to perform PEG because of gastrectomy, hernia, and large amount of ascites. The cases of patients with hemorrhage tendency, unable to find needle tract and recurrent nerve paralysis are contraindicated.

B. Replacement

The replacement is performed using a guidewire. It is not performed through the abdominal cavity; therefore, incorrect insertion into the abdominal cavity cannot occur when changing.

Solidification of Nutrients

Recently, the benefits of solidification of nutrients have been indicated. It is also indicated that vomiting and leakage from the fistula are prevented, the duration of infusion is shortened, diarrhea is improved, and reflux of esophagus is decreased.²⁾

A. Method Using Powdered Agar

Powdered agar is dissolved in boiling water, and then it is mixed with nutrients at body temperature. Usually, 1 g of powdered agar is mixed with 200 mL of water. It has almost jelly-like consistency.

The agar mixed nutrients are sucked into a catheter tip syringe and chilled. This allows nutrients to reach room temperature before use, and then the amount of nutrients required is infused.

B. RACOL-NF Semisolid for Enteral Use

RACOL-NF was applied under health insurance as the first semisolid preparation in April, 2015. It is a semisolid preparation containing agar and alginic acid as a thickener. It is administered using a syringe or a pressurized bag. It will become a mainstay of semisolid nutrients in the future.

C. Commercially Available Products

Semisolid nutrients are marketed as food. HINE Jelly[®] (Otsuka Pharmaceutical Co., Ltd.: 300 kcal/bag) and Recovery Newtreat[®] (SANWA KAGAKU KENKYUSHO CO., LTD.: 300 or 400 kcal/bag) are semi-solidified with agar. MEDI-F PUSHCARE[®] (Ajinomoto Pharma Co., Inc.: 300 or 400 kcal/bag) is gelled using vegetable fiber (galactomannan). It has the disadvantage of being expensive to produce, although not much effort is needed to manufacture it.

D. Advantage of Solid (Semisolid) Nutrients

As previously mentioned, reducing the reflux of esophagus and risks of vomiting and aspiration of pneumonia have been indicated. Solid nutrients may reduce leakage from gastric fistula. Agar and pectin improve diarrhea and excessive constipation because they act as vegetable fiber.³⁾

The main advantage is that duration of administration is 15 minutes for the solid preparations compared with approximately 2 hours for the liquid.

Gastric Fistula and Ingesting/Swallowing Care

Currently, gastrostomy by PEG has been a general procedure. On the other hand, there is much skepticism regarding gastric fistula in patients with advanced dementia,⁴⁾ because it has been indicated that the prognosis for patients with advanced dementia who are having a gastric fistula is poor overseas. The first indication for PEG is that patients with dysphagia who have normal mental status.⁵⁾ It is important to encourage resuming oral feeding if the patient with gastric fistula is able to contact and has motivation for ingesting/swallowing rehabilitation. Even if the gastric fistula is placed and tube feeding is initiated, oral feeding is not necessarily discontinued. Although it is not considered in patients with advanced dementia, a case of improvement in the prognosis has been reported in Japan.

Ethical concerns are considered when the patient with dementia has a prolonged survival after placing the gastric fistula. When patients have difficulty communicating with others and moving around, the physician who is in charge at home needs to make an appropriate plan after gathering various opinions.

It may not be easy to undergo ingesting/swallowing rehabilitation and orally obtain complete nutrition for patients other than patients with advanced dementia. However, encouraging them to resume oral feeding is significant, even if the amount ingested is small because oral intake is a part of their lives and home medical care is a health care system, which supports their lives.

(Hiroshi Suzuki)

References

- 1) 蟹江治郎：PEG チューブの種類と特徴. 胃瘻 PEG ハンドブック, 医学書院, 81, 2002. Jiro Kanie. Types and Characteristics of PEG tube: PEG Handbook, Igaku-Shoin Ltd.; 2002, 81.
- 2) 爲季清和：粘度調整食品 REF-P1 と経腸栄養剤メイバランス 1.5 を用いた胃食道逆流に伴う誤嚥性肺炎の予防効果. 静脈経腸栄養 23 : 263-266, 2008. Kiyokazu Tamesue. A case report: Prevention of aspiration pneumonia due to gastroesophageal reflux during enteral nutrition using a pectin gel of REF-P1 and an elemental diet of Meibalance 1.5. Japanese Society for Parenteral and Enteral Nutrition 2008; 23(2), 263-266.
- 3) 合田文則：胃瘻からの半固形化栄養材をめぐる問題点とその解決法. 静脈経腸栄養 23 : 235-241, 2008. Fuminori Goda. Problems and their solution for gastrostomy tube feeding of semi-solid nutrients. Japanese Society for Parenteral and Enteral Nutrition 2008; 23, 235-241.
- 4) 会田薫子：認知症末期患者に対する人工的水分・栄養補給法の施行実態とその関連要因に関する調査から. 日本老年医学会雑誌 49 (1) : 71-74, 2012. Kaoruko Aida. Artificial hydration and feeding methods for final stage dementia patients. Geriatrics and Gerontology International 2012; 49(1), 71-74.
- 5) PEG ドクターズネットワーク：経腸栄養剤の固形化 PEG Doctors Network. Solidifying enteral nutrients. <http://www.peg.or.jp/care/qa/kokeika.html>

5. Management of Intravenous Infusion

The goal of infusion therapy is 1) management of fluid, 2) management of nutrition, and 3) obtaining intravenous access. The management of intravenous infusion for nutritional therapy is a method whereby the amount of water, electrolytes, and nutrients required is parenterally administered when there is difficulty in or inadequacy of obtaining food and water intake. Although peripheral or central veins are used for the administration route, subcutaneous infusion, i.e., administering thorough the subcutaneous route, is used for palliative care.

Guideline

Nutrition infusions are described based on Japanese Society for Parenteral and Enteral Nutrition “Guidelines for Parenteral and Enteral Nutrition.”¹⁾ Please refer to that “scientific evidence ranking for papers” and “recommendation level” (Tables 1 and 2) are shown in each item.

The specific method of nutrition infusions has already been described in books. Therefore, the management skills based on scientific evidence in home-care settings that physicians and nurses need to perform are described, and this is the aim of this textbook.

Effects on the Body of Malnutrition

Malnutrition is morbidity caused by inadequate or imbalance of protein and calorie intake. The condition where energy deficit results in protein deficit is called protein–energy malnutrition (PEM). Primary PEM results from a diet that lacks nutrients and social and economic factors. In comparison, secondary PEM is due to an increase in the body’s requirements, and nutrient therapy is needed as the PEM is related to disease.

Table 1. Recommendation Ranking

Recommendation	Contents
A	Strongly recommended
B	Generally recommended
C	Own judgment

From References 1)

Table 2. Scientific evidence ranking for papers

Level	Contents
I	Evidence by at least one RCT or meta-analysis
II	Evidence by comparative studies other than RCT or cohort studies
III	Integrated case studies or opinions of experts

RCT: Randomized Controlled Trial

From References 1)

Standard for Selection and Management of Nutritional Routes

A. Nutritional Assessment

The guideline states “It is a method for a comprehensive evaluation of nutritional status using medical history, nutrient history, physical findings, physical measurements, and laboratory data. The nutritional screening is included in the nutritional assessment.” If recognized that the nutritional assessment is not adequately performed in home-care settings, it should be actively pursued.

B. Nutritional Screening

- (1) The nutritional screening is performed to identify patients with nutritional risks (A-III).
- (2) It is performed for all patients at admission and regularly after admission (A-III).
- (3) It is performed using a measurement that is easily obtainable, e.g., medical history, height, weight, and changes in weight (A-II).

It is easy to use the method, subjective global assessment, in home-care settings. Various assessment methods are available on other web sites.

C. Consideration for Being Measured by Serum Proteins

The guideline states that “It is determined based on the presence of any fluid retention in the body and the metabolism and disposition of proteins affected by a variety of invasions, including operations, injuries and infections (A-III).”

The nutritional status is generally measured by serum albumin in home-care settings, and there is no question that this is the standard. If the CRP increases because of infection, the serum albumin decreases, which is due to invasions and unlikely to be related to reduction of nutritional status. It is possible to make a mistake when using serum albumin only; therefore, it should be determined by using other laboratory data and conditions.

Inclusion Criteria for Nutritional Therapy

A. Inclusion Criteria for Parenteral Nutrition and Enteral Nutrition

- (1) If the small bowel is functioning, selecting the enteral nutrition is a standard (A-II).
- (2) If the enteral nutrition is unable to be used or the required amount of nutrition is unable to be administered by enteral nutrition only, then parenteral nutrition is selected (A-II).

Although the access for parenteral nutrition is tended to be placed easily due to the related issue in medical service fees for gastrostomy, it should not be forgotten that the medical indication is described above.

B. Methods of Parenteral Nutrition

There are two methods that parenteral nutrition can be administered: via the peripheral venous route, known as peripheral parenteral nutrition (PPN) and via the central venous route, known as total parenteral nutrition (TPN). TPN is mainly used at home, and PICC and port type are generally used as a CV access. The external tunneled catheter, Broviac–Hickman catheter is also used for pediatric patients.

Central Venous Catheter (CVC) Used at Home

A. Materials for CVC

The anticoagulant-effective catheter is selected due to its long-term placement. It is recommended that it is made from silicon and polyurethane.

B. Long-term CVC

The long-term catheter is recommended if it is required for more than 3 months placement or prevention of complications. However, continuing use of the CVC (short-term) during hospitalization and at home is not uncommon for infusions in a patient who has a prognosis for survival of 1–2 month.

- (1) Broviac-Hickman Catheter: There is a Dacron cuff around the CV catheter. The Dacron cuff buried under the skin tunnel anchors the surrounding tissue by fibrous adhesion and prevents it from being removed accidentally. It is possible to repair the damage using the repair kits. Although this type is not widely available in Japan, it is used at home compared to port type in the U.S. and Europe.
- (2) Totally implantable subcutaneous infusion port: It is a type that CVC and port are buried under the skin, and the greatest feature is that there is no exposure outside of the body. It includes a silicon catheter, which is inserted into a vein, and a port, which is buried under the skin. Access the septum made of compressed silicon by puncturing the overlying skin with a Huber needle and infusions and medications are administered. The Groshong port has catheter with distal side slits. When infusions and medications are administered, the valve (side slit) opens outward and opens inward during blood aspiration. Therefore, it is highly convenient for using at home. It must also be kept in mind that a surgical intervention is required for removal because of infections, although opportunities for infections and damage are reduced.
- (3) Peripherally inserted CVC (PICC): It is a method whereby it is inserted in a peripheral vein in the arm and then the end of the catheter rests in the superior vena cava. Although the catheter is very soft, it is relatively easy to insert by using a guide wire. The advantage is that no serious complications occur when inserting compared to central venous catheterization. The insertion is easy. However, it is not suitable to use long-term at home due to poor flow when bending the elbow. Therefore, the upper arm PICC insertion method where the catheter is inserted after inserting into an upper arm vein with ultrasound guidance has been widely available.

CVC Management

A. Recommended Skin Antiseptic Agents during CVC Placed

The guideline states “Chlorhexidine–alcohol or povidone iodine as a preferred agent for skin preparation before CVC placement is used (A-II).” The foreign data has reported that 2% chlorhexidine reduces the risk of catheter-related infection compared with povidone iodine and ethanol for disinfection. Although 0.5% chlorhexidine is only available in Japan, the difference between both agents is considered not to be significant. It is necessary to understand that for the antiseptic effect of povidone iodine to be effective, it needs to be in contact with the skin for more than 1–2 minutes or until it is dry.

The guideline states “Do not use” regarding the application of antibiotic ointment or povidone iodine gel on insertion sites.

B. CVC Dressing Management

There are three points in the guideline.

- (1) Use a sterile pad dressing or film dressing (A-I)
- (2) Dressing should be changed once or twice per week regularly (A-III).

- (3) Monitoring for redness, tenderness, and infection at the insertion site and check daily whether the dressing becomes loose (B-III).

Since there is no difference between dressing materials, it is selected based on convenience of use and the cost.

C. Infusion Lines Management

- (1) Use integrated infusion line (B-III)
- (2) Do not attach a 3-way stopcock to the infusion line except for using in the operating room or ICU (A-II)
- (3) Use ethanol for disinfection for sterilizing the connector when administrating through the 3-way stopcock (A-II)

It has been often reported that the contamination level of the 3-way stopcock, which was used for multi-purpose use, is high. Therefore, use at home should be avoided as much as possible.

D. Needleless System

- (1) It is necessary to understand that the prevention of bloodstream infections associated with a needleless system is not clear (A-II)
- (2) The surface of the device should be thoroughly sterilized when using a needleless system (A-II)

Do not have such a simple idea that the use of a needleless system can be used to prevent infection. The surface of the device should be thoroughly sterilized with ethanol for disinfection.

E. Need for In-line Filters

- (1) Use an in-line filter (A-III)
- (2) Use an in-line filter with symmetrical membranes (B-III)

CDC (2002) guidelines include “there is no data to support in-line filters’ efficacy in preventing infections when using it for infection control purposes.” There are different opinions about filters. Since there are some effects that it traps microbial contamination and pieces of glass and prevents air embolism, in Japan, it is recommended to use it at home as much as possible.

F. Frequency of Changing Infusion Line

- (1) Infusion line should be changed once or twice per week regularly (B-II)
- (2) The infusion line for administrating fat emulsion should be changed within 24 hours (A-III)

Fat emulsion is often injected through side line at home so therefore the line should only be changed. The frequency of changing the line is once a week if there is no problem. It is recommended to change it about twice a week if there is a higher risk of infections.

G. Other Considerations

Considerations of the placing period, infusion line, dressing, and infusion management for a peripheral catheter are described as follows:

- (1) Do not have in place for more than 96 hours (B-III)
- (2) The infusion line of the peripheral catheter should be changed when changing the catheter (B-II)
- (3) The insertion site should be covered by a film dressing and monitored every day for the presence or absence of redness, pain, and swelling (B-III)
- (4) When administering amino acid and glucose injection with electrolytes, avoid administering medication or any preparation through the side line at the same time. Therefore, the strict hygienic control is exercised (A-III)

Infusion Management in Patients with End-stage

A. Effect on Prognosis of Nutritional Status during Palliative Care in Cancer

It has been reported that 4%–23% of patients at the palliative stage to terminal stage died due to malnutrition and not cancer. The effect on prognosis of nutritional status in the guideline states the following;

- (1) The reduction of nutritional status decreases cancer patient's QOL and worsens prognosis (A-I)
- (2) Assess the nutritional status regularly and initiate nutritional management before becoming malnourished (A-I)

B. Nutritional Dose during Palliative Treatment

- (1) The dose of total energy and protein is the same as usual and is adjusted based on the amount of physical activity and metabolic state during palliative treatment (B-II)
- (2) The nutritional dose is adjusted based on the reduction of metabolic state and the amount of physical activity during terminal care (B-I)

Since patients who are entering treatment for terminal stage has a high risk of fluid retention in the body and metabolic disorder related to administration of nutrition, the nutritional dose needs to be reduced based on the clinical symptoms.

C. Hydration during Terminal Care

- (1) Since Patients with end-stage are prone to heart failure and respiratory failure related to fluid administration and resulting in exacerbations of edema, pleural effusion, and ascites, overhydration should be avoided (A-III)
- (2) The amount of infusion should be kept to a minimum, and the maintenance fluids should be kept at less than 1000 mL per day (A-II)
- (3) The minimizing invasive route should be selected for hydration. The use of subcutaneous administration is considered if intravenous administration is unable to be used (B-III)

If intravenous access is difficult to establish, a daily dose of 500–1000 mL saline is subcutaneously administered so as to be able to manage the intravenous administration.

Subcutaneous Infusion

A. Indication for Subcutaneous Infusion

There are cases where the management of peripheral vein infusions or the placement of a peripheral catheter is difficult.

B. Subcutaneous Infusion

In this method, a daily dose of 500 to 1000 mL infusion is subcutaneously administered, and there are two ways of administration, where either the infusion is continuously administered for 24 hours or intermittently administered within a given length of time. Although the safety rate of infusion dose is 1 mL per less than 1 minute, the rate of infusion dose for continuous infusion is 20–40 mL per 1 hour. The fluids are given with relative safety, and there is a lower frequency of complications such as bleeding and infections.

Plastic indwelling or butterfly needles are used for skin puncture. Plastic needles are recommended for safety. Precordium and abdominal regions are chosen for a skin puncture site and sometimes the femoral region, arms and back are also able to be used. Empirically, fixing the indwelling needle after making a bulge by infusion when puncturing the skin allows the rate of infusion dose to be stable.

There is the disadvantage that the dose is unstable from a free-running infusion, and it is not used for rapid administration. Adverse reactions such as pain and redness may occur by infusions other than isotonic solution. Infusions except with saline are not able to be subcutaneously administered. It is important to keep in mind that it is empirically used at home. Empirically, 5% glucose, maintenance fluids for peripheral subcutaneous administration and extracellular fluid are able to be administered without incident.

C. Procedure

1) Sterilize the puncture site using povidone iodine or alcohol pads. 2) A 21–23 gauge butterfly needle or a plastic needle should be used. 3) Puncture under the skin in the sterilized site using a 45°–60° angle and fix it in place.

(Noriyasu Shirotani)

References

- 1) 日本静脈経腸栄養学会 編：静脈経腸栄養ガイドライン第3版. 照林社, 2013. Japanese Society for Parenteral and Enteral Nutrition. Guidelines for Parenteral and Enteral Nutrition 3rd ed. Shorinsha Inc.; 2013.

6. Urinary Catheterization

Chronic indwelling urethral catheterization is avoided without proper indication while urinary catheters are frequently used in older patients because of prostatic hypertrophy or neurogenic bladder in home-care settings. Indication for surgery should be discussed first in urinary retention with prostatic hypertrophy. If it is no indication for surgery or urinary retention is caused by neurogenic bladder, clean intermittent catheterization is preferable. When disease needs an indwelling urethral catheter to be placed, the catheter is attached to the trunk or femoral region. The optimal frequency of catheter changes varies individually. Therefore, it is changed when catheter occlusion has occurred. Same catheter is not normally placed for more than 2 months. The separation of the drainage bag from the catheter should be avoided. Regular bladder irrigation is not effective for preventing urinary tract infection. Although the standard care is stated above, a flexible approach is required to be taken for individual circumstances in home-care settings.

Introduction

Many patients who are receiving treatment at home have an indwelling urethral catheter continuously due to dysfunction of the lower urinary tract or lower urinary tract obstruction. Prostatic hypertrophy should be discussed whether it is an indication for surgery; otherwise the catheter may be not required. In the case where there is no indication for surgery or urinary retention due to neurogenic bladder, clean intermittent catheterization is recommended because the infection and the urethral injury are unlikely to occur. However, difficulty in introducing intermittent catheterization at home is not rare, and many patients have a long-term indwelling urethral catheter.

Clean Intermittent Catheterization

The data from patients with spinal cord injuries showed that a clean intermittent catheterization is superior to an indwelling urethral catheter for complications such as infection, stone formation, and urethral injury.¹⁾ For the introduction, a patient himself/herself or his/her family need to perform it. A self-catheterization is needed to be performed 4–6 times per day depending on the volume of urine and bladder capacity. If patients have some ability of urinating on their own and the self-catheterization is burdensome, the reduction of the number of frequency is also an option. The urethral meatus is cleaned before inserting a catheter and self-catheterization is performed with a dedicated catheter. The catheter is washed well after the catheterization and kept in a provided sheath filled with an antiseptic solution and lubricating fluid. Disposable catheters eliminate the need to sterilize and store it. Catheterization by family can lead to increased caregiver burden. Although the frequency of complications is small, superiority to mortality and preservation of renal function is not clear. Therefore, if self-catheterization is difficult for the patient, a decision about introduction should be made in considerations of the patient and his/her family wishes and caregiver's circumstances.

Indwelling Urethral Catheter

A long-term indwelling urethral catheter is frequently unable to avoid being chosen in home-care settings (See p.105 for the indication). Asymptomatic bacteriuria in patients with chronic

indwelling bladder catheters is inevitable and cannot be treated. Complications include symptomatic urinary tract and genital infections, sepsis, bladder stone, urethral injury, fistula formation and urethral sphincter and bladder neck erosions. Long-term indwelling urethral catheter is a risk factor for urothelial cancer in patients with spinal cord injuries.

A. Standard Management of Catheter

The optimal use of a thin catheter and a closed urinary drainage system are recommended. Catheterization is performed under sterile conditions using sterilized equipment.¹⁾ Catheter fixation to the body is recommended for prevention of urethral tears. It is standard to secure the catheter to the abdominal wall (the penis facing the direction of the head) for male patients and to the thigh for female patients. Despite washing and disinfection of the surrounding urethral meatus, the frequency of bacteriuria does not decrease.²⁾ Although bladder irrigation is performed when the catheter may be blocked by blood clots or other substances, there is no evidence that bladder irrigation decreases the frequency of bacteriuria.²⁾ Be careful when bending the catheter, and keep the drainage bag at a level lower than the bladder to prevent urine flowing back up into the bladder. To prevent this, the use of a bed is necessary and the *futon* (traditional Japanese bedding) is not recommended. Prophylactic antibacterial agents are not recommended.²⁾ Because optimal frequency of catheter change varies individually, the catheter should be changed when occluded or finding other signs of occlusion.²⁾ It is, however, not always practical to know the occlusion at home. Changing it prophylactically based on a tendency for occluding is inevitable.

Supra Pubic Cystostomy

Supra pubic cystostomy is not rare in cases of long-term indwelling catheterization. A comparative study for assessing the superiority of cystostomy over indwelling urethral catheters has not been performed.²⁾ There is an additional advantage of low incidence of complications occurring in the urethra and the surrounding tissue, such as urinary tract and genital infections including urethritis, prostatitis and epididymitis, and urethrocutaneous fistula.^{1,2)}

The important point in the management of cystostomy is similar to indwelling urethral catheters. Because the fistula closes rapidly after accidental removal, prompt replacement is required. Nephrostomy balloon catheters are commonly used. As aberrantly migrating hair in the bladder serves as a nidus for stone formation, appropriate hair removal is required.

Common Complications

A. Urinary Tract Infections

Bacteriuria is inevitable in patients with chronic indwelling urethral catheters. Asymptomatic bacteriuria does not require treatment. Symptomatic bacteriuria is treated as a case of complicated urinary tract infection. A urine sample is collected before administration of antibacterial agent and a blood culture is performed if necessary. The catheter is changed before administration of antibacterial agent.¹⁾ Empirical treatment with antimicrobial agents is initiated considering the most common causal microorganisms, such as colon *Bacillus*, *Enterobacter*, *Pseudomonas aeruginosa*, *Acinetobacter*, *Proteus*, *Klebsiella*, *Serratia*, and *Staphylococcus*. After identification of the causative microorganism and its antibacterial sensitivities, drug selection should possess the narrowest antibacterial spectrum to limit the development of drug-resistant strains.¹⁾ Initial antibacterial treatment with quinolones or cephems is common. Purple urine bag syndrome may be observed in patients with urinary tract infections and a long-term indwelling catheter, but it does not require treatment.

B. Stone Formation

Stone formation is often caused by a long-term indwelling urethral catheter. Hematuria, catheter occlusion, rupture of the catheter balloon, and symptomatic bacteriuria contribute to stone formation. Although care should be taken to ensure adequate water intake and adjust the urine pH, a well-proven prophylaxis is not available. Thus, it often requires treatment such as endoscopic surgery.

C. Recurrent Urinary Catheter Blockage

P. mirabilis infection often contributes to recurrent urinary catheter occlusion. If the infection is established in a catheter placed in the urinary tract, the catheter is repeatedly occluded by crystalline biofilm. The occluded catheter is promptly replaced with a new one. If *P. mirabilis* is detected in a urine culture, early initiation of antimicrobial agents appears to be effective. It is often accompanied by urinary bladder stones.

D. Urethrocuteaneous Fistula

Compression of urethral mucosa by the catheter leads to necrosis around the urethra, and urethrocuteaneous fistula may be formed. The external urethral meatus necrosis in male patients often leads to conditions such as hypospadias or urethrocuteaneous fistula formed at the root of the penis or scrotum; in female patients, fistula necrosis may occur on the labia. Preventive measures such as correct catheter fixation technique are important. Once fistulas have developed, cystostomy is considered because no other effective procedure is available.

(Shigeru Onozawa and Hironori Oyama)

References

- 1) 日本排尿機能学会 / 日本脊髄障害医学会 脊髄損傷における排尿障害診療ガイドライン作成委員会：脊髄損傷における排尿障害の診療ガイドライン. RichHill Medical、65、2011. The Japanese Continence Society/ Japan Medical Society of Spinal Cord Lesion. Clinical practice guideline planning committee for urinary dysfunction in patients with chronic spinal cord injury. Clinical practice guideline for urinary dysfunction in patients with chronic spinal cord injury, RichHill Medical; 2011, 65.
- 2) 日本泌尿器科学会 泌尿器科領域における感染制御ガイドライン作成委員会：泌尿器科領域における感染制御ガイドライン. 2009. The Japanese Urological Association. The Japanese Urological Association Guideline planning committee for the prevention of health care-associated infection in urological practice. Guideline planning committee for the prevention of health care-associated infection in urological practice, 2009.




7. Continuous Subcutaneous Infusion

Continuous subcutaneous infusion at home is a pronounced therapeutic advantage. Particularly, it provides positive effective delivery of drugs in severe cases in which oral administration is difficult. The procedure is easier than intravenous injection and has no limitation on movement. Therefore, it is an essential item of home health care for severe cases.

Continuous Subcutaneous Infusion Devices

- (1) Disposable type: The disposable infusion device with balloon is inserted after filling the device with drugs. Volume flow rate can be maintained constant and the device can be changed every few days because of its capacity of approximately 50 mL. The prescription has been available at some pharmacies out of the hospital. Devices with patient controlled analgesia (PCA) have been widely distributed in later years.
- (2) Syringe pump type: Drugs are infused in small amounts using a portable syringe pump. The flow rate can be set for each case, and changing the pump is possible, depending on the condition. The syringe needs to be frequently changed.
- (3) Infusion pump type: Drugs are subcutaneously injected continuously using a provided infusion bag with 50–100 mL capacity. The frequency of changing is every few days because detailed settings and a larger capacity and being available for rental.

Table. Continuous Subcutaneous Infusion Device

	Disposable type	Syringe pump type	Infusion pump type (provided infusion bag)
Manufacturer's name	Baxter, Nipro, Create Medic	Terumo	JMS, Smiths Medical Japan
Images			
Advantages	Larger capacity (50–100 mL) allows for longer use without changing	Small and most convenient for carrying Easy to set flow rate	Possible to carry (slightly bigger than other types) Flow rate and CA settings can be changed Larger capacity (50–100 mL) allows for longer use without changing
Disadvantage	Standard flow rate is fixed, Different products based on with or without PCA Despite covered by health insurance, it is costly	Frequent replacement is needed because of small capacity (5–10 mL) Cost is a little expensive	Various settings are available Device's cost is a little expensive Bag for changing is expensive

From References 1)

Drugs for Continuous Subcutaneous Infusion

A. Pain Control (Opioids)

- (1) Morphine hydrochloride: Morphine is the most common opioid medication. 1% injection of 1 mL and 4% injection of 5 mL are used.

If being changed from oral administration, the daily dose must be determined first. The flow rate is set for 24-h administration of half a daily dose of oral morphine. The flow rate is set for the infusion of the rescue medication dose (one twelfth of a daily dose or infusion dose for 2 h). The infusion dose and rescue medication dose are adjusted based on symptoms.

- (2) Fentanyl: Fentanyl injection is used. The dose is 0.005% of 2 mL per 1A or 100 µg per 1A. If being changed from fentanyl MT patch, the flow rate is set at 25 µg per hour (4.2 mg of fentanyl). The standard rescue therapy dose setting is the 2 h dose of 24-h dose. If being changed from morphine, 10 mg of 1A morphine is equal to 100 µg of 1A fentanyl, as it is known that fentanyl is 100 times more potent than morphine.
- (3) Oxycodone: OxiFast® injection is used. There are two formulations: 1% injection of 1 mL (10 mg) and 1% injection of 5 mL (50 mg). A daily dose of OxiFast is determined. The flow rate is set for 24-h administration of three-fourths of a daily dose of oral oxycodone (40 mg/day oral oxycodone is equal to 60 mg oral morphine and 30 mg/day OxiFast®). The setting dose of rescue therapy is the 1–2 h dose of 24 h dose based on morphine injection.

B. Sedation

If the pain is severe and unable to be relieved by other treatments, sedation is used after consent is obtained from the patient and his/her family. Sedation must not be used because of convenience.

- (1) Haloperidol (Serenase®): Haloperidol is used for relatively moderate sedation. The patient is drowsy but he/she is easily awakened when asked to do so. It is effective in patients with delirium. Elderly patients are more likely to have a relatively deep sedation despite a small dose. The starting dose is commonly 20–30 mg/day.
- (2) Midazolam (Dormicum®): Midazolam is the most commonly used sedative. Deep sedation (sleeping deeply) can be provided by increasing the dose. A daily 30–50 mg dose offers some effects of sedation.
- (3) 10% phenobarbital (Phenobar®): Although phenobarbital needs approximately 12 h before eliciting a response, a relatively deep sedation can be provided. A daily 500 mg dose often offers the effects of deep sedation. It is a highly lipid soluble drug and can absorb into plastics, resulting in damaging the route when using plastic parts.

C. Ileus

- (1) Octreotide (Sandostatin®): Octreotide is a somatostatin analog and stops the vicious cycle of inhibiting digestive secretions and digestive tract movement and enhancing secretions associated with intestinal distention. A daily dose of 300 µg is used.

D. Continuous Subcutaneous Infusion

- (1) Injection site: Precordium and abdominal regions are often chosen for a skin puncture site as the needle is not easily pulled out from this position. The skin and underlying tissue are punctured using a 27 gauge butterfly needle, and the puncture site is sterilized with alcohol at the precordium region. A 24 gauge plastic needle is placed under the skin on the abdominal region.
- (2) Route changing: The route is changed every week because of skin redness.
- (3) Considerations: Placing subcutaneously or intramuscularly may induce ulceration and pain. It may be an irritant to the skin, resulting in developing redness and induration depending on the type of drug solution used. A small amount of steroids is occasionally mixed in for prophylaxis.

E. Patient Controlled Analgesia (PCA)¹⁾

Patient controlled analgesia (PCA) is a simple method of allowing a patient in pain with continuous subcutaneous injection to administer a rescue drug as a bolus injection. With most types of PCA devices, the patient has only to press the button once to complete the procedure.

(Hiroshi Suzuki)

References

- 1) 並木昭, 他 : PCA (自己調節鎮痛) の実際. 克誠堂出版, 2004. Akira Namiki, et al. Practice in PCA (Patient controlled analgesia), Kokuseido Publishing Co. Ltd.; 2004.

8. Complementary and Alternative Medicine (CAM)

We describe here the changes in CAM in recent years, the application of traditional medicine in the home medical care, the position of CAM in the home medical care and the positive and negative aspect, and the development of integrative medicine.

Complementary and Alternative Medicine

CAM (complementary and alternative medicine) is a general term for non-mainstream practice that is used together (complementary) with conventional medicine that is globalized and standardized, or a non-mainstream practice that is used instead of conventional medicine (alternative).

In the U.S., nearly 40% of the population uses CAM and a national research center has been operated. The name was changed to the National Center for Complementary and Integrative Health (NCCIH) in 2014. Integrative medicine refers to the use of a non-mainstream practice alongside conventional medicine, rather than altering conventional medicine from a non-mainstream practice for developing medicine.

In Japan, the “Study Group on Integrative Medicine Practice” (2012–2013) by the Ministry of Health, Labour and Welfare announced their position on “Integrative Medicine” as follows: It is a medicine that further improves the quality of life by a combination of modern Western medicine and complementary, alternative, and traditional medicines based on the premise of modern Western medicine, and it is initiated by physicians and is cooperated with a multiprofessional team as necessary (**Figure**).¹⁾ This article will deal with CAM including traditional medicine.

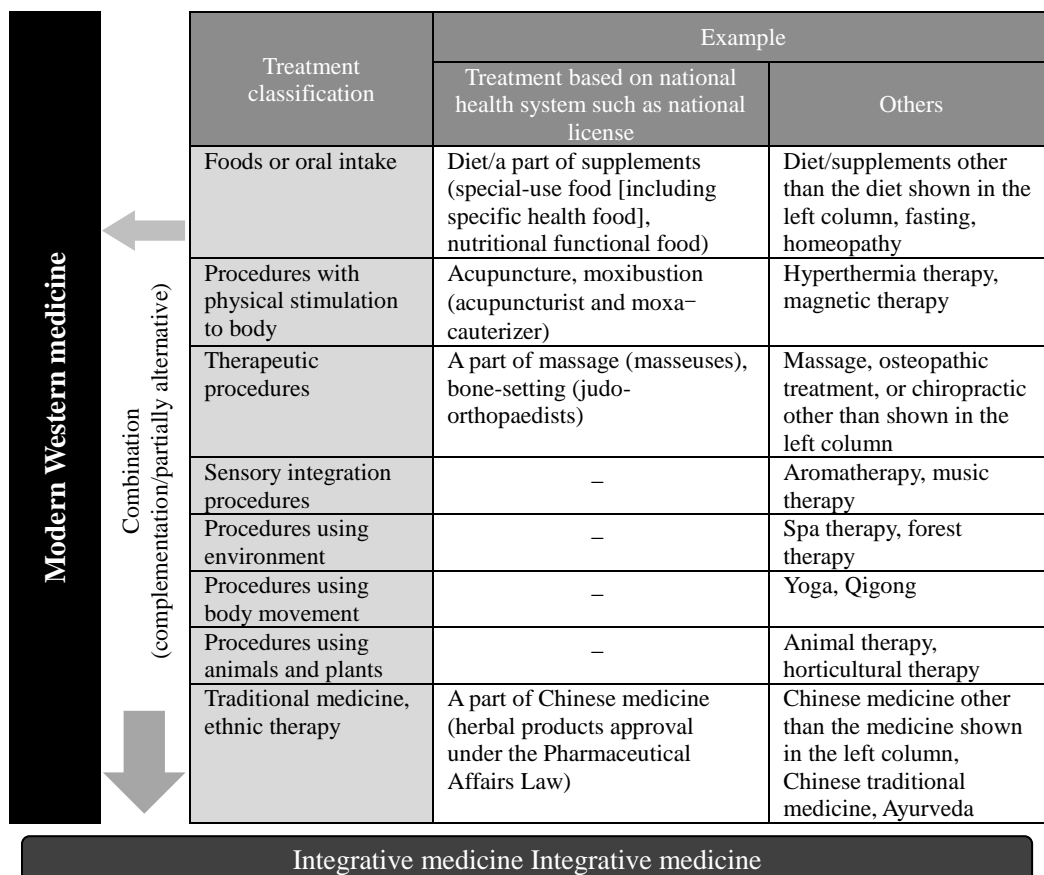
Integrating with CAM at Home

It is often said that there are a wide variety of CAM types. As Japanese patients and their family often do not disclose the use of CAM, the actual prevalence of CAM is not fully known. Particularly in the clinical setting of cancer, patients deny illness, resulting in excessively committing to CAM. Therefore, cases where the patient refuses all standard treatments are not uncommon.

The “Guideline for Cancer Complementary and Alternative Medicine” (2008)²⁾ systemically reviewed major CAM other than herbal medicines. Aromatherapy and Massage are categorized in Recommendation B (treatment is recommended) regarding items such as “Does it improve cancer patients’ physical and psychological symptoms?” but other CAM is categorized in Recommendation C (little evidence of recommendation) regarding all items.

As home care practitioners know all health care systems available for a patient, they are expected to coordinate all home medical care, including CAM, with certain understandings about CAM. If the CAM practitioner is available, making a decision with a patient at his/her home, as far as possible, is recommended. This allows for the maximum effectiveness of CAM and is the same system that is provided by a service staff providing home medical care. The home care practitioners should work hard so that various care approaches can function together regardless of one’s profession or different position.³⁾ This is consistent with the concept of “Integrative Medicine” by the Ministry of Health, Labour and Welfare as previously mentioned.

Figure. CAM Classification and Integrative Medicine Concept



From References 1), partially revised.

Home Medical Care and Traditional Medicine

In home medical care, clinicians often make decision under conditions where the use of front-line medical devices is difficult and diagnostic capabilities are limited. They provide a type of care that inevitably provides a “care” rather than a “cure” and respects the patient’s lifestyle and his/her wishes. The role of clinicians in home medical care is to continue to provide an essential part of medical care in such in home-care settings with the exception of a front-line medical care.

In contrast, “traditional medicine” includes no front-line care. All information for supporting the traditional medicine procedures is available at home. The understanding of the patient’s condition is based on his/her wishes, experiencing his/her life style, checking the pulse and tongue and touching the abdomen is closer to the patient’s explanatory model. Therefore, it may help guide treatment in place. Home medical care includes not only all medical care but also physical and psychological care. Organ cross approach and correlational approach of body and mind in the traditional medicine are highly compatible with home medical care. Therefore, problems related to conventional medicine, such as combination therapy and long-term or repeated administration, are expected to be resolved.

The “guidelines for safe pharmacotherapy in the elderly 2015” (it has still been revised at this time) by the Japan Geriatrics Society have dedicated one chapter for “Kampo and traditional medicine in East Asia” and it includes evidence for, recommended mode of use, and precautions

regarding Yi-Gan-San (抑肝散, Yokukansan), Ban-Xia-Hou-Po-Tang (半夏厚朴湯, Hangekobokuto) and Da-Jian-Zhong-Tang (大建中湯, Daikenchuto), which are commonly used in home medical care.

(Shiro Kitada)

References

- 1) 厚生労働省：「総合医療」の在り方に関する検討会（平成 25 年 2 月）The Ministry of Health, Labour and Welfare. Study Group on Integrative Medicine Practice; February, 2013.
<http://www.mhlw.go.jp/stf/shingi/2r9852000002vsubatt/2r9852000002vsv2.pdf>
- 2) 特定非営利活動法人日本緩和医療学会：がん補完代替医療ガイドライン The Japanese Society for Palliative Medicine. Guideline for Cancer Complementary and Alternative Medicine.
<https://www.jspm.ne.jp/guidelines/cam/cam01.pdf>
- 3) 北田志郎, 神津美子, 山崎浩二：代替医療. 在宅医学, メディカルレビュー社, 139-141, 2008. Shiro Kitada, Yoshiko Kouzu, Koji Yamazaki. Alternative Medicine. *Home care medicine*, Medical Review Co.; 2008:139-141.

Chapter III References

1. How to Use Antimicrobial Drugs
 2. Tracheostomy Management
 3. Home Mechanical Ventilation (HMV)
 4. Tube Feeding
 5. Management of Intravenous Infusion
 6. Bladder and Nephrostomy Catheters
 7. Continuous Subcutaneous Infusion
 8. Complementary and Alternative Medicine (CAM)
 - (1) National Center for Complementary and Integrative Health (NCCIH)
<http://nccih.nih.gov/>
 - (2) 川越正平：救急事態への備えと臨床決断。プライマリ・ケア救急，プリメド社，286-292，2007。Shohei Kawagoe. Preparation for emergency situation and clinical decision, Primary care Emergency medicine, PRIMED-SHA Co; 2007:286-292.
 - (3) 石田秀実：中国医学思想史。東京大学出版会，1992。Hidemi Ishida. A History of Chinese Medical Thought, The University of Tokyo Press; 1992.
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Chapter IV.

Medical Management of Advanced Stages of Each Disorder

If providing a definitive therapy is difficult and radical cure is not expected, common diseases may gradually become chronic and severe. Although patients in the acute exacerbation stage or complicated by acute disease are generally treated in the hospital, more cases can be managed medically at home if the condition is stable, regardless of the advanced stage of the disease. There is a need for expertise in the disease. However, there is a common idea when making therapeutic decisions including the timing for the introduction of palliative care and end-of-life care.

Although it cannot be denied that the need for in-hospital treatment tends to be decided depending on the severity of the disease, home medical care has been providing a treatment environment similar as that in the hospital. In addition, choice of continuing care at home is not uncommon based on the patient's values. In this chapter, we describe diseases, including intractable diseases, which are more likely to be treated in home-care settings.

(Hideki Ohta)

The Yuumi Memorial Foundation for Home Health Care website has a section providing a listing of medical facilities dedicated to home medical care.

Please contact our executive office if you are interested in signing up for the listing.

Note) The website only provides names with contact information of the physicians and medical facilities, which are not intended for recommendation.

1. Chronic Respiratory Failure—Procedures for Comprehensive Pulmonary Rehabilitation—

The treatment that improves shortness of breath and the QOL in patients at home with chronic respiratory failure is the comprehensive pulmonary rehabilitation and palliative care. We describe here practical programming for the comprehensive pulmonary rehabilitation centering on exercise.

Introduction

In Japan, although the comprehensive pulmonary rehabilitation (hereafter referred to as rehabilitation) is common in hospitalized patients and outpatients, the pulmonary rehabilitation aiming to improve patients at home with severe respiratory failure is not widely available.

Patients with chronic obstructive pulmonary disease (COPD) in Japan are 10 years older than patients in the U.S and are more likely to have orthopedic disorders and cardiovascular disease. In addition, ADLs severely decrease in patients at home with severe respiratory failure who require home-visit medical services compared to the outpatients. Therefore, pulmonary rehabilitation centering on exercise is often difficult to implement.

In addition, since assessment tests are not adequately performed and sufficient number of staff is not available in home-care settings, pulmonary rehabilitation is difficult to implement in the same manner as would be implemented in hospital. The widespread use of pulmonary rehabilitation at home needs to develop a comprehensive program that is simple to implement and evidence-based.

Effectiveness of Comprehensive Pulmonary Rehabilitation

The QOL in patients with chronic respiratory failure is specified based on shortness of breath. The primary aim of pulmonary rehabilitation is “reducing shortness of breath” and “improving ADL and QOL.”

Smoking cessation and oxygen therapy improve the prognosis, and exercise and drugs contribute to relieving shortness of breath. Exercise has been shown to be effective in the following: 1) increasing exercise tolerance, 2) reducing dyspnea, 3) improving health-related QOL, 4) decreasing the number of hospitalizations and days in the hospital, 5) reducing anxiety and depression associated with COPD, 6) preventing the decline of respiratory function, increasing exercise tolerance, and improving BMI (3 years) (Evidence level A for 1-6), 7) improving arm function by strength and endurance training, 8) continuing the efficacy after discontinuation of training, and 9) improving survival rate (Evidence level B for 7-9).

Assessment

There needs to be an understanding of the severity of shortness of breath, medication history, patient’s wishes for further treatment, diet and nutrition, changes in weight, smoking status, vaccination history and use of oxygen, and then a discussion about each component of pulmonary rehabilitation with the patient and then manage the issues. Opinions about invasive interventions (life-sustaining care), such as ventilation, in acute exacerbation are asked, if possible.

Blood tests should be performed regularly checking for inflammatory responses and nutritional status. Monitoring KL-6 and SPD regularly is helpful to detect interstitial pneumonia. NT-Pro BNP is also checked for the degree of cor pulmonale.

If chronic lower respiratory tract infection is observed, sputum is routinely tested for bacteria. Since the detection rate of bacteria is high in chronic lower respiratory tract infection, unlike community-acquired pneumonia, it is an important consideration in the choice of antibacterial agents when symptoms are exacerbated.

Use of a pulse oximeter is essential for respiratory management because it is highly portable and a noninvasive procedure. Interpretation of the SpO₂ should be taken with caution as there is a measurement error of $\pm 2\%$; it is not reliable when 50% or less, and the sensitivity can be poor when SpO₂ is close to 100%. SpO₂ is not able to be measured when there is decreased peripheral blood flow caused by cold, edema, peripheral circulation insufficiency, and hypotension.

Practice of Comprehensive Pulmonary Rehabilitation

The component of comprehensive pulmonary rehabilitation is summarized in the **Table**.

A. Home Oxygen Therapy (HOT)

The RCTs conducted in the early 1980s, such as NOTT¹⁾ (the U.S.) and MRC²⁾ (the U.K.), revealed that administration of oxygen improves prognosis in patients with COPD. The estimated numbers of patients with HOT is about 160,000 in Japan. Although the number of new cases is increasing steadily every year, the percentage of patients who fail to meet the criteria for use has reached 30%.

At the onset of HOT, the assessment of blood gas analysis (BGA) at rest, exercise stress testing such as the 6-min walk test, nighttime hypoxia by 24-hour SpO₂ monitoring, and pulmonary hypertension by echocardiography are needed. Since it is difficult to perform for exercise stress testing and echocardiography in patients who are decreasing ADLs and have difficulty visiting a hospital, a decision on whether or not to introduce HOT at home is often made by using the result of BGA at rest. SpO₂ may be used for the making the decision instead of BGA. However, if HOT is started without checking PaCO₂ retention, it causes CO₂ narcosis and is dangerous.

The oxygen therapy for dyspnea has only partial effects, such as “improving dyspnea due to improving hypoxia” or “preventing fatigue of the respiratory muscles in association with exercise.” If HOT is introduced and a comprehensive pulmonary rehabilitation is not done, the dyspnea worsens year by year and the patient’s QOL is significantly impaired.

The dose is set to maintain the SpO₂ at rest with 90%–93% for the daily management of HOT, but for primary pulmonary hypertension, the SpO₂ at rest is maintained at 95% to prevent tissue hypoxia. EtCO₂ (or PaCO₂ by BGA) is checked regularly by using a capnometer for type II respiratory failure.

Since patients with interstitial pneumonia often experience hypoxia on exertion, oxygen needs to be given to maintain the SpO₂ between 90% and 93% on exertion. If the patient on exertion receives 2–3 times of oxygen at rest, a concern with the occurrence of CO₂ narcosis is not necessary. The oxygen order should be simple, like 1 L/min at rest and 2 L/min on exertion, rather than being complicated.

The cases of sequelae of tuberculosis often occur at night time with hypoxia. Therefore, the introduction timing of noninvasive positive pressure ventilation (NPPV) is discussed based on the nighttime SpO₂ level and the presence or absence of respiratory depression by using a pulse oximeter with a memory function as well as PaCO₂ level.

If high dose oxygen is needed due to failing to maintain SpO₂ by nasal cannula or drying of the nasal passages by using a normal cannula (tends to dry up with more than 3 L/min), Oxymizer® is used. Use of nasal cannula at 4 L/min is equivalent to Oxymizer® at 2 L/min.

Table. Component of Comprehensive Pulmonary Rehabilitation

Social activities	Daily activities, social participation, travel support
Excise	Instructing to improve ADLs. Particularly, leg exercise is important to improve walking distance. Respiratory muscle stretching exercise and arm exercise are performed.
Chest physiotherapy	Breathing exercises (pursed-lip breathing, abdominal breathing), exercising to cough up phlegm
HOT	Instructing to operate the device, improving patient's compliance
Nutritional consultation	Increasing weigh, high-calorie diet, high-protein food (branched-chain amino acids intake)
Drug therapy	Taking appropriate drugs, improving patient's compliance, instructing how to use inhalers
Patient education	Advising regarding daily activities such as smoking cessation, nicotine-replacement therapy, transferring, bathing, eating, toileting and sleeping.
Psychologic support	Supporting to receive effectively total respiratory treatments

B. Nutrition

Although “severe wasting” and “severe dyspnea” associated with chronic respiratory failure are prognostic factors that are unrelated to respiratory failure conditions, “a BMI of less than 20” or “standard mass ratio <90%” are prognostic factors. The percentage of patients with malnutrition of HOT patients with chronic respiratory failure is 74% of patients with emphysema, 60% of patients with sequelae of tuberculosis, and 35% of patients with idiopathic interstitial pneumonia,³⁾ and they often have amino acid imbalance (decreased BCAA/AAA).

The standard mass ratio is calculated based on height and weight, and serum albumin (Alb) and rapid turnover protein (RTP), such as prealbumin, are measured for nutritional assessment (only RTP is often decreased in the case of chronic respiratory failure). If Alb or RTP are decreased or the standard mass ratio is 90% or lower, nutritional interventions are necessary.

The basic nutritional therapy in patients with chronic respiratory failure is high-calorie/high-protein diet. The calorific requirements are generally calculated using the stress factor with at least 1.3. In the actual nutritional prescription, 500–600 Kcal/day of oral nutritional supplements and 16 g/day of branched-chain amino acids are necessary.

C. Smoking

A percentage of the risk of developing COPD associated with tobacco is 80%–90%, and the forced expiratory volume in 1 second percentage (FEV1%) decreases an average of 60 mL/year (2–3 times a normal condition). It certainly worsens prognosis. It takes two years until the percentage reduction of lung function in patients who are smoking is comparable to that in patients who are non-smokers.

D. Exercise

Exercise is important to improve dyspnea and QOL for patients with chronic respiratory failure. Exercise should be included in pulmonary rehabilitation for the majority of the patients with chronic respiratory failure, regardless their age and ADLs.⁴⁾ Patients with respiratory failure

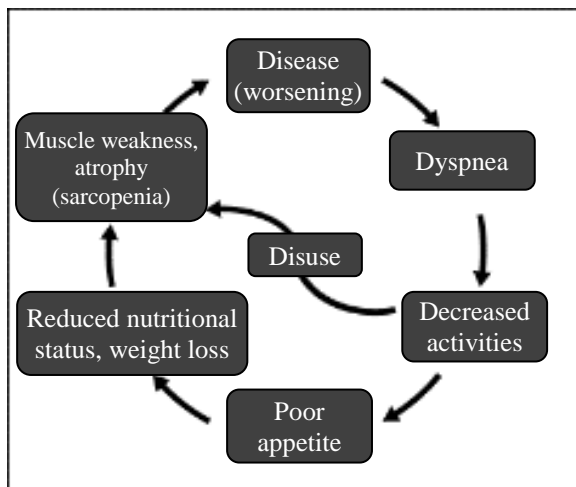
continue the vicious circle (**Figure**) of the following: “Do not want to move because of breathlessness” → “Losing appetite and muscle weakness due to not moving, which then worsens dyspnea.”

Specific skeletal muscle atrophy is observed in the limb muscles in patients with chronic respiratory failure. Functionally, decreasing the amount of oxygen used for aerobic respiration and the aerobic exercises threshold are observed, and anaerobic respiration occurs in muscle cells soon after exercise and the lactic acid accumulates. The cause of dyspnea is not only abnormal lung, but also abnormal skeletal muscle. If aerobic exercises are able to be done, it improves dyspnea on exertion and increases exercise tolerance. Exercise is effective in the majority of the patients with chronic respiratory failure except contraindications, regardless of their age and ADLs.

The most effective exercise is leg exercise (Ranking A).⁴⁾ Rehabilitation at home often focuses on ambulation exercises. Although strenuous exercise is more effective, begin with light exercises such as stamping and then proceed to improve the walking distance in elderly patients at home who have severely decreased ADLs. Encouragement by staff and provision of a secure environment are important.

Exercise for elderly patients at home’s intensity is adjusted using a maximal heart rate of 0.6 calculated by the HRR method ($[220 - \text{age}] - 100 \times 0.6 + 100$). If the patient does on his/her own, the level 3 (moderate shortness of breath) in the Borg scale is used as adequate level for walking. The goal of exercise is established for each patient and walking duration increases slowly and the exercise should be done for at least three days/week.

Figure. Vicious Spiral of Dyspnea



Begin with respiratory muscle stretching exercise and then proceed to do the low stress arm training (Ranking B) in patients who have severely decreased their ADLs or patients who should not be allowed to do leg exercise. Respiratory muscle stretching exercise includes six exercises, such as “lifting and lowering the shoulder” and “stretching respiratory muscle, which is used for breathing,” and reducing residual capacity and improving dyspnea are expected. Arm exercise aims to improve the accessory muscle. Put a 500 g wristband on your wrist and lift the arm in front and side for about 2 min. When

getting used to do it, do few times with 2 min resting between exercises. Since arms have small muscle mass, a long exercise is difficult. Therefore, the duration should be within 20 min.

Exercise is not suitable for the following patients: patients with pulmonary vascular disease such as primary pulmonary hypertension, which can result in sudden death, patients with idiopathic pulmonary fibrosis and end-stage lung cancer patients whose progression of the disease is faster than the appearance of rehabilitation effect, patients who have complications of cardiovascular disease, such as uncontrolled severe heart failure and ischemic heart disease, and patients who have inevitable hypoxia on exertion under administration of high dose oxygen.

E. Treatment

Reversible airway is observed in 10%–30% of patients with COPD. Bronchodilators reduce airway resistance, the overexpansion of the lung and dyspnea. Since parasympathetic activity in the airway is elevated in patients with COPD, and β -receptor is reduced in elderly patients; anticholinergic inhalation, which is first-line treatment, improves dyspnea and acute exacerbations in patients with COPD. Anticholinergic medications have fewer side effects and no drug resistance, even when continuously and long-term.

Treatments should be considered for each disease as the following: macrolide therapy for chronic lower respiratory infection, such as diffuse panbronchiolitis (DPB), administration of pirfenidone (Pirespa®) for idiopathic interstitial pneumonia, continuous administration of prostaglandin for idiopathic pulmonary hypertension, and introduction of NPPV for sequelae of tuberculosis and emphysema.

F. Breathing Techniques and Relaxation

Pursed-lip breathing is the most important to learn of breathing techniques and abdominal breathing is an option.

Relaxation aims to relax the muscular strength and reduce unnecessary oxygen consumption and tension.

G. Chest Physiotherapy

Postural drainage is effective for preparation before daily activities and exercise in patients with respiratory failure who produce large volumes of sputum such as in bronchiectasis, chronic bronchitis, and DPB. The area where mucus collects is estimated based on image diagnosis and auscultation. Mucus is expelled when keeping the body positioned for 10–15 min. Adequate water intake and expectorants inhaled before drainage is effective. Effective coughing facilitates expectoration after postural drainage.

The most effective manual expectoration techniques are by squeezing. Applying force at the beginning of expiration, mucus is brought up with the residual air. Be careful to not add excessive force (about 500 g), and it is performed by placing the whole palm with even force.

H. Infection Control

When patients with ventilator dysfunction are infected with pneumonia or influenza, the rate of mortality is high. Therefore vaccination is recommended. Influenza vaccination is also effective for the elderly due to preserving humoral immunity. The effect is maintained for six months from the first injection before outbreak. Pneumococcal vaccine is effective against 80% of pneumococcal infections, and the effect is maintained for five years.

(Satoshi Hirahara)

References

- 1) Nocturnal Oxygen Therapy Trial Group. Continuous nocturnal oxygen therapy in hypoxic chronic obstructive lung disease. *Ann Int Med.*1980;93(3):391-398
- 2) MRC Working Party. Long-term domiciliary oxygen therapy in chronic hypoxic cor pulmonale complicating chronic bronchitis and emphysema. *Lancet.*1981;1(8222):681-685.
- 3) 成田亘啓, 他 : 慢性呼吸不全 (準呼吸不全を含む) 患者の栄養状態. 呼吸不全調査研究班平成 6 年度報告書 : 24-28, 1995. Nobuhiro Narita, et al. Nutritional status in patients with chronic respiratory failure (including quasi-respiratory failure). Report on Research Committee of Respiratory Failure 1994.1995;24-28.
- 4) AACVPR 編 : 呼吸リハビリテーション・プログラムのガイドライン (第 2 版). ライフサイエンス出版, 1999. AACVPR. Guidelines for Pulmonary Rehabilitation Programs 2nd ed. Life Science Publishing Co., Ltd.;1999.

2. Amyotrophic Lateral Sclerosis (ALS)

ALS is a rapidly progressive degenerative disease that causes multiple dysfunctions in series and lowers activity levels. It becomes lethal by triggering respiratory failure. Maintaining as much QOL as possible requires appropriate informed consent and response based on predicted progression. The disease poses many ethical issues as to how to help patients accept their death.¹⁾

Summary of Disease

Voluntary movement is progressively impaired. Approximately 5%–10% of the cases are hereditary (about 20% of which are due to SOD1 gene abnormality). Apart from voluntary movement, sensory disturbance, cerebellar ataxia, and autonomic nervous system disorders are generally not observed with few exceptions in hereditary cases. In cases that are on a ventilator with prolonged duration of the disease, external ophthalmoplegia and nonmovement disorders occur. Cognitive function was believed to remain intact in the past. However, approximately 20% of the cases entail cognitive dysfunction early on, and approximately 50% of the progressive cases develop a higher cerebral dysfunction.²⁾ Primary and secondary motor neurons are degenerated and lost, and abnormal proteins accumulate in the remaining neurons. It was recently found that TDP43 accumulation, which is observed in frontotemporal dementia, also occurs in ALS, suggesting pathological continuity between the two diseases.³⁾ With a prevalence of 2–7 cases per 100,000 people, ALS is slightly more common in men than in women. Although the peak age of onset was believed to be 50–60's, late onset is lately increasing.

Summary of Symptoms and Progression

At the onset, muscular weakness (such as inability to skillfully use chopsticks) and muscle atrophy typically appear in the distal upper extremity. The condition gradually starts to affect the proximal muscles as well as upper and lower extremities on the opposite side (manifesting a tendency to stumble and inability to stand up). Patients become bedridden as limb weakness progresses and become unable to articulate and choke easily with the development of dysarthria and dysphagia, respectively. Later on, verbal communication is impaired, and tube feeding is necessitated. During the advanced stage, respiratory muscles are impaired, inducing respiratory failure and infectious diseases that cause death. Without a ventilator, the life expectancy of an ALS patient averages about 2–4 years. Because the initial manifestation and how and how fast the disease progresses greatly vary, patient care needs to be on an individual basis. Although radical cure is unlikely, appropriate symptomatic therapy can significantly improve QOL. Thus, the disease requires early intervention that considers how the disease state may unfold.

Diagnosis and Disclosure

A neurologic examination finds primary motor neuron signs (pyramidal signs: paralysis spastic, increased tendon reflex, and emerging pathological reflex) and secondary motor neuron signs (flaccid paralysis, decreased tendon reflex, muscle atrophy, and fasciculation). Because some signs may be absent at the first consultation, ALS is suspected for cases manifesting minor sensory disturbance and major motor dysfunction. At present, no reliable diagnostic marker exists, and therefore, the diagnosis is chiefly made by exclusion. This leaves some chance of

misdiagnosis.⁴⁾ A needle EMG finds abnormality in anterior horn cells and nerve roots. ALS is often associated with spinal osteoarthritis at the peak age of onset, making the differentiation difficult. If doubt arises with the progression of a case, the case should be re-examined.

“Disclosure” is not just to disclose the name of the disease but also to help the patients and families live better. Patients with sufficient understanding can accept the disease better. However, disclosing uncertain prognosis does not always benefit patients because it deprives them of hope. Informing patients of “no treatment available” is also problematic because symptomatic therapy also treats patients. Because of ALS’s nature of being relatively rapidly progressive and lethal, many cannot readily accept that they have the disease. Therefore, it is important to repeatedly explain and provide suitable mental care each time. It is also important for healthcare workers to encourage patients in daily consultation focusing on the functions they retain and not the ones they lost. It is recommended to read “Clinical Practice Guideline for Amyotrophic Lateral Sclerosis”²⁾ by the Japanese Society of Neurology for the actual narrative to inform patients of ALS, EBM, and diagnostic criteria.

Therapy

No radical care exists for ALS. Riluzole, a glutamate antagonist known to delay the progression of ALS for up to six months, was the only agent covered by insurance. The medication could cause side effects such as nausea and hepatic dysfunction, which can be alleviated in a month or so by using an antiemetic agent in combination; discontinuation is very rare. Edaravone IV injection newly became available under insurance since July 2015. Furthermore, methylcobalamin IM injection completed its trial and is currently being studied for insurance coverage. Regenerative therapy is also possible.

Symptomatic Therapy

Symptomatic therapy and informed consent suited to each stage should be performed by evaluating the patients’ acceptance of the changing disease state and progression as well as their predicted status 1 or 3 months later. Patients are forced to make various medical treatment decisions and often refuse if possible without specific reasons. Both undergoing treatment and not undergoing treatment have their pros and cons. Thus, health care workers need to provide sufficient information on medical treatments to support the patients’ understanding and decision making.

A. Quadriplegia

To diagnose quadriplegia, ALSFRS²⁾ is used for understanding the progression of dysfunction such as manual muscle weakness. Advice should be given according to the extent of the progression. The body weights of patients need to be recorded without fail.

Rehabilitation (hereinafter abbreviated as “rehab”) and orthotics are considered for quadriplegia patients. Because excessive rehab is counterproductive, controlled rehab should be conducted if persistent fatigue is noted. Because contracture could cause pain, joints need to be maintained lax all the time.

For upper extremity muscle weakness, various easy grip nursing care products and balancers such as BFO can be introduced. It is also advised to place a box on a desk to raise the height of the desk when patients eat. For lower extremity twitch and cramp, spasmogenic substances may be administered. Patients can be advised to use a crane, walker, wheelchair, elevating chair, and elevating toilet seat when necessary. Consultation with care managers is required before arranging house adaptation covered by the long-term care insurance. Because patients gradually

spend more time on bed, ingenuity is required to prevent bed mattresses from causing pain. Patients are recommended to rent objects and experience them first before making any purchase.

B. Dysphagia

In collaboration with speech-language-hearing therapists (ST) and otolaryngologists, laryngoscopy and videofluorography are performed to examine swallowing function and conduct swallowing training. Food items that patients easily choke on need to be avoided. Patient food needs to be minced and thickened. Oral ingestion of enteric nutrient is also considered. Periodic body weight measurement and blood sampling are conducted to monitor the nutritional condition. Tube feeding is introduced for patients who develop pneumonia aspiration or who spend 1 hour or more eating despite of all ingenuity. Tube feeding is adopted before patient starts losing weight. Gastrostomy is preferable for cases that are deemed to survive for at least 6 months. To perform gastrostomy comfortably and safely under intravenous anesthesia, respiratory function needs to be %VC50% or more. When patient declines tube feeding upon sufficient understanding and family consent, he/she continues oral feeding or, alternatively, only takes injections to be followed up.

To prevent increased hygrostomia, which could cause aspiration, anticholinergics (such as Pollakis) and tricyclic antidepressants may be administered while balancing their side effects. Also recommended are the application of scopolamine ointment (special prescription, not covered by insurance) and the use of continuous low pressure suction machine for oral cavity. Suction device and CoughAssist are used for drainage dysfunction.

C. Dysarthria and Communication Disorder

Inability to communicate is extremely frustrating. Thus, means of communication need to be prepared at an early stage. At first, ST should instruct patients to speak slowly in a low pitch with punctuations so that listeners can easily discern voices with dysarthria. Written communication is encouraged for those who can write. Communication board and portable communication device (Talking Aid® and Let's Chat®) may be introduced for those unable to write. Computer training should be provided to patients so that they can cope with advanced dysfunction. All-in-one PC called "Den-no-Shin®" and software developed for the disabled (Operation Navi® and HeartyLadder®) are commonly used. These systems detect slight movements (subtle limb movements, oculomotor and forehead wrinkles). Also commercially available are the ones that enable brain waves and cerebral blood flow to input information. Less than 20% of cases on a ventilator for at least 5 years develop the totally locked-in state (TLS) syndrome. Many cases, however, retain the ability to communicate and remain socially active even after using a ventilator for 10 years or longer.²⁾

D. Respiratory Muscle Disorder

Respiratory rehab, requires caution because, although it is effective to some extent, it could cause respiratory muscle fatigue at the advanced stage. Respiratory function test should be performed every 3 months if available. Ventilator-related policy needs to be made at %VC50%. Because %VC readings are often inaccurate, PCO₂ values should also be referred. Ventilator-related policy should be verified at 45 Torr or more, and at least NPPV-related policy should be finalized before reaching 50 Torr.

NPPV can be introduced at night only to improve daytime ADL in patients who start to experience daytime fatigue and show a PCO₂ elevating trend. As patients need time to accustom to NPPV, early introduction is necessary, in which the trial is gradually increased over time. To note, early introduction can increase adherence in cases with bulbar paralysis. Patients are usually hospitalized to be introduced with and instructed on NPPV, but introduction may be performed on an out-patient basis. For some cases experiencing difficulty with drainage, NPPV may be introduced in conjunction with drainage assistance device (such as CoughAssist®). The duration

of NPPV is gradually increased until it reaches 24 hours a day without weaning off. The therapy cannot sustain life for a long time because it can get complicated with bulbar paralysis. Therefore, end-of-life care should be carefully planned prior to NPPV introduction. The therapy is also applicable for cases unwilling to choose TPPV but want to buy a little more time. Tracheostomy and tracheal separation are considered for cases with repeated painful aspiration. Adequate explanation should be given as to how to deal with the progression of respiratory muscle paralysis.

As a general rule, TPPV is chosen as a home mechanical ventilation therapy. Patients unable to stay at home by any means are referred to hospitals for admission. Realistically, long-term hospitalization while maintaining a certain degree of QOL is often difficult. It is preferable to ask a medical institution familiar with home mechanical ventilation therapy to introduce and instruct patients on the treatment. Home care requires visiting examination by a primary care physician, nursing, and rehab. The disease continues to progress even after a ventilator is being applied. Thus, it is preferable to periodically consult with a neurologist or have a doctor visit every one or few months. Multiple professionals can provide care under the home care system. However, some regions face a difficulty with recruiting caregivers and health care professionals.

Informed Consent at the Progressive Stage

A. Choosing a Ventilator

ALS is a rare disease that forces patients to choose themselves whether to live or die by making choices on ventilator. It is essential for patients to think thoroughly and convince themselves without being imposed upon by the physicians' opinion in the decision making process. Patients require appropriate disclosure and information to be provided to them from early stage to deliberate.

Adequate disclosure includes ensuring patient understanding on specific patient condition after implementing a ventilator, either good or bad; informing about nursing and economic issues; informing that the disease progresses even after implementation; and informing that the current condition does not allow the patient to wean off the ventilator. It is also important to hear directly from other ventilator-assisted patients who are satisfied with their choice. ALS does not deprive patients of humane feelings. Disability does not necessarily make people unhappy. Patients should be told that TLS, which is often misunderstood, affects only a few (approximately 10%) cases.²⁾

B. Dealing with Cases Choosing Not to Implement a Ventilator

Anguish over ALS starts at the time of diagnosis. Palliative care must continue to provide mental support for patients to accept the disease and to deal with the fear of disease progression and death as well as to take care of various pains associated with limb paralysis. Care usually involves adequately repeated IC, listening to the patient, and the administration of anti-inflammatory analgesics, anxiolytics, antidepressants, and oxygen. Cases with slowly progressive respiratory disorders have little awareness of respiratory discomfort. Oxygen administration in terminal phase easily causes CO₂ narcosis, resulting in slow death. It is, however, difficult to deal with respiratory discomfort in cases with rapidly progressive respiratory disorders, cases with high arousal, and cases on NPPV unlikely to develop CO₂ narcosis. In such cases, appropriate dosage of morphine (available under insurance from September 2011) can relieve pain without disturbing consciousness. The dose is approximately half the dose administered for cancerous pain. An initial dosage of 2.5 mg/time (1.25 mg for CO₂ >60 Torr) should be gradually raised to 5, 7.5, and 10 mg until the desired effect is obtained. The medication is initially taken on an as-needed basis before taking a bath or making movements prone to respiratory discomfort. It can be taken at 3-hour intervals when necessary. The daily requirement of morphine should be properly understood with multiple administrations per day, and should be replaced by the equivalent amount of morphine sulfate. The maintenance dose is often 10–30 mg/day. Fine

granular powder such as Morphes® is chosen to prevent clogging of the feeding tube often used. Suppository can be used in cases without oral and enteric administration. The dose is increased to 100 mg or more as the patient approaches the terminal phase. It is replaced by continuous injection immediately before death to stabilize condition in some cases. Although insurance covers injectables if administered at home, it does not cover pumps if used outside malignant tumors. Oxygen is administered in conjunction with morphine if needed. Consciousness disturbance has to be tolerated before death. Similarly to cancer patients, anti-psychotics and atypical psychotics are effective for patient restlessness. Medication other than benzodiazepine, which often causes respiratory depression, should be prioritized. Medications unlikely to induce respiratory depression including SSRI, SNRI, suvorexant (Belsomra®), ramelteon (Rozerem®), zolpidem (Myslee®), and anti-anxiety lorazepam (Wypax®) are recommended by the guideline. Alleviation of pain enables a comfortable death at home.^{2,5,6)} Unlike malignant tumor cases in terminal phase, ALS patients can survive with a ventilator under tracheostomy. Patient decision, which may change even after opioid initiation, should be checked time to time.

Other Supporting Systems

ALS is a designated intractable disease, in which part of medical expenses are exempted. Retroactive refund is paid back to the point of application by completing prescribed procedures. Health nurse in charge of intractable diseases starts engaging upon the filing of application.

Patients over 40 years of age can apply for long-term care insurance as a second insurance. Patients receiving physical disability certificate are eligible for services provided under the Services and Supports for Persons with Disabilities Act (including visiting nursing). Nationwide patient networks provide various information and offer exchange forums.

(Mieko Ogino)

References

- 1) 福永秀敏：ALS 患者の介護・在宅医療。神経内科 54：41-47，2001。Hidetoshi Fukunaga: ALS patient nursing and home medical care. Neurology 54: 41-47, 2001.
- 2) 日本神経学会 筋委縮性側索硬化症診療ガイドライン 2013。南江堂，2013。Japanese Society of Neurology Committee for the drafting of guideline for amyotrophic lateral sclerosis: 2013 Guideline for amyotrophic lateral sclerosis. Nankodo Co., Ltd., 2013.
- 3) 長谷川成人，他：ALS でみられるユビキチン化封入体の構成蛋白。BRAIN and NERVE 59 (10)：1171-1177，2007。Masato Hasegawa *et al.*: The component protein of ubiquitin-positive inclusions in ALS. BRAIN and NERVE 59 (10): 1171-1177, 2007.
- 4) Belsh JM: Diagnostic challenges in ALS. NEUROLOGY 53 (Suppl 5), S26-30, 1999.
- 5) 荻野美恵子：侵襲的人工呼吸療法を選択しない ALS 患者さんの緩和ケア。難病と在宅ケア 12 (9)：23-26，2006。Mieko Ogino: Palliative care for ALS patients not choosing invasive positive pressure ventilation. Intractable diseases and at-home care 12 (9): 23-26, 2006.
- 6) 成田有吾 編：神経難病在宅療養ハンドブック よりよい緩和ケア提供のために。メディカルビュー社，2011。Edited by Yugo Narita: At-home care handbook for intractable neurological disorders To provide a better palliative care. MEDICAL VIEW CO., LTD., 2011.

3. Parkinson's Disease

In 1817, an English physician James Parkinson proposed a “shaking palsy” disease to describe what later was named as Parkinson’s disease (PD) by a French neurologist Charcot. The prevalence of PD in Japan is 100–150 per 100,000 and is expected to rise as the population ages. Home care of PD patients requires 1) accurate understanding of the disease stage, 2) accurate differential diagnosis, 3) treatment that respects the patient’s lifestyle, and 4) collaboration between medicine, nursing, and welfare. This article outlines the disease and illustrates the key features of the home care.

Parkinson's Disease

In Parkinson’s disease (PD), dopaminergic neurons are lost in the substantia nigra, and abnormal accumulation of α -synuclein induces Lewy bodies, thus impairing a dopamine neuron network that spans from the substantia nigra to the striatum. Patients exhibit motor symptoms (the four most common symptoms): tremor, muscle rigidity, hypokinesia/akinesia, and postural reflex impairment/gait disturbance. Nonmotor symptoms are also attracting attention recently.

Tremor is a frequent motor symptom in early stages of PD in which resting tremor regularly occurs at 4–6 Hz. Unlike spasm, rigidity promotes hypertonia in both the flexor and extensor muscles. A common type of rigidity in PD is cogwheel rigidity, which is felt as an intermittent wobble. These initial symptoms develop on one side of the upper or lower extremity and later spread to both the upper and lower extremities on both sides. When postural reflex is impaired, patients become prone to losing balance. With the progression of this disease, anteversion-anteflexion posture becomes prominent. Pulsions, frozen gait, and a tendency to fall also develop. Approximately 20% of the cases first manifest muscle rigidity, bradykinesia, and gait disturbance without any conspicuous tremor. In either case, L-dopa becomes less effective and causes many issues by its long-term administration over time.

Nonmotor symptoms often develop in PD, sometimes predicting motor symptoms. These include affective disorders such as depressive state and anxiety; autonomic symptoms including constipation, abnormal sweating, urination disorder, and blood pressure fluctuation; and pain. Psychiatric symptoms such as REM sleep behavior disorder, impulse control disorder, and apathy (loss of motivation) are often accompanied. The form of dementia in PD is Lewy body dementia in many cases or, more specifically, 83% of the cases according to a 20-year follow-up study. It is reported that hyposmia precedes the onset of PD in some cases, possibly associated with the future development of dementia. Some facilities include olfactory test when they make initial diagnosis.

Differential Diagnosis of Parkinson's Disease

Accurate differential diagnosis is essential to treat PD, predict its prognosis, and utilize necessary social resources. Some cases are, however, difficult to differentiate in early stage. More than few cases, which had been receiving PD treatment, turned out to have different diseases. Recently, new diagnostic imaging technology useful for differentiating PD is gaining popularity. MIBG myocardial scintigraphy is used to examine sympathetic nerve function in cardiac failure and cardiomyopathy. When PD progresses to cause autonomic nerve system disorders, 123I-MIBG no longer aggregates in the cardiac muscle. Similar change is also seen in Lewy body dementia and multiple system atrophy. However, decreased accumulation is absent in progressive supranuclear palsy and corticobasal, both of which are related to PD. SPECT test (scintigraphy),

also known as dopamine transporter (DAT) scan, which detects DAT in the brain, is useful for diagnosing Parkinson's syndrome and Lewy body dementia. When it is difficult to diagnose cases on the basis of clinical symptoms in home-care settings, these diagnostic imaging should be used without reservation to ensure accurate diagnosis and prompt prognosis prediction. Drug-induced Parkinsonism requires particular attention. Antipsychotics and antidepressants are well known to exert adverse effects. But some of the antiemetic, antiulcer, antihypertensive, antitumor, antiviral, and antifungal agents cause drug-induced Parkinsonism as well.

Treatment of Parkinson's Disease

Currently used medications in Japan include combination preparations comprising L-dopa and dopa decarboxylase, dopamine receptor stimulants, anticholinergic agents, dopamine release enhancers, monoamine oxidase B (MAO-B) inhibitors, catechol-O-methyltransferase (COMT) inhibitors, noradrenaline supplements, zonisamide, apomorphine injections, and adenosine A_{2A} receptor antagonists. Various formulations and combination preparations have been developed according to patient needs (See **Table**).

According to "Clinical Practice for Parkinson's Disease" from Japanese Society of Neurology, cases less than 70 years old not entailing dementia are initiated with a dopamine receptor stimulant at a small dose, which is then gradually increased to a maintenance dose. Nonergot agents are generally used to avoid cardiac valvulopathy and retroperitoneal fibrosis, which may be induced by ergot agents. Elderly PD cases over 75 years old or cases associated with dementia have L-dopa as their first-line therapy. The 2011 revision of the guidelines recommends to respect patient diversity in treatment.

Medications are combined to respond to the progression of motor symptoms. Additionally, agents to treat nonmotor symptoms are administered. For autonomic symptoms, agents acting on urination function, orthostatic hypotension, and digestive tract peristalsis as well as agents that promote defecation are used. Agents for psychiatric symptoms and symptoms of dementia must be administered with consideration for the impact on Parkinsonism when used.

L-dopa, which is effective in early stage, starts to pose issues associated with its long-term use after 5 years of therapy because of decreased dopamine nerve terminals. These issues include psychiatric symptoms (hallucination and delusion), neurological symptoms (dyskinesia and dystonia), diurnal fluctuations, unstable drug effect, symptoms caused by dopamine agonist resistance (frozen gait and postural reflex impairment), autonomic symptoms, and diminished intellectual function.

Dyskinesia, either choreiform or tremor type, develops when blood drug concentration is high, increasing, or decreasing.

Motor symptoms that become problems as treatment proceeds include wearing-off phenomenon, on-off phenomenon and no-on phenomenon. Wearing-off phenomenon is related to blood drug level, with which motor symptoms either alleviate or worsen. The on-off phenomenon is an abrupt emergence and transient duration of advanced immobility, which occurs regardless of when medication is administered. During the no-on phenomenon, use of medication cannot improve immobility and other motor symptoms. To address these phenomena, the time of doses may be modified and number of doses may be increased. Moreover, low-protein diet; coadministration of dopamine receptor stimulants; and administration of monoamine oxidase inhibitors, catechol-O-methyltransferase inhibitors, and zonisamide are known to be effective. Some dopamine receptor stimulants are available in the form of sustained-release tablets and patches, which can maintain stable and sustained blood drug concentration. Issues that emerge with the long course are almost inevitable in cases treated at home with prolonged duration of illness and decreased motor function. Therefore, treatment policy must be prepared while considering the patient's lifestyle as well as how to reduce the patient's and family's burden.

Malignant syndrome is considered to occur in relation to D2 receptor antagonization. It is induced by withdrawal/dose decrease/irregular dosing of L-dopa or general conditions exacerbated by dehydration and infectious diseases. Patients with malignant syndrome develop fever, sweating, tachycardia, acute aggravation of muscle rigidity and immobility, and consciousness disturbance. Myoglobinuria could cause renal failure, resulting in death. Cases developing malignant syndrome must undergo systemic management and continue the same dose of L-dopa as that before the onset. When enteric administration is difficult, L-dopa infusion ranging from half the dose to the same dose is given. Severe cases are treated with dantrolene sodium (Dantrium®) IV administration. The most important is administration supervision in daily consultations.

Table. Types of Parkinson’s disease medications

<ul style="list-style-type: none"> ● Levodopa Levodopa Levodopa/carbidopa combination preparation Levodopa/benserazide combination preparation Levodopa/carbidopa/entacapone combination preparation
<ul style="list-style-type: none"> ● MAO-B inhibitor Selegiline
<ul style="list-style-type: none"> ● COMT inhibitor Entacapone
<ul style="list-style-type: none"> ● Dopamine agonist Bromocriptine Pergolide Cabergoline Talipexole Pramipexole Ropinirole Rotigotine *Patch Apomorphine *Injection
<ul style="list-style-type: none"> ● Anticholinergics Trihexyphenidyl Biperiden Profenamine Piroheptine Mazaticol
<ul style="list-style-type: none"> ● Dopamine release enhancer Amantadine
<ul style="list-style-type: none"> ● Noradrenaline precursor Droxidopa
<ul style="list-style-type: none"> ● Adenosine A2A receptor antagonist Istradefylline
<ul style="list-style-type: none"> ● Levodopa activator Zonisamide

Nonpharmacologic therapy includes rehabilitation (abbreviated as “rehab” hereinafter) and surgical treatment. The reason to perform rehab on PD patients is to address not only physical function but also psychiatric symptoms such as depression, sleep disorder, and dementia in

addition to aging in order to restore their daily life activities and improve QOL. Engagement is the key to support treatment motivation among patients and their willingness to change their mindsets and lifestyle patterns.

Rehab to be performed on PD patients includes kinesitherapy, occupational therapy, speech therapy, oral cavity function therapy, breathing exercise, physical therapy, orthosis prescription, and house adaptation advice. On the basis of the patient's condition, independent, safe, and comfortable living should be kept in mind when developing a rehabilitation program. To maintain and strengthen basic physical ability, some form of kinesitherapy should be performed on a daily basis. To prevent falling and to slow down and improve weakening muscles and cardiopulmonary function, patients should train their walking, turning, daily activities, rolling over, and rising up, which are all likely to be impaired in PD. Music therapy contributes to QOL enhancement in addition to motor function. To prevent aspiration and deterioration of respiratory function, comprehensive dysphagia and respiratory rehabilitation is considered effective.

Surgical treatment for PD had been available before the advent of L-dopa therapy. Presently, an insurance-covered deep brain stimulation (DBS) method is applied to treat medically intractable cases with marked diurnal variation. Vector-based gene therapy was previously drawing attention. Now, iPS cell-based transplantation therapy of dopaminergic neurons is at the stage of practical use. Its application for drug discovery is also expected.

Home Medical Care for Parkinson's Disease Patients

The principle of home medical care is to respect the patients' daily lives and treat them in "living settings." Needless to say, a patient should always be treated on the basis of a "treat to live" principle and not "live to treat."

L-dopa and dopamine receptor stimulants are effective in early phase of the disease. Thus, it is important to ensure early diagnosis of PD for early treatment. It is reported that dopamine receptor stimulants have a neuroprotective effect. While receiving pharmacotherapy based on the manual developed by Japanese Society of Neurology, patients should be encouraged to naturally incorporate training routines such as walking, stretching, and muscle strengthening into their daily lives. Moreover, a dose that is necessary and sufficient should be administered. When L-dopa is less effective, the dose of L-dopa is increased; alternatively, dopamine receptor stimulants are added. When a sufficient dose of dopamine receptor stimulant fails to be effective, L-dopa is added. Various formulations of dopamine receptor stimulants are available including sustained-release tablets and patches. Formulations and properties of the medication should be considered before administration. The occurrence of adverse effects should be monitored upon administration. When L-dopa is less effective, other forms of Parkinsonism are suspected. Specialists must be consulted to arrange prompt detailed examination and differential diagnosis.

For wearing-off in advanced stage, which is often consulted in home-care settings, following treatment options should be considered: 1) to increase L-dopa frequency, 2) to use agents acting on dopamine metabolism such as selegiline and entacapone, and 3) to use nondopamine agonists including zonisamide and istradefylline. Small doses of anticholinergics, which are effective for tremor in youngsters, may worsen dementia in the elderly. Droxidopa and amantadine are effective for frozen gait and dyskinesia, respectively.

Sexual delusion and pathological gambling are common psychiatric symptoms in PD, imposing enormous mental burden on caregivers. In such cases, treatments for psychiatric symptoms should precede even at the expense of motor function. More specifically, to determine an optimum dose that produces the desired effect without causing psychiatric symptoms, doses of L-dopa and other dopamine agonists are reduced, and atypical antipsychotics are tested. It is recommended to collaborate with physicians versed in PD treatment and to utilize a regional cooperative healthcare system. When PD patients feel nervous in consultations, they tend to

perform beyond what they are capable of in daily lives. Therefore, home physicians should inform specialists on patients' daily living skills and nursing condition, thereby supporting and ensuring that patients are benefited from appropriate treatment not just in consultations but in daily lives as well.

When the disease progresses to a stage where cases are no longer treatable on an outpatient basis, complication prevention and systemic management are important. Efficacy of medication shortens throughout the day. Orthostatic hypotension manifests with aggravating motor symptoms, making it difficult for patients to perform daily activities and maintain standing and sitting positions. Syncope in some cases leads to prolonged resting state, further worsening the bedridden state. The bedridden state then exacerbates urination disorder, constipation, and the overall disuse syndrome. Hallucination, delusion, and depressive state, either induced by disease progression or medication, substantially impair the patient's QOL. Such cases should be treated as follows: 1) The state of "on" with drug effect should be extended as much as possible; 2) even in the state of "off," mental stimulation should be given to consciousness, which remains intact; and 3) physical care should be given to prevent disuse syndrome and complications. Treatment schedules are decided on the basis of patients' own lives and nursing conditions.

Treatment and nursing of PD accompanied by severe disability imposes enormous burden on patients and families. Attending doctors should recommend the use of various systems and social resources to assist reducing their burden. Patients and families should be recommended to apply for incurable disease and physical disability certificates when dysfunction categorized as Stage III or more on the Yahr stage starts to surface. Because application for both certificates requires a medical certificate prepared by the designated doctor, patients should be referred to a designated doctor that they know well. At this stage, patients should consult with their primary care doctor for possible visiting examinations, contemplating home care in the future.

Conclusion

PD is the most common intractable neurological disease whose cases are increasing with advancing treatments and aging population. The author believes that homes are the best settings to take care of PD patients because it allows them to maintain hope and dignity. However, the reality is that many patients cannot stay home even though they wish to. It is the author's wish that this article will be of some help to home physicians involved in PD treatment.

(Yasunori Ishigaki)

4. Renal Failure

Chronic renal failure is an irreversible and progressive loss of functional nephrons. With end-stage renal failure, about 30,000 patients initiate dialysis per year, and the proportion of elderly patients has been increasing. Peritoneal dialysis is a home-based therapy contributing to the enhancement of QOL and integration of patients back into society. It is also one of the choices for patients with difficulties in adapting to maintenance hemodialysis due to unstable hemodynamics or patients who are incapable of conducting safe extracorporeal circulation.

Assessment of Renal Failure

Chronic kidney disease (CKD) is defined as either kidney damage (e.g., proteinuria) or decreased renal function demonstrated by a glomerular filtration rate (GFR) of $<60 \text{ mL/min/1.73 m}^2$ for at least three months. The Japanese Society of Nephrology has revised the severity classification of CKD. However, the post-revision version has become more complicated than before; thus, it has been partially modified and presented in **Table 1**.¹⁾ The severity is classified by importance of risk; however, drug dosage is determined by GFR alone. Therefore, the GFR category has also been established using a six-point scale. Estimated GFR (eGFR) is calculated from age, serum creatinine level (s-Cr), and sex, which is useful in home medical care.

Chronic renal failure gives little subjective symptoms and objective findings until it has progressed, although some differences exist depending on the primary disease. Therefore, chronic renal failure is diagnosed by increases in s-Cr and serum urea nitrogen by a blood test or eGFR. When the s-Cr level exceeds the upper limit of normal range, renal function is decreased, and the condition could be aggravated to chronic renal failure. Therefore, the severity classification of CKD using eGFR is useful for the assessment of renal function, whereas a definite differentiation may be difficult. Creatinine generation rate increases in proportion to muscle mass. Therefore, it should be noted that an increased s-Cr level may not be observed in elderly patients with reduced muscle mass (e.g., sarcopenia), even when the renal function is decreased. In patients with CKD Stage 3 or higher, nephrogenic anemia, hypocalcaemia, and hyperphosphatemia are observed. In patients with CKD Stage 5, uremic symptoms associated with disruption of the fluid control function and accumulation of uremic substances are seen (**Table 2**).

Table 1. Severity Classification of CKD

<Primary disease> Diabetes mellitus, hypertension, nephritis, polycystic kidney disease, transplanted kidney, etc.			Proteinuria		
			A1	A2	A3
			Normal (-)	Mild (\pm to +)	Severe (2+ to 3+)
GFR category (mL/min/1.73 m^2)	G1	≥ 90	A	B	C
	G2	60–89	A	B	C
	G3a	45–59	B	C	D
	G3b	30–44	C	D	D
	G4	15–29	D	D	D
	G5	< 15	D	D	D

According to the severity classification of CKD, the risk of death or aggravation to end-stage renal failure increases in the order of (A) \rightarrow (B) \rightarrow (C) \rightarrow (D). Partially modified from References 1).

Table 2. Symptoms of Renal Failure

Fluid retention	Edema, pleural effusion, ascites, pericardial fluid retention, pulmonary edema
Body fluid abnormalities	Severe hyponatremia, hyperkalemia, hypocalcaemia, hyperphosphatemia, metabolic acidosis
Digestive symptoms	Inappetence, nausea/vomiting, diarrhea
Cardiovascular symptoms	Cardiac failure, arrhythmia
Neurological symptoms	CNS damage: disturbance of consciousness, involuntary movement, sleep disorder Peripheral neuropathy: itching, numbness
Blood abnormalities	Severe nephrogenic anemia and bleeding tendency
Visual impairment	Visual acuity reduced, retinal hemorrhagic symptoms, and retinal detachment symptoms

Cited from References 4).

Current State of Chronic Dialysis Patients

In Japan, more than 310,000 patients are on chronic dialysis, which is equivalent to 1 in 400 people in Japan.²⁾ Although the number of dialysis patients has been increasing every year, the number of patients initiating dialysis hit a peak in 2011 and has remained at the same level. In a few years from now, the number of dialysis patients is expected to start decreasing. Home hemodialysis is performed in only 461 patients (0.15%), indicating that it is an extremely special treatment; however, the number of patients has doubled in the last five years. Peritoneal dialysis (PD) is used by 9245 patients (2.94%), and the number of patients tends to decrease gradually. The remaining 97% of the patients receive hemodialysis.²⁾

The mean age of dialysis patients is 67.2 years, and the mean age of patients initiating dialysis is 68.7 years, showing aging of patients, which is similar to that in the entire Japanese society. Therefore, hemodialysis should be initiated or continued in consideration of ethical aspects. For this issue, the Japanese Society for Dialysis Therapy made a proposal,³⁾ which will be discussed below.

Determination for Initiation of Dialysis

The Japanese Society for Dialysis Therapy has published the guidelines for hemodialysis initiation.³⁾ According to the guidelines, whether dialysis should be initiated should be determined not only by decreased renal function but also by comprehensive evaluation of symptoms of renal failure (uremia), activities of daily living, and nutritional status. Only when dialysis therapy cannot be avoided, the initiation should be determined. The procedure can be also applied to PD.⁴⁾

Specifically, in cases with progressive aggravation of renal function, even when receiving adequate conservative treatment and GFR reduces to $<15 \text{ mL/min/1.73 m}^2$, the symptoms of renal failure, activities of daily living, and nutritional status should be comprehensively evaluated. When the score increases to 60 or higher, maintenance dialysis is suggested.

Determination of the Dialysis Method (Advantages and Disadvantages of PD)

By filling 1.5 to 2.0 L of dialysate into the peritoneal cavity, the peritoneum acts as a semipermeable membrane, and waste products (solutes) and water are transferred to the dialysate

on the basis of the principle of diffusion and osmosis, respectively. PD is a home dialysis therapy based on these properties.

The most standard method is continuous ambulatory PD (CAPD) that allows 24-hour slow dialysis by exchanging dialysate of the peritoneal cavity four or five times a day. The number of exchanging dialysates and retention period vary depending on the patient's condition.

Table 3. Comparison between Hemodialysis and CAPD

	Hemodialysis	CAPD
Basic principle	The patient's blood is taken outside the body and passed through a dialysis membrane to clean the blood. The clean blood is returned back to the body.	Dialysate is infused into the peritoneal cavity and retained for a certain period of time to remove wastes from the blood through the peritoneum.
Surgery to be performed in advance	Shunt placement. The artery and the vein are connected to provide sufficient blood flow.	Catheter implantation for PD to establish a route for infusion and drainage of dialysate.
Frequency of treatment	The patient visits a dialysis center 3 times a week regularly. It takes 4 to 5 hours per dialysis.	The patient completes 4 dialysate exchanges every day. It takes about 30 minutes per exchange. Monthly hospital visit in a basic manner.
Duration of treatment	Semipermanent. Depending on physical conditions, the duration may be limited.	Less than 10 years. Depending on the peritoneal function, the duration may be shortened.
Level of self-management	Requires less self-management.	Self-management is absolutely necessary.
Freedom in terms of time	The patient is free on nondialysis days.	The patient is relatively free in terms of time but is required to exchange the dialysate every day.
Scope of activities limited (e.g., traveling)	Relatively limited. However, the patient is free on nondialysis days.	Not limited. However, the patient has to carry medically necessary goods.
Social rehabilitation	Having a slight disadvantage due to restrictions of time.	The treatment is relatively adjustable to the patient's lifestyle and work.
Bathing	Free	Inconvenient because of care of the exit site.
Diet	Restriction of protein and potassium (K) intake. Salt-restricted diet (≤ 7 g/day). Phosphorus- (P-) restricted diet.	A slightly increased dietary protein intake is recommended. Less potassium (K) intake restrictions. Depending on the patient condition, a slightly increased potassium (K) intake is required. Salt-restricted diet (≤ 7 g/day). Phosphorus- (P-) restricted diet.
Fluid intake	Restricted	In some patients with residual renal function and capable of removing extra fluid, fluid intake is rarely restricted.
Urine output	Likely to decrease	Likely to be unchanged
Remaining renal function		Development of complications associated with long-term dialysis may be delayed. After loss of the residual renal function, few medical advantages are gained.

The most common advantage of PD is that the residual renal function is likely to be maintained because PD does not produce sudden hemodynamic changes and results in fewer hospital visits (**Table 3**). In contrast, the most common disadvantage of PD is that, after loss of the residual renal function, PD alone may be insufficient for the treatment and deterioration of

the peritoneum limits the available duration of conducting PD. Thus, PD is more adequately indicated for patients maintaining urine output during the initial phase of dialysis and elderly patients with difficulty in visiting a dialysis clinic.

Nephroprotective Therapy

Prior to initiation of dialysis, blood pressure control is the most important component of nephroprotective therapy, with a target of <130/80 mmHg. Previously, a desirable blood pressure was established as <125/75 mmHg under the specific conditions. However, recent clinical research revealed that excessive depression may aggravate renal function. For patients aged 65 years or older, the target blood pressure is established as 140/90 mmHg, and a decrease in systolic blood pressure (SBP) to <110 mmHg should be avoided.

First-line antihypertensive agents are renin-angiotensin system inhibitors, such as ACE inhibitors or ARB, because they have nephroprotective effects. Adverse drug reactions include an increase in serum K level; therefore, the dose should be carefully adjusted along with the reduction of renal function. After initiation of dialysis, these antihypertensive agents may also be effective in preserving the residual renal function.⁵⁾ In particular, PD patients have a lower risk of serum K elevation; therefore, the antihypertensive agents should be used in a positive manner. If the target blood pressure is not achieved, long-acting calcium-channel blockers should be combined. It is desirable not to combine ACE inhibitor and ARB.

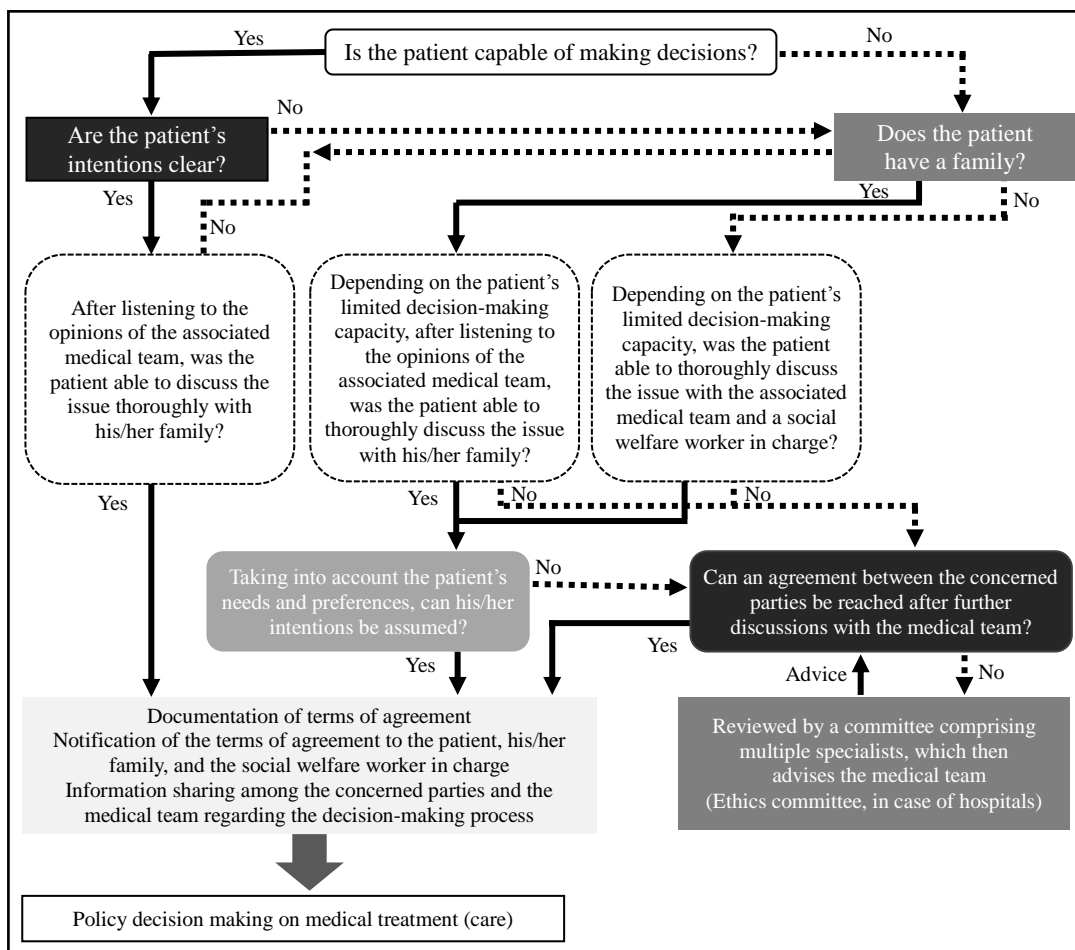
Home Dialysis Management –PD Management–

PD is a choice of treatment that can preserve the residual renal function. Maintenance dialysis is initiated to eliminate the possibility of developing uremia over time because the patient's renal function alone is insufficient for the removal of water and solutes. Originally, the shortfall alone can be removed by dialysis. Thus, 4 L of dialysate per day is sufficient during the initial phase of PD. With regard to water, urine output is maintained during the initial phase of dialysis; therefore, water removal by PD is unnecessary.

Advantages of a PD prescription by limiting water removal to a minimum level include reduction of the risk of peritoneal damage induced by dialysate, preservation of the residual renal function, reduction of a temporal burden to exchange dialysate, and reduction of medical cost for dialysate and supply equipment. Disadvantages include that the extracellular fluid is likely to be retained. Sodium (Na) concentration of dialysate is almost equivalent to that of the extracellular fluid; therefore, little Na diffuses into the dialysate. Thus, when water removal volume is zero, the release of Na into the dialysate should also be zero. When water removal is kept at a minimum level, Na removal is dependent on urine output. In that condition, salt restriction is required to the level that can be excreted in urine.

PD offers a high degree of freedom in a temporal and spatial manner; however, it gives a large burden of self-management. Weight gain should be recognized as accumulation of Na rather than water retention, which should be instructed to patients. Infectious peritonitis is a complication specific to PD, and it causes early withdrawal from PD. Education of patients for a clean procedure is critical. Cloudy drainage is a sign of early peritonitis. Therefore, when cloudy drainage is detected, drainage culture is needed to identify the causative organism prior to antibiotic administration, and then immediate proper antibiotic treatment should be started.

Figure. Decision-making Process for the Forgoing of Hemodialysis



Ethical Aspects of Maintenance Hemodialysis

In recent years, dialysis patients have been getting older. Also, an increasing number of dialysis patients are complicated with cancer or long-term recumbency. Dialysis itself has been shifting from a treatment aiming at social rehabilitation to that containing a factor of life prolongation. Under such circumstances, the Japanese Society for Dialysis Therapy published Proposal for the Shared Decision-Making Process Regarding Initiation and Continuation of Maintenance Hemodialysis in 2014 (Figure).⁶⁾ The basic policy of this proposal is that a treatment plan of end-stage renal failure patients should be determined not only by a physician alone but also by a medical team, and that, in consideration of patients' dignity, withdrawal from maintenance hemodialysis is also one of the choices. However, it should be kept in mind that these are the proposal by the Society and are not legally binding.

In this proposal, ethical aspects of PD are not mentioned, probably because of the following reasons. In comparison to hemodialysis requiring short-time intermittent extracorporeal circulation, PD offers 24 hour slow continuous dialysis with an extremely low effect on hemodynamics. PD patients are free from puncture site pain for each dialysis and from restraint by equipment for safety maintenance of the dialysis circuit. PD is very unlikely to require sedative agents. Also, PD can be done at home. On the basis of these characteristics, PD has substantially different physical and psychological effects on patients from those of maintenance

hemodialysis. Therefore, it would probably be difficult to apply the same criteria as maintenance hemodialysis.

PD is considered as an alternative choice for patients with difficulty in maintaining hemodialysis. For PD patients, sufficient information and safety should be provided according to the patient conditions, and also, whether or not the treatment follows the patient and family wishes should be thoroughly examined by the medical team.

(Makoto Nishina and Mitsunori Yagame)

References

- 1) 日本腎臓学会 編：CKD 診療ガイド 2012. 東京医学社, 1-4, 2012. Japanese Society of Nephrology (Ed): Clinical practice guidebook for diagnosis and treatment of chronic kidney disease 2012. Tokyo Igakusha, 1-4, 2012.
- 2) 日本透析医学会：わが国の慢性透析療法の現況（2013年12月31日現在）The Japanese Society for Dialysis Therapy: An overview of chronic dialysis treatment in Japan (as of Dec. 31, 2013) <http://docs.jsdt.or.jp/overview/index.html>
- 3) 日本透析医学会：維持血液透析ガイドライン 血液透析導入. 日本透析医学会雑誌 46 (12) : 1107-1155, 2013. The Japanese Society for Dialysis Therapy. Guidelines for Maintenance Hemodialysis: Hemodialysis Initiation. *Journal of Japanese Society for Dialysis Therapy* 46(12): 1107-1155, 2013.
- 4) 日本透析医学会：腹膜透析ガイドライン. 日本透析医学会雑誌 42 (4) : 285-315, 2009. The Japanese Society for Dialysis Therapy. Guideline for Peritoneal Dialysis. *Journal of Japanese Society for Dialysis Therapy* 42(4): 285-315, 2009.
- 5) Suzuki H, et al: Effects of an Angiotensin II Receptor Blocker, Valsartan, on Residual Renal Function in patients on CAPD. *Am J Kidney Dis* 43 (6): 1056-1064, 2004.
- 6) 日本透析医学会血液透析療法ガイドライン作成ワーキンググループ, 他：維持血液透析の開始と継続に関する意思決定プロセスについての提言. 日本透析医学会雑誌 47 (5) : 269-285, 2014. Working Group for the Preparation of Guidelines for Hemodialysis in the Japanese Society for Dialysis Therapy, et al.: Proposal for the Shared Decision-Making Process Regarding Initiation and Continuation of Maintenance Hemodialysis. *Journal of Japanese Society for Dialysis Therapy* 47(5): 269-285, 2014.

5. Management of Cardiac Failure at Home

The role of home medical care of patients suffering cardiac failure is comprehensive management, including (1) starting home management from the early stage rather than long-term hospitalization, (2) preventing readmission and care, (3) providing treatment at the time of acute exacerbation, and (4) end-of-life care at home. With proper management, patients with end-stage cardiac failure are able to live at home while maintaining quality of life (QOL).

Characteristics of Cardiac Failure in the Elderly

For the elderly patients, comprehension of medical history is relatively difficult, and nonspecific and poor symptoms make it difficult to make a diagnosis of chronic cardiac failure, especially in the compensation phase. In home-care settings, ultrasonography or chest X-ray cannot be used promptly, which causes difficulty in differentiating cardiac failure from respiratory disease in many cases. As an auxiliary diagnostic method of chronic cardiac failure, determination of brain natriuretic peptide (BNP) by blood sampling is useful. Patients with BNP of ≥ 100 pg/mL or NT-proBNP of ≥ 400 pg/mL may require treatment and immediately undergo tests, including echocardiography, to identify the cause.

In the elderly, more women are likely to experience cardiac failure than men, and common complications include hypertension and atrial fibrillation. Underlying diseases include ischemic heart disease, which is an arteriosclerotic disease, and those associated with aortic stenosis. In general, cardiac failure in the elderly is characterized by atypical symptoms, involvement of many aggravating factors, and narrow safety margin of treatments. A survey of 100 cardiac failure patients living at home conducted by our hospital revealed the following: the patients' mean age was 83 years, 22% of the patients lived alone, 15% of the patients were diagnosed with the New York Heart Association Functional Classification Class IV, and underlying cardiac diseases including ischemic heart disease accounted for 28%, valvular disease accounted for 25%, hypertensive heart disease accounted for 22%, and comorbid diseases including dementia accounted for 21% of the cases. These results reflect the social background in Japan, such as many elderly live alone and are complicated with dementia.

For the elderly, appropriate measures should be taken not only for medical conditions of the heart itself but also for aggravating factors in the whole body, such as infections, pneumonia aspiration, urinary tract infection, anemia, renal failure, and chronic obstructive pulmonary disease. Also, lifestyle factors, such as poor compliance, excessive intake of salt or fluid, hyperkinesia, should be taken into consideration. Overdose of therapeutic drugs for cardiac failure, such as beta-blockers, diuretics, or digoxin, may worsen the cardiac failure. Depending on the situation, "drug reduction treatment," such as dose reduction or treatment discontinuation, may be required in the treatment. The research on prognosis of cardiac failure in the elderly in Japan showed a one-year readmission rate of about 30%, a three-year readmission rate of 42%, a one-year mortality rate of 15%, and a three-year mortality rate of 25% in cardiac failure patients aged 80 years or over.

Treatment Plan for Cardiac Failure in the Elderly

For elderly cardiac failure patients, the treatment target is to relieve symptoms and to prevent readmission to maintain the patient's own QOL. Home medical care of cardiac failure in the elderly requires a comprehensive point of view, including living environmental aspects.

Adequate treatment of cardiac failure itself will relieve the symptoms. The treatment consists of “symptom relief” by medication, including diuretics, “rehabilitation” aiming at maintenance of the physical function, and proper “anticoagulant therapy” to prevent cardiogenic cerebral infarction associated with atrial fibrillation. For elderly patients with cardiac failure, it is important to extend healthy lifespan by conducting these treatments.

- (1) Contractile dysfunction: For treatment of cardiac failure associated with reduced left ventricular contraction, renin-angiotensin system (RAS) inhibitors or beta-blockers are initiated. For symptomatic cardiac failure, diuretics, digitalis, or aldosterone antagonists are used. Caution should be exercised for the use of beta-blockers in the elderly because even the normal dose may induce excessive decreased blood pressure or bradycardia. For this reason, beta-blockers should be carefully administered from not more than half of the normal initial dose. The initial dosage of beta-blockers for which the efficacy on cardiac failure has been demonstrated should be as follows: carvedilol (Artist[®]) at 1.25 mg/day twice daily in the morning and evening and bisoprolol (Maintate[®]) at 0.625 mg once daily in the morning. Then, the dosage can be gradually increased. For patients with difficulty in taking oral drugs, bisoprolol patch (Bisono[®] Tape) is also effective for the use at home. As non-medication therapies, implantable cardioverter defibrillator (ICD) or cardiac resynchronization therapy (CRT) should also be taken into consideration for prevention of sudden death or treatment of intractable cardiac failure.
- (2) Diastolic dysfunction: For cardiac failure with primary condition of diastolic dysfunction, no effective medication has been established yet; however, RAS inhibitors and beta-blockers have been used in many cases in the same manner as contractile dysfunction. For symptom relief, diuretics and nitrate (vasodilator) agents are effective. Also, treatment of the disease that aggravated cardiac failure as well as controlling symptoms and pulse rate are also important.
- (3) Aortic stenosis: With an increase in development of aortic stenosis in the aging society, an increasing number of severe valvular disease patients are cared for at home. The relationship between subjective symptoms and life expectancy is as follows: five years for angina pectoris symptoms, three years for syncope, and two years for cardiac failure, as the three major symptoms. Home-care patients with severe aortic stenosis are more likely to experience sudden death after evacuation, and this information should also be added to explanation to patients and families. As one of the therapeutic choices for the elderly or high-risk patients who are not indicated for surgery, transcatheter aortic valve implantation (TAVI) is reimbursed by insurance since October 2013. For the application, consultation with a cardiologist is required.
- (4) Atrial fibrillation and anticoagulant therapy: In Japan, not less than 30% of elderly patients with cardiac failure are complicated with atrial fibrillation. For maintenance of QOL, initiation of anticoagulant therapy is critical to prevent cerebral thromboembolism. Elderly cardiac failure patients aged ≥ 75 years with complication of atrial fibrillation are graded as the CHADS2 score ≥ 2 points, which are indicated for anticoagulant therapy. For cases with non-valvular atrial fibrillation, the recommended warfarin anticoagulant therapy consists of a target international normalized ratio (INR) of 2.0 to 3.0 for patients aged < 70 years and a target INR of 1.6 to 2.6 for elderly patients aged ≥ 70 years. Regarding new oral anticoagulants (NOACs), apixaban (Eliquis[®], twice-daily dosing) and edoxaban (Lixiana[®], once-daily dosing) with an equivalent or lower bleeding risk to that of warfarin, even in patients aged ≥ 75 years, are also available. Still, for very elderly patients, sufficient evidence of NOACs has not yet been obtained; therefore, warfarin is recommended. It is desirable to

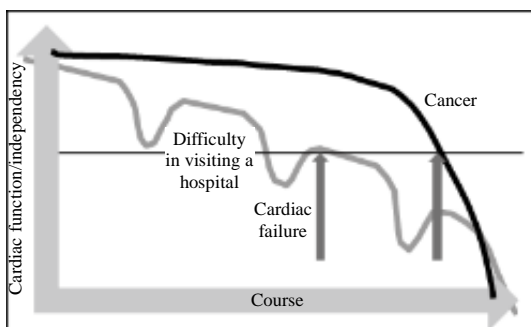
follow up with patients at monthly intervals with INR checks, in consideration of the bleeding risk.

- (5) Use of diuretics: Diuretics are the most effective medications to relieve congestion-induced exertional dyspnea or edema in cardiac failure patients, and the method of use is important in home medical care. Mainly, four types of diuretics (loop diuretics, thiazide diuretics, aldosterone antagonists, and water diuretics) with different action sites are available. Depending on the stage and severity of patients, the most suitable type should be selected by taking the respective properties into consideration, such as presence or absence of anti-aldosterone effect, bioavailability, half-life, and duration of action. Rather than a high dose of a loop diuretic alone, the concomitant use of low doses of different diuretics with different mechanisms of actions is more effective for cardiac failure, as well as for maintenance of the renal function. Among the loop diuretics, furosemide has an advantage of prompt effect; however, it also activates sympathetic nerves and RAS. For this reason, RAS inhibitors or beta-blockers should be combined as a basis of medication for cardiac failure. Also, switching to other diuretics with more gradual effects, such as torasemide or azosemide, should be considered. Of these, torasemide is a long-acting loop diuretic with a high bioavailability of $\geq 80\%$. Even in patients with cardiac or renal failure, torasemide is not likely to be affected by drug metabolism and has supplementary effects of an anti-aldosterone and vasodilatation effects. In the use of diuretics in elderly cardiac failure patients, caution should be paid to prevent electrolyte abnormality, metabolic abnormality, and aggravation of renal function. Also, it should be noted that diuretics may cause low cardiac output syndrome, such as general malaise and anorexia.

Home Medical Care for Cardiac Failure and Indication for Hospitalization

Cardiac failure is likely to relapse into acute exacerbation with progression of stage, which causes a gradual decrease in the activity of daily living. For this reason, many patients initiate home medical care in the early stage (**Figure**). Also, prognosis of cardiac failure is difficult to anticipate. For possible future acute exacerbation, discussions should be held on a regular basis or at times of condition changes to talk about the patient's and family members' desired medical treatment and care. In our hospital, a medical social worker provides "living will questionnaires" with the patient or family at initiation of home-visiting care to confirm terminal care wishes. The survey of living will in cardiac failure patients receiving home-visiting care by the hospital in fiscal year 2013 revealed that the proportion of patients wishing the end-of-life care at home and at hospital was 60% and 27%, respectively. The more severe patients had stronger wishes for home remedy. For determination of a place of terminal stage care, the patient's wish should be respected.

Figure. Initiation Timing of Home Medical Care in Cardiac Failure Patients and Cancer Patients



At aggravation of cardiac failure, it is important to determine how far the patient can be treated at home. At the time of acute exacerbation, SBP-based treatment is effective, and it is also used in cardiovascular hospitals. Clinical scenario (CS) concept of acute cardiac failure is as follows. On the basis of SBP of ≥ 140 (CS1), 140 to 100 (CS2), and ≤ 100 (CS3), appropriate measures should

be taken for the respective types of cardiac failure (**Table 1**). In CS1, which is characterized by sudden cardiac failure associated with pulmonary congestion, immediate oxygen administration (combined with non-invasive positive pressure ventilation, if possible) and vasodilator administration (e.g., intravenous nitrate infusion) may contribute to resolving the symptoms at home and avoid hospitalization in many cases. Still, patients with poor response to the initial treatment, absence of improvement even by prompt oxygenation or worsening in the state of consciousness, are indicated for hospitalization. In CS2 and CS3, gradual aggravation of cardiac failure is commonly observed. Patients and families are instructed to contact the hospital when any symptom indicative of low cardiac output syndrome, such as weight gain of at least 2 kg a week, shortness of breath, general malaise, or anorexia, is detected. In such cases, appropriate lifestyle management should be instructed, and the cardiac failure treatment should be reviewed, including the use of diuretics. When the symptom does not resolve, admission to a cardiovascular hospital should be considered (**Table 2**). For patients with a strong will to continue home care or those in a terminal state, home care can be continued after symptom relief.

Table 1. Clinical Scenario (CS) and Treatment of Acute Cardiac Failure

CS 1	CS 2	CS 3	CS 4	CS 4
SBP >140 mmHg	SBP 100–140 mmHg	SBP <100 mmHg	Acute coronary syndrome	Right cardiac failure
Treatment				
<ul style="list-style-type: none"> • NPPV and nitrates • Diuretics are rarely indicated, excluding cases with volume overload. 	<ul style="list-style-type: none"> • NPPV and nitrates • Diuretics are used in cases with chronic and generalized fluid retention 	<ul style="list-style-type: none"> • In the absence of fluid retention findings, volume load is attempted. • Cardiotonics • When the condition does not relieve, pulmonary artery catheter is indicated. • When blood pressure <100 mmHg and hypoperfusion persists, a vasoconstrictor is indicated. 	<ul style="list-style-type: none"> • NPPV • Nitrates • Cardiac catheter test • ACS management recommended by the guidelines: aspirin, heparin, reperfusion therapy • Intra-aortic balloon pumping 	<ul style="list-style-type: none"> • Avoiding volume load • When SBP >90 mmHg and chronic and generalized fluid retention are observed, diuretics are used. • Cardiotonics are used in cases with SBP <90 mmHg • When SBP does not return to >100 mmHg, vasoconstrictors are indicated.
Treatment target				
<ul style="list-style-type: none"> • Relief of dyspnea • Improvement of conditions 	<ul style="list-style-type: none"> • Reduction of heart rate • Urine output >0.5 mL/kg/min 	<ul style="list-style-type: none"> • Maintenance and normalization of SBP • Return to proper perfusion 		

Table 2. Home-cared Cardiac Failure Patients Indicated for Hospitalization

- Even after the initial treatment for CS1, poor improvement of oxygenation and worsening in state of consciousness are observed.
- In CS2 and CS3, even after adequate lifestyle management and diuretic administration, no particular improvement is observed.
- Complication with pneumonia aspiration, gastrointestinal hemorrhage, ileus, or disturbance of consciousness.
- Further adequate treatment (e.g., both ventricular pacemaker, transcatheter aortic valve implantation) may improve cardiac failure.

Relief of Cardiac Failure Symptoms

Cardiac failure involves a total pain consisting of physical, psychological, social, and spiritual aspects, in the same manner as terminal cancer. To understand the pain, comprehensive care should be provided by team health care. In home medical care, end-of-life care is less likely in cardiac failure patients than in cancer patients. The reasons are presented in **Table 3**. Our hospital places an emphasis on the points shown in **Table 4** for end-of-life care of cardiac failure patients at home. Particular importance is placed on interprofessional team health care, appropriate medical care for cardiac failure, evaluation of individual symptoms in a quantitative manner and taking prompt measures, and assessment of burden on caregivers, in the same manner as that on patients. In the future, ICD may be used in patients with end-stage cardiac failure. Its operation should be handled, including switching on and off, in cooperation with a cardiologist. In the terminal stage, Cheyne–Stokes respiration is observed at high frequency. Natural respiration is interrupted with repeated apnea and tachypnoea, which increases the caregiver’s psychological anxiety; therefore, appropriate explanation should be given and proper measures should be taken. Liquid transfusion should not be used if possible. Also, four kinds of treatments (home oxygen therapy, home respirator, oral benzodiazepine or sedative suppository, and opioid) are available depending on cases of end-of-life care at home.

Table 3. Reasons for a Low Frequency of End-of-life Care of Cardiac Failure Patients at Home

1. Obscure definition of end-stage cardiac failure
2. Treatment and care for end-stage cardiac failure have not been generalized.
3. Lack of knowledge/understanding and anxiety for home medical care of cardiac failure patients by an interprofessional team
4. Underestimation of care level
5. Opioid and therapeutic drugs for cardiac failure are not covered by insurance.

Table 4. Points of End-of-life Care at Home for End-stage Cardiac Failure Patients

1. Adequate treatment of cardiac failure
2. Introduction of advance directive in the early phase
3. Determination and handling of various symptoms in a quantitative manner
4. To consider intervention to burden of caregivers
5. To understand medical conditions and treatments of end-stage cardiac failure (e.g., Cheyne–Stokes respiration, operation of an ICD)
6. To avoid liquid transfusion, as much as possible
7. Four kinds of treatments, including (1) home oxygen therapy, (2) home respirator, (3) oral benzodiazepine or sedative suppository, and (4) opioids, are used depending on cases.

Future Discussion

Treatment of chronic cardiac failure is one of the representatives of multidisciplinary and intensive medical care. Among various treatment methods and progression stages, the most proper treatment must be selected by paying respect to patients' individual way of living. Thus, a model should be constructed for home medical care of cardiac failure patients so that even non-specialized health care providers can be involved in home medical care. Also, advanced stage/end-stage cardiac failure should be clearly defined. In addition, insurance coverage for opioids and an increase in medical fees associated with extended use of medications for cardiac failure and transfusion pumps are left for future discussion. Lastly, it has to be emphasized that home medical care for cardiac failure patients is not end-of-life care, but positive medical care to maintain QOL of patients and families and to prevent repeated aggravation of cardiac failure.

(Dai Yumino)

6. Management of Cerebrovascular Disorders at Home

Cerebrovascular disorders develop in 34% of care level 5 patients and 30% of care level 4 patients,¹⁾ showing the largest proportion among diseases that are taken care at home. Cerebrovascular disorders require long-term care and impose a large physical and psychological burden on the family; therefore, management of home care is important.

Characteristics and Handling of Cerebrovascular Disorder Patients

Cerebrovascular disorder patients suffer not only physically (paralysis) but also emotionally and psychologically to some extent. Therefore, caregivers may have difficulty in communicating with the patient to comprehend the patient's suffering and condition changes. During a relatively long course of the disease, a gradual decrease in ADL with aging may cause a sudden exacerbation at the development of any event, such as relapse or complication. Therefore, unforeseeable prognosis is one of the characteristics and problem of cerebrovascular disorders.

In addition to a large physical burden, caregivers may have difficulty in interacting with the society, which causes caregivers' feeling of loneliness or isolation. At the time of event development, caregivers are often required to make decisions instead of the patient, which also causes a considerable psychological burden.

During routine care, health care professionals should respect the patient and family members (caregivers) and explain the possibility of sudden exacerbation at the time of relapse or complication. Thus, a thorough discussion should be held to comprehend the patient's wish if he or she suffers sudden exacerbation or becomes unable to eat food.

At the time of visits, health care professionals should express that they always care about the patient and caregivers and show empathy for their opinions and feelings. In addition, the most important thing is to praise them in a casual manner for undergoing hard treatment, rehabilitation, and long-term care.

Points to Confirm Prior to Initiation of Home Medical Care

At predischarge conference before the start of home management of cerebrovascular disorder patients, it is important not only to comprehend the patient's conditions and future intention but also to confirm backup cooperation at the time of sudden exacerbation to start home care without fear.

In addition to the patient's conscious and paralysis levels, visual, swallowing, and speech functions should be confirmed.

Particularly, in patients with homonymous hemianopsia or unilateral spatial neglect, an approach from the affected side may not only cause a blunt response but also cause astonishment or fear in the patient due to sudden appearance of the visitor. Rehabilitation involves practicing approaches from the affected side; however, approaches from the healthy side are the standard in general practice so that the patient can recognize the visitor even from a distance. Therefore, bed's location and pillow direction should be adjusted such that the room entrance and approach side are positioned to the healthy side.

Dysphagia involves a condition in which the basic need of appetite cannot be fulfilled, causing various sufferings. Thus, the swallowing function assessment and cooperation with a

dentist for oral care and swallowing rehabilitation are required to not let the patient give up oral intake.

Aphasia is not only a language disorder but also likely to be accompanied by impairment of thoughts and situational judgment. It is desired that the caregiver talks to the patient slowly by dividing words into clauses, shows letters and drawings, uses gestures, and provides the patient with questions that can be answered by yes or no so that the patient may be able to present his or her intentions even without words.

Dysarthria is a disorder of speech only, unlike aphasia; therefore, the caregiver can talk to the patient normally. The patient is trained to pronounce each word slowly and correctly. Repeated questionings may cause unnecessary tension and decreased speech clarity, which may make the patient feel uncomfortable with communication and lose motivation to talk. Therefore, it is recommended to combine communication in writing and pointing words of a Japanese syllabary table.

In addition, it is important to adjust housing environment to enhance life rehabilitation. Specifically, installment of handrails around the entrance, bathroom, bath, and stairs will create areas in which the patient can easily move around. For patients with hemiplegia, it may be more comfortable to use handrails set a little higher than normal height. The patient should decide a desirable height after actually walking with handrails. Prior discussions should be held with physical therapist, occupational therapist, guidance officer for welfare aids, housing environment coordinator for elderly and disabled people, and care manager. What is required is not repair or rental goods but adjustment of housing environment to support activities that the patient is unable to do by himself or herself to keep his or her desired lifestyle.

Chronic Phase Management

In routine medical care, the patient's ADL and instrumental activities of daily living should be assessed on the basis of conversations with the patient and caregivers with a brief neurologic evaluation. The patient should be supported in terms of the following seven points to maintain his or her own lifestyle as much as possible.

A. Maintenance and Improvement of Remaining Functions

In the chronic phase, the remaining functions are almost fixed. Still, a great influence is exerted by the patient's level of motivation, relationship with family members, and involvement of interprofessional support by the care manager, such as visiting care and rehabilitation. Many patients and families feel that they have no particular roles in the family or society, and they may not have room to enjoy their lifestyles. It should be considered that individuals and environmental factors inhibit participating in activities and society. To address this issue, measures should be proposed.

It goes without saying that praising their efforts of rehabilitation is important. However, it is important to listen to stories about their hobbies that brighten their lives, grandchildren, and themselves and their thoughts with respect so that their interests and concerns are not concentrated only on the functional training. Information should be shared in an interprofessional team, such as how much functions are currently pending, what kind of rehabilitation is required for them, and what the purpose is. Particularly, information sharing is important, which the patient was previously able to do but is currently not able to do.

Enjoying conversations with family members, enjoying recreations using day care services, involving in the society, or doing whatever the patient wants to, such as gardening, will lead him or her to be independent, which will also be associated with maintenance and improvement of their life and cognitive functions. Such lifestyle will reduce the caregiver's burden, and it is important to establish such a plan.

B. Management of Eating, Swallowing, and Nutrition

Dysphagia is observed in at least 50% of stroke patients in the acute phase.²⁾ In the home-care phase, dysphagia is likely to have resolved to some extent. However, dysphagia often recurs upon recurrent stroke or aggravation of general condition. It should always be remembered that the patient has a risk of not being able to eat sufficient food at any time. When undernutrition state or dysphagia is suspected by periodic body weight measurements, appropriate measures should be taken.

Even in the home-care phase, the swallowing function may improve by rehabilitation. Therefore, the patient should not be deprived of the joy of eating because of the caregiver's intention to avoid aspiration and too much priority on the safety (see p77–82 for the specific care).

By continuing oral care and swallowing rehabilitation, it is common that even gastrostomy-fed patients become capable of tasting. In cooperation with a speech-language-hearing therapist and dentist, rehabilitation should be continued. One of the simple and easy trainings is to swallow small pieces of ice in a lateral recumbent position with the paralyzed side up. When the patient has become able to eat sufficient foods, weaning from gastrostomy feeding is possible. Great satisfaction can be obtained by enjoying oral intake of even a small amount of food, and the remaining fluid and nutrition can be supplied by gastrostomy.

C. Prevention and Handling of Recurrence

The recurrence rate of stroke is reported as about 5% a year and about 30%–50% in 5 years, and it increases with age and reaches to 24% a year in the 70s.³⁾ In patients with risk factors, such as hypertension, diabetes mellitus, atrial fibrillation, smoking, and heavy alcohol drinking, the recurrence rate can be suppressed by improving lifestyle habits or by medication.^{3,4)} Therefore, medication compliance management is critical. However, in the elderly, very strict control of lowering blood pressure and blood glucose may worsen the prognosis. Therefore, the target blood pressure should be established as 140/90 mmHg, and a little lower target should be set for patients on anticoagulant treatment or with a history of cerebral hemorrhage. For patients with aspiration risk, the use of ACE inhibitors should be considered to increase substance P, which regulates the swallowing reflex and cough reflex. For the elderly, the use of antiplatelets or anticoagulants should be determined through a thorough discussion with the patient and family members, keeping in mind the risk of fall, dementia, and frail.

D. Prevention and Handling of Complications in the Chronic Phase

About 10%–25% of patients after stroke experience respiratory infection, dehydration, or undernutrition associated with reduced swallowing function; dysuria or urinary tract infection associated with neurogenic bladder; bowel problems; pressure sore; or reduced cognitive function.⁵⁾ Complications that are characteristic to cerebrovascular disorder are convulsion and central pain.

a. Seizure

Seizure is a sudden event accompanied by loss of consciousness or neurological symptoms; therefore, the patients and caregivers are under fear and intensely upset. During a seizure, the caregiver is instructed in a sympathetic manner to not panic but to handle the situation with a calm mind. When possible, the patient is positioned in a lateral recumbent position to prevent aspiration, and any dangerous materials should be kept away. An explanation is given that anything including fingers must not be put in the mouth. Normally, seizures stop in a few minutes. However, the following cases are needed to be transferred to a backup support hospital:

- (1) First seizure (not being able to understand what is happening)
- (2) Convulsion lasting for at least 5 minutes (with a low possibility of spontaneous resolution)
- (3) Recurrence of seizure before return of consciousness (status epilepticus)
- (4) Any new neurological symptom or aggravation is observed (with a possibility of recurrence)
- (5) The patient fell hard and hit his/her head (with a possibility of traumatic intracranial hemorrhage)

b. Central pain

Central pain is a spontaneous pain expressed by a burning, tingling, or stinging sensation, which is also accompanied by anesthesia or sensory loss. Contact stimulation may also induce pain (allodynia). The characteristics include emotional responses called as mental responses, such as depression and anxiety. ADL is also affected. Currently, no satisfactory treatment is available. Nonsteroidal anti-inflammatory drugs often result in treatment failure. The first-line drugs are amitriptyline (Toryptanol[®]), lamotrigine (Lamictal[®]), and gabapentin (Gabapen[®]).⁶ clonazepam (Rivotril[®]), carbamazepine (Tegretol[®]), selective serotonin/norepinephrine reuptake inhibitors (SNRIs), and pregabalin (Lyrica[®]) may also have effects.

c. Spasms and contracture accompanied by pain

Spasms and contracture accompanied by pain may interfere with care; therefore, appropriate range of motion (ROM) training should be conducted. For spasms and contracture, baclofen (Lioresal[®]), dantrolene sodium (Dantrium[®]), and tizanidine (Ternelin[®]) are indicated. After e-learning, the use of botulinum toxin type A (Botox[®]) is also allowed, which will lead to an extended ROM and a reduced burden on the caregiver.

E. Prevention of Accidents

Not only medical and care staffs but also patients and families should be explained about the risk of fall, aspiration, and asphyxia to recognize and prevent possible accidents. In particular, 25% of patients experience fall. Therefore, places with a tripping hazard must be checked around the lines of flow in everyday activities, such as door step, carpet edge, and electric code.

F. Attention to Caregivers

When discussing care of cerebrovascular disorder patients, explanation and attention to caregivers are indispensable. In the same manner as patients, the caregivers go through the following 4 steps to accept the disorder.⁷ (1) Phase of shock and confusion, (2) phase of excessive expectation for recovery and anxiety, (3) phase of despair and depression, and (4) phase of accepting the disorder. The caregivers are likely to be affected by stress-induced diseases. The caregivers' health management and a system to ensure time for caregivers themselves are important for maintenance of care. Also, the caregivers should be taught on a routine basis not to push themselves too hard, and that whatever they can do to an extent possible is enough. In the chronic phase, the caregivers are also likely to feel loneliness and isolation from the society. Therefore, the caregivers' anxiety and questions are listened in a positive manner, and they should be prompted to use services, such as respite admission and teleconsultation, and to participate in meetings of patients and families for social involvement.

G. Purpose of Life

Maintenance and improvement of motivation and remaining functions should be always kept in mind, and specific purposes, such as "cooking" or "meeting grandchildren," should be established. Also, it is recommended to take full advantages of visit rehabilitation and day care rehabilitation. Even if practical gait cannot be achieved, a great enhancement of motivation and satisfaction will be achieved in the patients and families by gait training.

Management of the Terminal Stage

The terminal stage of cerebrovascular disorder is difficult to define; however, reduced conscious level may be a sign of initiation of the terminal stage. Based on the result of the registration and follow-up survey of stroke patients by the Research Institute for Brain and Blood Vessels–Akita, long-term causes of death were recurrent of stroke at 20%, pneumonia at 23%, cardiac failure at 13%, malignant tumor at 20%, and others at 24%. In this section, handlings of the terminal stage patients with recurrence are presented.

Disturbance of consciousness accompanied by a new neurological symptom, such as paralysis, is highly likely to be a sign of recurrence. However, seizure, hypoglycemia, electrolyte abnormality, pyrexia, and cardiac failure may induce such condition. Therefore, a comprehensive determination is required based on results of blood test, etc. Under the state of conscious coma plus respiratory disorder, it may be difficult to save the patient's life even after being transferred to hospital by ambulance. Caregivers are likely to be upset about the sudden condition changes, which often results in transferring the patient to the backup support hospital. Also, the caregivers are likely to have a guilty feeling. Thus, it should be explained that sudden exacerbation was inevitable and that nothing was wrong with care.

A reduced conscious level may induce respiratory disorder caused by glossoptosis. When the condition does not improve even in a head-tilt or lateral recumbent position, the use of airway devices or endotracheal intubation should be considered. However, treatments should be chosen by a thorough discussion with the caregiver. The same goes for liquid transfusion, and an excess fluid induces respiratory disorder due to generalized edema and airway secretion. Therefore, it should be explained that a moderate transfusion regimen makes the patient comfortable. Then, the treatment should be determined.

Eventually, Cheyne–Stokes respiration and jaw breathing develop. It has been said that, at this stage, the brain function is generally reduced, and that the patient does not suffer. However, the caregivers often feel that the patient is suffering by looking at the face with agony, and they also suffer and feel anxiety. The caregivers' feelings should not be denied but they should be explained that the patient is close to the end of life. Then, they are led to have last touches with the patient and are told things such as “Would you massage his/her hands or chest so that he/she feels a little better?” Whether the patient still has the auditory perception is unclear, but family members talking to the patient is one of the preparations for grief work.

At the death bed, it is an important care of the family members by appreciating them such as “Both name (the patient) and you (family members) did so well.”

(Naoyuki Kuwahara)

References

- 1) 厚生労働省：平成 21 年度人口動態統計 Ministry of Health, Labour and Welfare. Vital statistics in 2009
- 2) Crary MA, Groher ME: Adult Swallowing Disorders. Ishiyaku Pub, Inc., 2007.
- 3) 鈴木一夫：脳卒中の再発. 治療 91 (11) : 2560-2564, 2009. Suzuki K.: Recurrent stroke. *The Journal of Therapy* 91(11): 2560-2564, 2009.
- 4) Tallelli P, Greenwood RJ: Recurrent stroke: where do we stand with the secondary prevention of noncardioembolic ischaemic strokes? *Therapeutic advances in cardiovascular disease* 2(5): 387-405, 2008.
- 5) Langhorne P, et al : Medical complications after stroke (a multicenter study). *Stroke* 31(3): 1223-1229, 2000.
- 6) Frese A, et al: Pharmacologic treatment of central post-stroke pain. *Clin J Pain* 22(3): 252-260, 2006.
- 7) Holbrook M: Stroke; social and emotional outcome. *J Roy Col Phys London* 16(2): 100-104, 1982.

7. Home Medical Care of Mental Disorders

Mental disorders with a possibility that home medical care providers may encounter at home are surveyed, and the clinical characteristics are described. Also, significance of involvement of psychiatrists in home medical care is noted through the discussion of service model.

Introduction

Of mental disorders, which home medical care providers may encounter at home, the major ones are presented in the table according to the International Classification of Diseases (ICD) (**Table**). Of them, the information of dementia belonging to F0 has been available from accumulation of a numbers of practices and researches by home care physicians. (It is expected that a predominantly high proportion of clinicians do not necessarily have clinical experiences as a psychiatrist.) Also, delirium belonging to F0 is described in detail in the separate section. Therefore, in this section, home medical care for other mental disorders than these diseases is described, including discussions of the service model.

Schizophrenia

In 1995, the “Mental Health Act” was revised to the “Act Related to Mental Health and Welfare of the Persons with Mental Disorder (Act on Mental Health and Welfare for the Mentally Disabled).” This was a landmark revision in terms that medical care and welfare were integrated in the psychiatry field by the law. For this revision, the proposal by Hachiya¹⁾ played a critical role to regard schizophrenia as “coexistence of diseases and disorders” and not to be treated by medical care (treatment) alone but to be supported also by rehabilitation and welfare (livelihood support). By following this idea, it is obvious that the desirable schizophrenia care is conducted by medical-and-welfare integrated services mainly in the living field of home.

In 2002, an integrated program for community mental health service (Assertive Community Treatment [ACT]) started in the National Center of Neurology and Psychiatry Kohnodai Hospital (currently, Kohnodai Hospital, National Center for Global Health and Medicine) as the Health and Labor Sciences Research. In the next year, clinical activities were also initiated. Up to then, doctor’s visit and visiting care had been conducted mainly in the psychiatric rehabilitation field. However, the activities have evolved to more comprehensive forms by interprofessional visiting teams. Starting from the ACT, various ACT services started at various parts of Japan. (The ACT is not only for schizophrenia patients, but one of the main target disorders of the ACT is schizophrenia). The effects of ACT include preventing readmissions due to symptom recurrences associated with disorganized lifestyle, called “revolving door phenomenon,” promoting returning of long-term inpatients into community, and providing opportunities to receive treatments for untreated or treatment-withdrawn patients who have difficulty in visiting medical institutions in a spontaneous manner due to lack of consciousness of disease.

Table. Major Mental Disorder That Home Medical Care Providers May Encounter at Home

ICD code	Disorder
F0: Organic, including symptomatic mental disorders	Dementia, delirium
F1: Mental and behavioral disorders due to psychoactive substance use	Alcoholism
F2: Schizophrenia disorders	Schizophrenia
F3: Mood (affective) disorders	Depression, manic-depressive psychosis
F4: Neurotic disorders	Social phobias, panic disorder, obsessive-compulsive disorder, somatoform disorder
F5: Physiological disorders	Eating disorders, nonorganic sleep disorders
F7: Intellectual impairment (mental retardation)	Mental retardation
F8: Disorders of psychological development	Pervasive developmental disorders

Other Mental Disorders

Regarding home medical care of other mental disorders, few reports have yet been published. The author is a physician specialized in psychiatry and has been engaged in visiting medical care in a clinic of internal medicine only. The knowledge obtained is mainly from experiences and is presented below.

Regarding mood disorders, they mainly consist of depression. Most cases have difficulty visiting hospitals with aging and belong to the so-called “transitional area to depression or dementia.” Of them, some cases were diagnosed as dementia or intractable neurological disease and were initiated visiting medical care by referral; however, their true condition was determined as depression by the visiting medical care. In addition, some cases became unable to visit the hospital while not realizing psychotropic-induced Parkinsonism, and after consultation from a substitute person, the patient concerned was finally referred to an appropriate medical institution. By appropriate adjustment of medications, these cases may improve to a condition that will enable them to visit hospital.

Disorders to aim at ambulatory treatment as a primary treatment mode include extreme undernutrition and eating disorder with a tendency of social withdrawal causing difficulty in visiting the hospital, social phobia, panic disorder, and obsessive-compulsive disorder.

Some home-cared advanced-stage cancer patients also seek consultation for depressive or anxiety condition.

Among patients diagnosed with diseases of internal medicine and initiated visiting medical care, more patients than expected were suspected as having mental disorder, such as somatoform disorder, as the true condition. Through visiting medical care, the existence of complicated family dynamics was perceived, as well as cases with alcohol dependency.

Discussion on Service Model of Home Medical Care and Psychiatric Care

Physicians engaged in home medical care are required to have a wide variety of clinical skills, regardless of the original specialty. The physicians with such clinical skills are called primary care physicians, family doctors, or general practitioners (GPs) in Japan. In this article, the author calls such physicians as GPs.

Japan has entered an era of unprecedented aging society unparalleled in the world, and many home-care patients are likely to be complicated with multiple disorders both in physical and mental aspects. Between the early- and middle-stage of dementia, cases with particularly severe

behavioral and psychological symptoms of dementia (BPSD) are likely to be diagnosed as mental disorders. In contrast, in the middle and the subsequent stages of dementia in which visiting medical care is indicated, the importance of physical management gradually increases. Under such condition, an extreme shortage of medical institutions treating physical complications of schizophrenia has long been a problem.

Also, the actual status of untreated cases and withdrawals from psychiatric treatment has not been elucidated. It has been said that “for the most needed ones, the service is often unavailable.” It has been reported that, in countries outside Japan, untreated patients with mental disorders are often found by GPs.

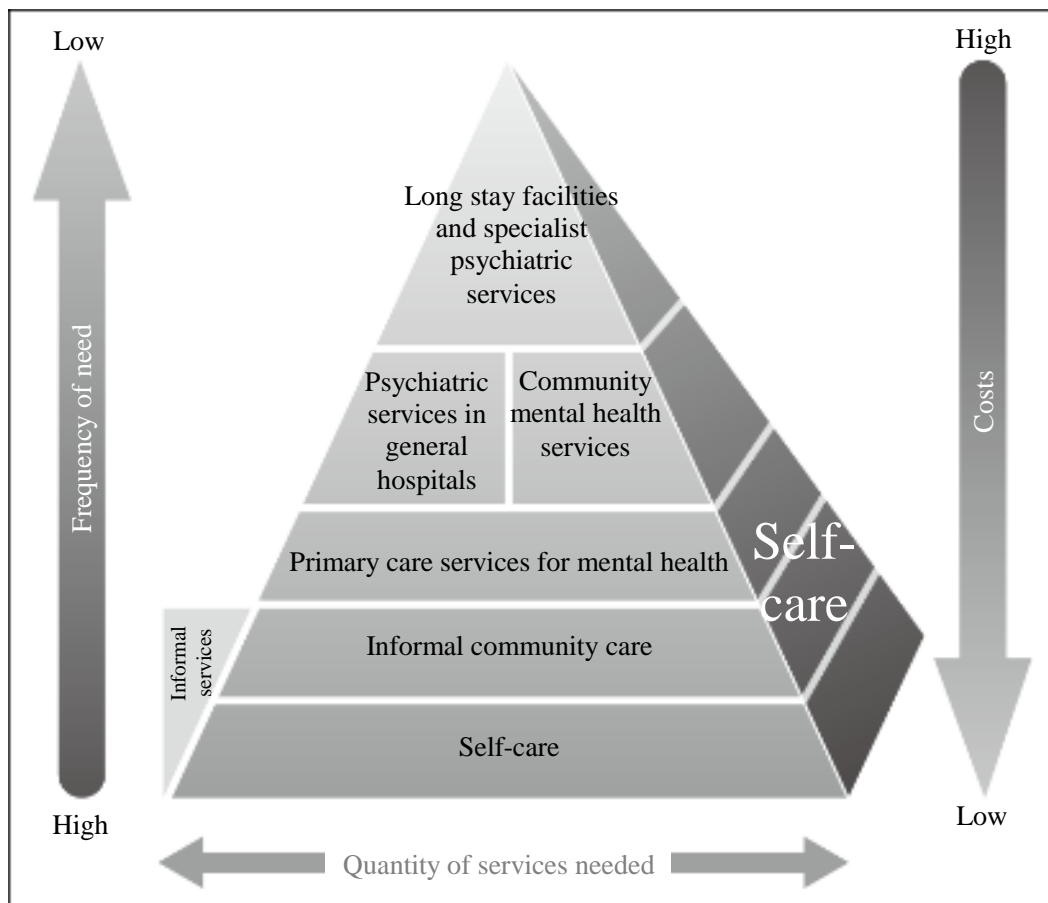
In 2008, the world health organization (WHO) and the world organization of family doctors (Wonca) issued in cooperation a booklet called “Integrating mental health into primary care.”²⁾ Contrary to world-wide growth of demand for psychiatric treatment, the supply has been totally insufficient. To solve the problem of the present condition, a proposal has been made to integrate mental health care into primary care. Then, a desired structure of mental healthcare service has been visualized in the Figure.

Self-care and informal community care constitute the foundation of the service pyramid. The GPs’ primary care services for mental health are the first level of service provided by the experts. The upper layer is composed of psychiatric services by general hospitals and community mental health services. Functioning of these factors in an optimal combination minimizes the number of cases requiring long stay in facilities.

However, comparison between the present situation in Japan and this **Figure** revealed that both primary care services for mental health by GPs and community mental health services represented by ACT are still immature. In addition, regardless of an increasing need of psychiatric services in general hospitals, the number of psychiatry has currently been decreasing. In Japan, patients with psychiatric disorders, including schizophrenia, have difficulty leaving facilities, and a surprisingly large number of psychiatric beds have been filled compared to the world status. It has been realized that, to resolve this condition, enhancement of the pyramid’s foundation of informal services and promotion of the three intermediate layers of medical care are required.

To deal with this issue, for example, Okayama Prefectural Mental Health and Welfare Center has their own outreach team. The team plays a role in a network mainly consisting of community health nurses and local clinics with departments of physical management and psychiatry. The activity aims at enhancement of the overall community support power with a view and methods of bringing up the supporters consisting of the network. The psychiatry of Asahi Hospital in Chiba Prefecture owns an interprofessional team called the “community support group.” Through this group, a large number of long-term inpatients have been satisfactorily returned to the community, while keeping providing inpatient services by the psychiatry in the general hospital. Also, a notable trend was the establishment of the “Study Group of Multifunctional Psychiatric Clinics in Japan” in 2015, which intends to develop community life support centers for mental health that are tentatively called as “community mental health centers.”

Figure. Service Organization Pyramid for an Optimal Mix of Services for Mental health (WHO & Wonca)



The above examples are recent movements of the mental health care providers' side. What kind of directions are considered for home medical care organizations with nonpsychiatric care providers? For example, it is expected that a large number of home medical care organizations will be requested to intervene with patients who have a strong tendency for social withdrawal and who do not have a chance to receive medical care by public health centers or other institutions. Of course, it is important for home medical care providers themselves to gain a higher ability to provide psychiatric medical care. However, the author also agrees with a choice that the visiting team involves a psychiatrist. An interprofessional visiting team is made in cooperation with a home care physician with the ability of a GP and a psychiatrist in the same facility, and the author calls this service model as "GP-psychiatrist-interprofessional visiting team model." The author, et al.,³⁾ conducted the survey through visiting medical care of schizophrenia patients. The result revealed that through the "GP-psychiatrist-interprofessional visiting team model," a prompt and effective handling of issues on psychiatric and physical complications is possible, and that the model may be an effective pathway for untreated or withdrawal cases to receive psychiatric treatments. The "GP-psychiatrist-interprofessional visiting team model" can be said as hybrid-type or developed-type model of the above 3 medical care services, and it will also play a certain role in home medical care in Japan. In addition, the

model will contribute to provide one of the career paths for psychiatrists who used to work or works in psychiatry in general hospitals.

Psychopathological Discussion

Kato described the relation between schizophrenia patients and the society and living environments, using the terms of the dehiscence phase in which the patient opens him or herself to the society and community and the autosynnoia phase in which the patient withdraws from such environments.⁴⁾ Kato also said that “lives of humans for both healthy and sick people are continuity of ‘balance crisis and balance creation’ by looking at physical and mental performances in details.”⁵⁾ “New balance creation of schizophrenia patients is likely to be inflexible and stiff and often tends to confine themselves into the side of autosynnoia phase.”⁴⁾ In consideration of these findings, the foundation of home care for schizophrenia patients should establish a human bond with family members and reliable health care providers and to maintain the patient in the “soft autosynnoia phase.”⁴⁾ Such positioning of treatment may solve issues of compulsive treatment and invasiveness of visiting in outreach service and address concerns over depriving patients’ autonomy.

To be more detail, home medical care has characteristics of “medical care associated with the patients’ autosynnoia phase” in general, and it is positioned as medical care to keep the patients’ physical and mental balance crisis to a minimum level in the autosynnoia phase and to assist the balance creation. In psychopathological aspects, home medical care is provided not only for patients but also for families and homes.

(Shiro Kitada)

References

- 1) 蜂矢英彦：神経障害論試論。臨床精神医学 10：1653-1661, 1981. Hachiya H.: Personal opinions on impairments, disabilities and handicap, *Japanese Journal of Clinical Psychiatry* 10: 1653-1661, 1981
- 2) WHO, Wonca: Integrating mental health into primary care; a global perspective.2008.
- 3) Kitada S, et al : The Intervention Effectiveness of Home Medical Care Provided for Schizophrenic Patients by an Internal Medicine Clinic- A Challenge for Comprehensive Care Including Treatment for Physical Disorders -. *Jichi Medical University Journal* 35: 35-47, 2012.
- 4) 加藤敏：統合失調症の語りと傾聴 EBM から NBM へ。金剛出版, 107-135, 2005. Kato S.: Talk and listening to schizophrenia patients—from EBM to NBM—. Kongo Shuppan, 107-135, 2005.
- 5) 加藤敏：統合失調症慢性期，寛解期の病態を踏まえた外来診療。精神科治療学 20 (5) : 455-462, 2005. Kato S.: Outpatient treatment of schizophrenia in consideration of chronic- and remission-phase conditions. *Japanese Journal of Psychiatric Treatment* 20(5): 455-462, 2005.

Chapter IV References

1. Chronic Respiratory Failure—Procedures of Comprehensive Respiratory Rehabilitation—
 2. Amyotrophic Lateral Sclerosis (ALS)
 3. Parkinson's Disease
 4. Renal Failure
 5. Management of Cardiac Failure at Home
 - (1) 慢性心不全治療ガイドライン (2010年改訂版) Guidelines for Treatment of Chronic Heart Failure (JCS 2010)
http://www.j-circ.or.jp/guideline/pdf/JCS2010_matsuzaki_h.pdf
 - (2) Hamaguchi S, et al: Predictors of Long-Term Adverse Outcomes in Elderly Patients Over 80 Years Hospitalized With Heart Failure – A Report From the Japanese Cardiac Registry of Heart Failure in Cardiology (JCARE-CARD) –. *Circulation Journal* 75: 2403-2410, 2011.
 - (3) 急性心不全治療ガイドライン (2011年改訂版) Guidelines for Treatment of Acute Heart Failure (JCS 2011)
http://www.j-circ.or.jp/guideline/pdf/JCS2011_izumi_h.pdf
 - (4) Yumino D, Bradley TD: Central sleep apnea and Cheyne-stokes respiration. *Proc Am Thorac Soc.* 15: 226-36, 2008.
 6. Management of Cerebrovascular Disorder at Home
 7. Home Medical Care of Mental Disorders
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Chapter V. Home Palliative Care

A healthy long life is a wish of all people. However, we have to realize that we cannot keep living forever, and everyone dies eventually. Also, the day to hand over our wishes to someone else will come someday. Then, when the time of end is near, where to spend last days of life and with whom should be the major subject of concern.

Currently, about 80 percent of people spend the last days of life in clinics or hospitals with health care professionals apart from relationship with the community and daily life. In contrast, more than half of citizens wish to spend last days of life with family at home, if possible. Anxiety about medical conditions and issues of care ability are the reasons of unfulfilled wishes. Still, the most common reason is an insufficient medical support system to assist living at home.

This chapter provides specific explanations for what kinds of medical support are required not only for cancer diseases but also for noncancer diseases, hoping that a number of health care professionals will participate in the activity to prepare for the home medical support system.

(Yoshikazu Ashino)

The Yuumi Memorial Foundation for Home Health Care website has a section providing a listing of medical facilities dedicated to home medical care.

Please contact our executive office if you are interested in signing up for the listing.

Note) The website only provides names with contact information of the physicians and medical facilities, which are not intended for recommendation.

1. General Introduction of Home Palliative Care

Home palliative care is a system providing palliative care at home, residence, or dwelling house in cooperation with medical, welfare, and care organizations as an interdisciplinary team. It is the core of “integrated community care” to build a “system to keep living in our own way at the familiar community till the end of our lives.” For smooth operation of this system, activities for establishment of the home medical care system, including 24/7 medical and life support and community-based palliative care are desired.

Home Palliative Care

Everyone will die someday. When the death is foreseeable, the biggest concern in life for many people is how to spend the rest of life and with whom and where. At the same time, the decision will have effects on the lives of related people, such as families, relatives, friends, and acquaintances, in both good and bad ways.

Many people wish home or close-to-home environments as the place of death, rather than medical facilities, such as hospitals. To fulfill this wish, the home palliative care will provide an effective system of medical and life support (palliative care) at “home” to relieve various sufferings (total pain/total suffering) of patients caused by organ derangement or ADL disorders from diseases or aging.

As a synonym, the term of “home hospice care” is also used. The author differentiates the synonyms of the same phenomenon as follows: “home palliative care” is used when it is looked at from a medical point of view, and “home hospice care” is used when looked at from a social point of view.

Philosophy of Home Palliative Care

Philosophy of the current hospice care and palliative care was founded from “hospice care as movement for human right” by Mary Aikenhead who is called as mother of the modern hospice movement. Then, it was almost accomplished by activities of Cicely Saunders who is called as mother of the current hospice movement. The philosophy is in the message of Cicely Saunders, “You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Mary Aikenhead set up hospice care at convents, and at the same time, she also provided home care. Cicely Saunders established hospice wards in 1967, and in 1969, she started home hospice care. Therefore, homes and residences are recognized worldwide as the main field of palliative care practices.

Concept and Present Conditions of Home Palliative Care

The concept of home palliative care has changed as social circumstance changes. Also, it has kept changing because lifetime has prolonged, the population has gotten older, and various ways of living of individuals have been accepted and respected.

Specifically, places of home palliative care have spread to homes, residences (e.g., apartment houses, day care and short-term stay homes), aged-care facilities (e.g., nursing-care facilities, apartments for the elderly), and welfare facilities for the disabled. Diseases treated by home palliative care are not limited to cancer but expanded to noncancer diseases (e.g., chronic disease,

intractable neurological disease, severe pediatric diseases, dementia). Also, care providers consist not only of health care professionals but also of care workers, indicating that interdisciplinary team care based on medicine and care has become necessary.

Diffusion of home palliative care is an important issue for the Japanese communities. In the United States, it is estimated that 1.5 to 1.6 million people underwent hospice care in 2013, with the mean duration of 72.6 days. The most frequent duration was <7 days, accounting for 34.5%. Places of hospice care were home at 41.7%, in-home facility such as nursing home at 24.9%, hospice ward at 26.4%, and acute phase hospital at 7%, showing a remarkably high proportion in home-related facilities. The diseases consisted of cancer at 36.5% and noncancer diseases at 63.5%, revealing that hospice care has been commonly introduced also for noncancer diseases. Regarding the scale, the mean number of patients for which one office provided care per day was ≤25 patients at 29.5%, 26 to 100 patients at 31.6%, and ≥100 patients at 38.9%, showing scaling-up of the business.¹⁾

Details of Home Palliative Care

The details of palliative care are as follows: (1) support of patients for everyday activities, (2) medical support (symptom relief treatment) for physical and psychological sufferings, (3) support for social and spiritual sufferings, and (4) support of family members. The supports can be roughly classified into medical support and life support. The care providers consist of health care professionals, such as physicians (including dentists), nurses, pharmacists, physical therapists, occupational therapists, speech-language-hearing therapists, dental hygienists, and dieticians for medical support, and care managers, professional caregivers, care workers, health-care professionals, such as community health nurses, and local residents including volunteers for life support. In cooperation with these staffs, the care is provided as a team, which is also the major characteristics of this system.

Differences in Palliative Care between Cancer Diseases and Noncancer Diseases

Even in noncancer diseases, various sufferings occur with disease progression, for which palliative care is considered necessary and carried out. Differences from cancer diseases include that noncancer diseases have complicated terminal medical conditions with a longer duration, medical condition changes depending on respective diseases, various physical symptoms with a high frequency of pain, shortness of breath, and general malaise depending on diseases, and difficulty predicting prognosis. Thus, no particular differences are found in the symptoms and handling of psychosocial suffering. However, at the time of condition exacerbation of noncancer disease, it is often difficult to determine whether to keep monitoring the course at home or to transfer to a backup support hospital to receive treatment.

Goals of Home Palliative Care

The definitive goals of home palliative care is that the patient and family members comfortably spend the rest of the patient's life together at home without anxiety. This may lead to end-of-life care at home; however, end-of-life care at home itself is not the final target. Home palliative care ends at patients' death; however, it must also include grief care of families after patients' death.

Conditions for Smooth Practice of Home Palliative Care

A number of inhibitory factors are reported for home palliative care. The survey result of preferences for place of end-of-life care in Japanese population, supposing the life expectancy of 1 to 2 months, was as follows: home at 43.7%, acute phase hospital at 14.8%, palliative care unit at 19.2%, public nursing home at 9.9%, and private nursing home at 1.9%. The factors of preference for hospitals, palliative care unit, and public nursing home than home were as follows: (1) regular hospital visiting, (2) no experience of end-of-life care at home, (3) having no opportunity to think about how to spend last days of life, (4) a lower cost of home remedy that is about 30% of hospitalization cost, and (5) insufficient knowledge of visiting care and home care support clinics.²⁾

The survey result revealed that it is important to provide the information of home palliative care in a positive manner during the term of the patients' hospital visit and to establish a structure so that people in the community positively have a supportive relationship to share end-of-life care experiences.

Also, it is prerequisite that the system is all set to provide medical and life support depending on the needs, when patients or families wish to spend last days of life at home.

A. Preparation for the Medical Support system

a. Assurance of a 24/7 visiting medical care system

Assurance of the following system is necessary. Physicians (not only palliative care specialists, but also hospital doctors, GPs, family doctors, and primary care doctors in the community) and nurses with knowledge and skills of palliative care visit patients on a regular basis. At the time of any trouble in patients or families, an immediate telephone contact should be available at any time around the clock, and where necessary, an extraordinary visit (by nurse or physician) should be available. Also, suffering is relieved, as much as possible, by appropriate symptom relief treatment.

b. Establishment of team health care and cooperation with medical care

Basically, the care is provided in cooperation with physicians, nurses, and pharmacists. Even if institutions of respective occupations are separated, the team health care with close cooperation is required.

c. Assurance of backup support beds

A bed has to be assured whenever the patient or family wishes for admission. Clinics without beds are required to have a system to cooperate with hospitals available for emergency admission at all times or clinics with beds.

B. Preparation for Life Support System

Without care ability, home palliative care cannot be established. With a current increase of nuclear families, caregivers may be the elderly with a low care ability or may go to work during daytime, resulting in no caregiver at home. Also, many patients live alone without caregiver. For patients with cancer diseases, the duration of home palliative care is short, in particular. By investing as much available resources (human resources) as possible, the care ability is likely to be assured. The integrated community care system enhances this possibility. It is hoped that public-assisted and/or mutual-assisted support systems will be established for each community.

C. Wishes of Patients and Families

It is ideal that the patient wishes for home palliative care upon understanding the medical condition by him or herself, and the family also wishes to stay together. However, in many cases, their wishes do not match.

In some cases, the family wishes for home palliative care, but the patient is not willing to. The most common reason for this is that the medical condition is not explained to the patient.

While the family members wish to stay home together, the patient plans to go back home after recovery from the medical condition. This is such an unfortunate circumstance. In contrast, the patient wishes for home palliative care, but the family is not willing to in some cases. The most common reason for this is the family members' lack of consciousness (motivation) for end-of-life care and anxiety for the medical condition. In extreme cases, some of the families misunderstand that it is ordinary to leave the end-of-life care to health care providers. Also, they have very intense anxiety for medical conditions, especially for the condition changes in the pre-mortal stage. If the patient is admitted, physicians and nurses are always around and will provide required treatments at aggravation of medical conditions. However, at home, anxiety remains that they may not hurry home and may not do anything for the patient. Anyway, families especially with a high motivation can spend last days with patients at home under any medical conditions, if at least appropriate medical support is available.

D. Awareness of Managers and Staff Members in Facilities

End-of-life care in aged-care facilities and welfare facilities for the disabled is also an important issue in the future. At present, an excessive burden has been placed upon acute-phase medical care including emergency care, because many cases with aggravation of medical conditions are transferred as emergency patients. In contrast, it has been known that end-of-life care is available without confusion by backup support of health care professionals with deep understanding of end-of-life care by facility managers and staffs. Recently, workshop for the end-of-life care has been held in a number of communities.

Community-based Palliative Care Support Network

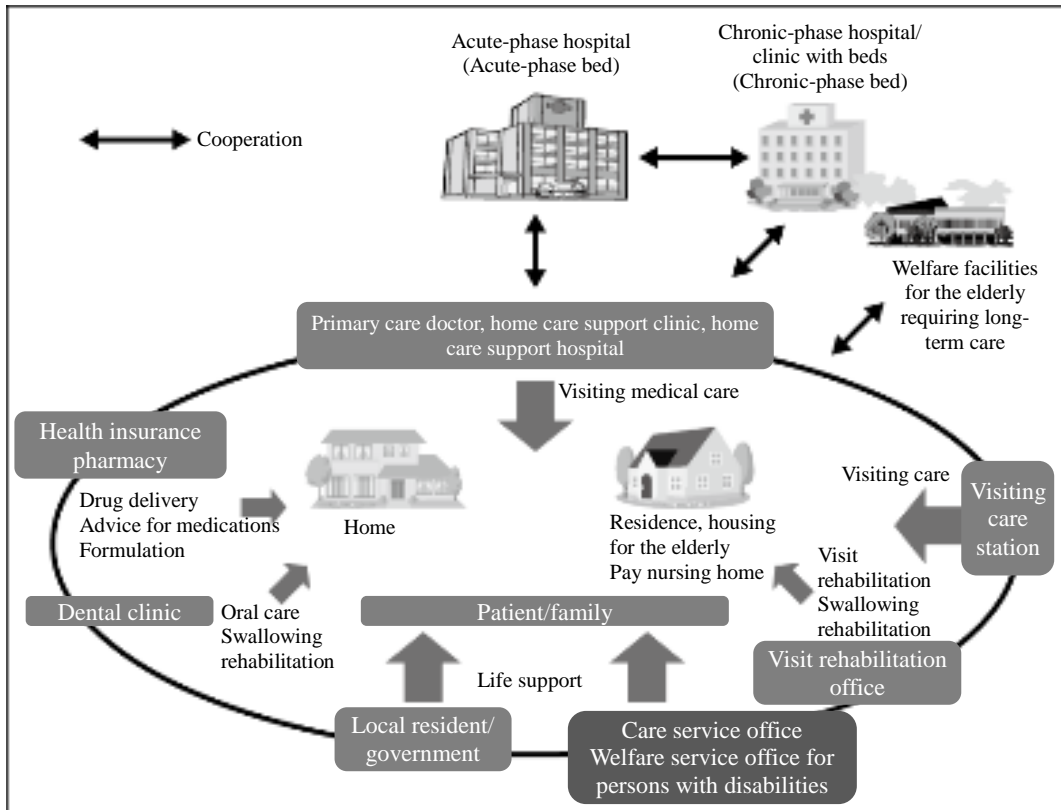
For patients suffering due to advanced cancer or chronic disease, palliative care services by health care professionals and care providers who can handle total pain and various needs of patients and families and respect their lives are needed "to keep their own lives in homeland community till the end of life." The realization of this requires efforts of the overall community, including hospital palliative care teams, for palliative care and establishment of a system to provide integrated palliative care in the community. The system is so-called as the community-based palliative care support network or community-based palliative care. In European countries, the United States, and Kerala State in India, the system has already been incorporated as a part of health care and is called "regional palliative care," "community-based palliative care," or "regional community-based palliative care."^{3),4),5)}

The author usually uses the diagram presented below (**Figure**). Based on the system, the patient basically lives at home (including welfare facility for the disabled), and depending on medical conditions or care circumstances and wishes of patients and families, acute-phase beds or chronic-phase beds are available. The final target is to provide high-quality palliative care at such places.

The roles of each section in this diagram are shown below.

- (1) Acute-phase bed (severe acute-phase bed, bed of acute-phase hospital, palliative care unit): Instruction of patients for home medical care (including providing information about home medical care and symptom relief treatment for suffering), early cooperation with primary care doctors, backup support (temporary hospitalization for symptom relief treatment and providing places for families with intense anxiety of end-of-life care at home), and palliative care training for community staffs.

Figure. Community-based Palliative Care Support Network



- (2) Chronic-phase bed (chronic-phase hospital, clinic with beds, palliative care unit): Instruction of patients for home medical care, backup support (temporary hospitalization for symptom relief treatment, providing places for families with intense anxiety of end-of-life care at home, temporary hospitalization for family members' respite care), palliative care training for community staffs, sending information of home palliative care. Home care support hospitals have two roles for home care support clinics and chronic-phase beds that are described below.
- (3) Home care support clinic, primary care doctor: Symptom relief treatment, explanation of medical conditions, decision-making support, training of end-of-life care, death confirmation.
- (4) Visiting care station: Assessment of symptoms and symptom relief treatment, training family members for nursing and care, training of procedures and treatments, decision-making support, training of end-of-life care, intermediation between patients or family members and physicians.
- (5) Health insurance pharmacy: Drug delivery, advice for medications, formulation of various injections, supply of medical materials and hygienic materials, health consultation for family members, drug control.
- (6) Care service office: Preparation of care plan, care support adjustment according to ADL status, comprehension of implementation status and adjustment for medical care and care support services, training of end-of-life care.
- (7) Dental clinic: Oral care, swallowing rehabilitation.

- (8) Visit rehabilitation office: Visit rehabilitation, swallowing rehabilitation.
- (9) Government: Development of home-care-nursing-cooperated services based on the long-term care insurance service.
- (10) Community volunteers: Life support, end-of-life care support. For effective function of the network, it is important that each occupational group recognizes the respective roles. At the same time, it is also important to share the role of activities depending on cases in consideration of limit of individual ability. An overall coordinator is also needed. To raise candidates for the role of the coordinator, training for total health planners has also started.

Recently, an increasing number of patients with cancer, in particular, have to start home palliative care upon aggravation of medical conditions under the condition of extremely short life expectancy. In the same manner as in Germany (spezialisierte ambulante palliativversorgung; SAPV)⁶⁾ and in the United States, development of special palliative care team is also needed to handle such situation and cases with highly difficult medical conditions.

Issue for Diffusion of Home Palliative Care

The construction of the integrated community care system started from fiscal 2014. It is a countermeasure for the coming declining birth rate and super-aged society and high mortality rate society. The nature of the system is “to create new community (regeneration of the 21st-century community).” Also, it is the major reform from the traditional medical care “for cure” to “for cure and support,” and from “hospital-completed medical care” to “community-completed medical care.”

“The national assembly report of the social security system reform (August 6, 2013)” presents the future direction to construct the integrated community care system. The intended direction of the social security system is as follows. “The functions of hospitals, units, and institutions should be assured in the community to establish a structure to end an excessive relying on hospitals for maintenance and improvement of QOL and to keep the patients’ own lives in homeland community till the end of life.” “Necessary review should be performed so that individual patient’s dignity is ensured and that patients’ wishes are highly respected. Also, environments should be prepared especially for the peaceful final stage of life.” “The objectives of medical care should be changed from the traditional medical care ‘for cure’ to ‘for cure and support’ that places emphasis on QOL. The medicine and care providing system should be examined also from the view point of town development. Also, public debate will be held in terms of ideal terminal stage care and end-of-life care from the point of view of how the care should be to keep living our own ways till the end of our lives.”

Therefore, realization of this reform requires the system construction of end-of-life care accompanied by home medical care according to the actual circumstances of the community. In that sense, diffusion of home palliative care is the core and the most important issue of the reform.

Towards the diffusion of home palliative care, law-based policies have been steadily carried out. In June 2014, “Act on Arrangement of Relevant Acts for Promoting Comprehensive Secure of Healthcare and Care in the Region” was established. The Medical Service Law was amended (the 6th amendment of the Medical Service Law), and the community medical care has started to develop. The community medical care has designed to promote functional differentiation and sharing of beds. It is not redistribution of traditional beds but the redistribution in consideration of acceleration and shifting to home medical care. Then, the Long-Term Care Insurance Act was amended to incorporate home-care-nursing-cooperated services into community support services. From fiscal 2015, the municipal governments are basically responsible for the promotion of home medical care.

However, to end the “hospital-completed medical care (belief in large hospitals, about 80% of people die in hospitals),” which lasted for about 40 years, and to develop communities in which home palliative care is available for everyone according to the wish in every Japanese communities, specific actions should be taken for the following issues.

<Most important issues>

- (1) Assurance of visiting care station available for 24/7
- (2) Assurance and training of physicians conducting visiting medical care
- (3) Diffusion for visiting advice of medications
- (4) Primary palliative care training for visiting physicians and visiting nurses
- (5) Mindset reform of health care professionals in acute-phase hospitals (accelerated understanding of home medical care and palliative care)
- (6) Enhancement of activities in backward cooperation in the community cooperation division of acute-phase hospitals (enhancement of cooperation in consideration of end-of-life care at home)
- (7) Assurance of backup support hospital for home palliative care (acceleration of hospital and clinic cooperation)
- (8) Education of care workers for palliative care and end-of-life care
- (9) Improvement in the hub function of home medical care cooperation among the municipal governments and medical association
- (10) Construction of the community-based palliative care support network
- (11) Development of a specialized home palliative care team
- (12) Survey to demonstrate the efficacy of home palliative care, collection of related data and information disclosure by the government

<Important issues>

- (1) Education and edification of local residents for end-of-life care
- (2) Training of community volunteers associated with home palliative care
- (3) Acceleration of end-of-life care at housing for the elderly and welfare facilities for the elderly requiring long-term care
- (4) Assessment of medical fee for visiting nurses
- (5) Expansion of the scope of medical care that visiting nurses can provide
- (6) Establishment of a care system for patients living alone
- (7) Diffusion of life insurance products that can be used also for home palliative care (home-palliative-care special contract) and diffusion of special contract for living needs
- (8) Construction of an education system for the related occupations (physicians, nurses) before graduation of schools

(Yoshikazu Ashino)

References

- 1) National Hospice and Palliative Care Organization: HHPCO facts and figures (Hospice Care in America). 2014.
http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf
- 2) Fukui S, Yoshiuchi K, Fujita J, Sawai M, Watanabe M: Japanese people's preference for place of end-of-life care and death: a population-based nationwide survey. *J Pain Symptom Manage* 42(6): 882-892, 2011.
- 3) Kumar SK: Kerala, India: a regional community-based palliative care model. *J Pain Symptom Manage* 33(5): 623-627. 2007.
- 4) Kamal AH, Currow DC, Ritchie CS, Bull J, Abernethy AP: Community-based palliative care: the natural evolution for palliative care delivery in the U.S. *J Pain Symptom Manage* 46(2): 254-264.2013.
- 5) Higginson IJ, Sarmiento VP, Calanzani N, Benalia H, Gomes B: Dying at home-is it better: A narrative appraisal of the state of the science.
<http://pmj.sagepub.com/content/early/2013/05/22/0269216313487940.full.pdf>
- 6) Schneider N, Mitchell GK, Murray SA: Palliative care in urgent need of recognition and development in general practice: the example of Germany. <http://www.biomedcentral.com/1471-2296/11/66>

2. Home Palliative Care for Cancer Diseases

For home care physicians, managing terminal-stage cancer and conducting proper end-of-life care at home is difficult. However, for home medical care to be widely used, accumulation of such end-of-life care cases is indispensable. This article presents the methodology of home palliative care of cancer diseases.

Assessments of Home Palliative Care

The essence of home palliative care is probably “consideration”: consideration of medical conditions, sufferings, measures, patients, and families. Considerations and respects are always needed, so that the patients realize that “they are not abandoned.” This is definitely one of the important essences of home palliative care.

In home palliative care, caregivers care patients in their living fields. Through the living field, the caregivers get to know the patients and families and face numerous problems. Consequently, a little deeper assessment becomes possible.

Then, what is needed to be considered?

A. Comprehension of Patients’ Medical and Pathological Conditions to the Extent Possible

In many cases, home palliative care starts from the time when patients become unable to visit hospitals. The majority of patients have some type of physical problems and issues to be resolved, such as pain and psychological problems. Clarification of these issues and comprehension of the pathological conditions will enable the prediction of future medical conditions. Therefore, medical information, which is as detailed as possible, should be obtained from a physician who had previously assessed the patient. Also, only limited tests are available at home to comprehend the pathological conditions; therefore, it is desirable to obtain as much information related to imaging tests, such as computed tomography (CT), as possible.

Based on this medical information, you will observe, examine, and assess the patient.

Patients are likely to have physical symptoms, such as pain, dyspnoea, nausea, edema, and ascites. However, focusing only on the patient’s medical conditions may result in an overlook of his or her “inner feelings” hidden. The patients often suffer from fear of possible harder future suffering as being close to death, feeling of disappointment despite going through such a hard treatment, which ended in vain, and sense of isolation to be abandoned by hospital, medical care, and society. Further, they cannot accept the fact that they are going to die.

Don’t forget to assess the patients’ “inner feelings.”

B. What Is Going to Afflict the Patients?

It is important to predict the types of symptoms that will be encountered in future as the disease progresses and to plan countermeasures for them.

For example, an additional analgesic should be prepared to be able to be used as a “rescue dose” at the time of exacerbation of pain. Also, in cases where hematemesis is expected, the treatment may not be called as palliative care anymore. To prepare such case, prior discussions should be held with the patient and family members to determine the handlings.

Furthermore, changes in the “inner feelings” should be considered. Depending on circumstances, various aspects including just keeping an eye on the circumstances or daring to intervene it should be considered. When intervention is considered as an option, the way of intervention should be considered.

C. What Can Be Done?

With progression of diseases, patients start to have difficulty walking and decreased meal intake. Then, they spend most of the day on bed. Further disease progression causes significant physical exhaustion, difficulty walking to bathroom, and swallowing foods and even fluids, resulting in a reduction in the level of consciousness. Eventually, the patient starts mandibular breathing and completes his or her life. This is a common course to death.

It is difficult to control such course to death. What we can do is to ease pain that modifies the processes, unpleasant symptoms, such as dyspnea and delirium, and fluctuating feelings of patients and families, as much as possible.

D. Staging of Home Palliative Care

Home palliative care requires prediction of life expectancy in unit of months, weeks, days, or hours, in general. It can be very vague prediction, because precise prediction of life expectancy is impossible and of no value. Details of intervention and rough flow of care are presented according to vital prognosis (**Table**).¹⁾

E. Support of Families

In home palliative care, family members are going to have two sides, which are a calm observer as a “carer” and a “sufferer” who is going to lose the loving family. The gap between the two positions becomes a considerable stress and imposes a heavy burden on the family members. It may also make them falter in their determination of caring the patient till the end of life and may cause repeated determination changes between hospitalization and home care. Sometimes they are deeply grieved by foreseeing bereavement and cannot do anything.

Respecting and listening to them at all times, which will offer great support to the family and will help them recover in the course of time.

Treatments for Symptom Relief

A. Pain

a. Cancer pain assessment

What is important in pain assessment is how much pain they have and where and why. Based on the assessment, the pain relief measures according to the WHO’s pain ladder (**Figure 1**)²⁾ will relieve approximately 90% of pain.

b. Causes of pain

Cancer pain is mostly caused by the involvement of surrounding tissues. In cases of neuropathic pain involving the nerves, the pain is unlikely to be eliminated by opioid alone. Pain caused by bone metastasis may also be difficult to manage. Therefore, different treatment approaches are required for the respective pains.

c. Location and pain

When the patient complains of pain, the complaint should be entirely accepted at face value. Of course, placebo should not be used.

Table. Care of Patients and Families during the Terminal Stage

Terminal stage	Vital prognosis	Care of patients	Care of families
Early terminal stage	1–6 months	Pain control, Symptom relief treatments for other symptoms than pain, Psychological support, Consideration for putting patient’s affairs and things in order	Care for distress of notifying a patient of the disease, Notification of disease to elderly or pediatric patients, Assistance for accepting death
Middle terminal stage	Several weeks	Use of steroids, Discontinuation of high-calorie infusion, Support for everyday activities, Support for spiritual suffering	Consideration for anticipatory grief, Consideration for conflict between life extension and pain relief
Late terminal stage	Several days	Comfort position finding, Continuous subcutaneous injection, Measures to reduced conscious level	Consideration for care fatigue, Discussion about resuscitation, Preparation and training for death
Stage of immediately before death	Several hours	Serving the patient by keeping in mind that he or she is a person with personality, Handling of wheezing prior to death, Nonverbal communication	Explanation of symptoms during the stage immediately before death, Notification that what family members can do for the patient, Notification that auditory perception remains active

Modification from References 1)

The following three targets should be established for pain control and are tried to be achieved one by one. A sudden large dose may induce sleepiness or delirium.

- First target: Helping patients so that night sleep is not disturbed due to pain
 - Second target: Resolution of pain at rest
 - Third target: Resolution of pain at activities
- These analgesics should be prescribed according to the WHO’s five principles of pain relief.
- By the mouth
 - By the clock and regular analgesia
 - By the WHO’s pain ladder
 - For the individual
 - With attention to detail

B. Characteristics and Methods of Use of Drugs to Relieve Cancer Pain

The drugs are presented below according to the WHO’s pain ladder.

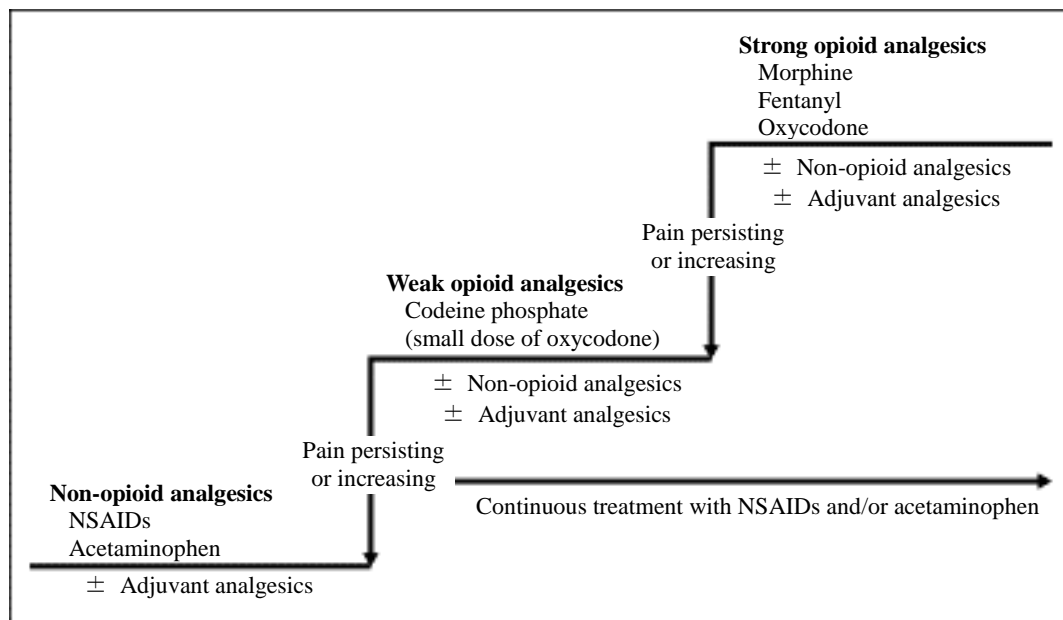
a. First step: NSAIDs and acetaminophen

When the patient complains of mild pain induced by cancer, non-opioid analgesics, in other words nonsteroidal anti-inflammatory drugs (NSAIDs), and/or acetaminophen are administered.

NSAIDs should be selected in consideration of possible gastrointestinal disorders and that the antipyretic effect should not be too strong. Development of gastrointestinal disorders should be prevented by combination with prostaglandins, proton pump inhibitors, or high-dose H2 blockers, or by the use of highly COX-2 selective drugs or COX-2 selective anti-inflammatory drugs (coxib NSAIDs) with a low risk of gastrointestinal disorders. Celecoxib, one of the coxib

NSAIDs, is slightly likely to induce drug eruption, but based on its moderate analgesic effect it can be one of the choices. Other highly COX-2 selective drugs include etodolac (Hypen[®]), meloxicam (Mobic[®]), and nabumetone (Relifen[®]) with a low risk of gastrointestinal disorders, in the same manner as COX-2 inhibitors.

Figure 1. WHO's Pain Ladder



Cited from References 2)

Acetaminophen has analgesic and antipyretic effects; however, it does not have an anti-inflammatory effect. It does not induce gastrointestinal disorders and has a small effect on bleeding time and renal function. However, large doses of ≥ 4 g may induce hepatotoxicity. A starting dose for cancer pain should be generally 1.5 to 2.4 g/day, and the dose can be increased up to 4 g/day.

b. Second step: Weak opioid analgesics

If pain persists even after providing the treatments of the first step, or in cases with moderate pain, the second-step drugs should be used. Combination with NSAIDs is desirable. Previously, the use of codeine was recommended. In recent years, tramadol and tapentadol are commonly selected, and a low dose (10 mg/day) of oxycodone is also recommended. Early measures for constipation and queasy are necessary.

c. Third step: Strong opioid analgesics

If pain persists even after the above analgesic treatments, strong opioid analgesics should be used. Also, for cases with strong pain, the third-step strong opioid analgesics should be used from the beginning. In Japan, the strong opioid analgesics to be used for cancer pain include morphine, fentanyl, oxycodone, and methadone.

(1) Morphine

(a) At start of administration

While sustained-release drugs (e.g., MS Contin[®]) are commonly used in recent years, fast-acting morphine hydrochloride should be used at the beginning. morphine hydrochloride oral

solution (Opso[®]) has the fastest effect. Both morphine hydrochloride tablets and powder exhibit the effect in about 5 min. Once a maintenance dose is determined, the formulation should be switched to sustained-release medication.

(b) Initial dose

An initial oral dose of morphine hydrochloride should be 20–40 mg per day. The standard regimen is 5 mg per dose four times daily (after each meal and before bed). For cases with severe pain, each dose may be increased to 10 mg. When pain occurs in the morning, the dose before bed time should be increased to double. When pain persists, each morphine dose can be increased from 5–10 mg, 10–15 mg, 15–20 mg, 20–30 mg, 30–40 mg, 40–60 mg, and 60–80 mg. Assessment is available at 24-hour intervals. The dose is increased to the level at which pain disappears.³⁾ Once a stable daily dose is established, the formulation should be switched to sustained-release medication.

When a patient becomes unable to take medicine orally, morphine suppository or injection should be used. The dose should be 1/2 to 2/3 of oral dose for suppository and 1/2 to 1/3 of oral dose for intravenous infusion or subcutaneous injection.

(c) Measures against adverse drug reactions

Adverse drug reactions (ADRs) to be monitored from the beginning are constipation and queasy. Morphine's analgesic effect cannot be obtained without overcoming constipation and queasy. For this reason, measures against queasy and constipation should be taken without fail.

For constipation, magnesium oxide should be administered as a basis. For a low frequency of evacuation, a stimulant laxative should be used. During opioid treatment, either or both of these drugs should be combined without fail.

For queasy, central antiemetics, such as prochlorperazine maleate (Novamin[®]) and haloperidol (Serenace[®]), should be used. If any problems occur associated with extrapyramidal symptoms or anticholinergic effects, serotonin-dopamine antagonists (SDAs) such as risperidone and olanzapine should be used. Queasy is likely to resolve within 1–2 weeks.

Respiratory depression is frequently noted as one of ADRs of opioids. However, unless a rapid and high dose is used, respiratory depression rarely occurs. If respiratory depression occurs, a reduction of the opioid dose to 1/3 will relieve the symptom within a few hours. Also, deep anxiety for the risk of habituation and dependency has been expressed; however, the recent research revealed that habituation and dependency do not develop when opioid is used for "pain" relief. It is also important to provide sufficient explanation of opioid treatment using leaflets before initiating the treatment so that patients' anxiety to ADRs of opioid disappears.

(d) Rescue dose

Cancer pain is frequently accompanied by a transient increase in pain, called as breakthrough pain. For this pain, a supplemental opioid dose, called as rescue dose, should be given. As the supplemental dose, rapid-release morphine hydrochloride or oxycodone should be used, because they exert rapid and certain effects. A rough standard dose is 1/6 of daily dose for morphine and 1/4 to 1/8 of daily dose for oxycodone.

For example, for patients usually taking MS Contin[®] at a daily dose of 120 mg, a rescue dose is calculated as 20 mg of morphine hydrochloride oral solution per dose. It is ideal to use the formulation that exerts the effect in the shortest time possible.

(e) Explanation of morphine treatment

Prior to the use of morphine and opioid, the author always obtains approval from patients. A number of patients have strong anxiety toward morphine treatment, such that a possible dependency may induce mental abnormalities, which the patient may not be able to live without morphine due to a possible tolerance and habituation, and that life expectancy may be shortened due to development of ADRs.

Of course, they are needless anxieties. The research results revealed that the above conditions do not occur in the presence of chronic pain. So far, few cases have been reported regarding morphine-induced addiction in cancer patients. Though it may be a time-consuming explanation, health care providers should not save steps in this process. As previously described, it is useful to use existing leaflets. Also, all health care providers and caregivers associated with patients must have common recognition (sense) of morphine.

(2) Fentanyl patch

Currently, two types of fentanyl patches are available. One is a 24-hour patch to be changed at 24-hour intervals, and the other is a 72-hour patch to be changed at 72-hour intervals. No particular difference has been reported in their analgesic effects. Thus, these two types of patches should be properly used depending on the patients' adherence. At present, the 24-hour patch has been predominantly used. However, the 72-hour patch is more likely to be used in patients requiring visiting-nurse's assistance for applying the patches. The patch is very useful for patients having difficulty in oral intake, and it is more frequently used in patients receiving home care. Therefore, it is necessary to understand the properties of these drug products and to have full knowledge of the use. The points are summarized below.

(a) Percutaneous absorption

Fentanyl is percutaneously absorbed from the subcutaneous fat layer and transferred to blood flow through the local capillary vessels. Subcutaneous fat thickness varies depending on location of the body; therefore, it is important to apply the patch on a physically stable site with an about equal subcutaneous fat thickness. The recommended sites are the precardium, abdomen, upper arm, and femoral region. However, fentanyl is fat soluble. Therefore, the drug is likely to be accumulated in the region with thicker subcutaneous fat than in the region with thinner subcutaneous fat, and the accumulation may result in a smaller concentration gradient with the patch and poor absorption.

(b) Switching from previously used opioids

Both types of fentanyl patches are a sustained-release preparation. Thus, a maintenance dose is determined using morphine or oxycodone in advance, and the formulation is switched to fentanyl patch, in a basic manner. It takes time for the fentanyl patch to increase blood fentanyl concentration. Thus, up to 12 h from the first fentanyl application, the previous opioid should be combined. For switching, oral morphine dose of 60 mg/day is converted to fentanyl patch 25 µg/hr (fentanyl 0.6 mg/day; fentanyl citrate (Fentos Tape®) 2 mg) as an equivalent dose (in a rate of 1:100).

(c) Dose adjustment

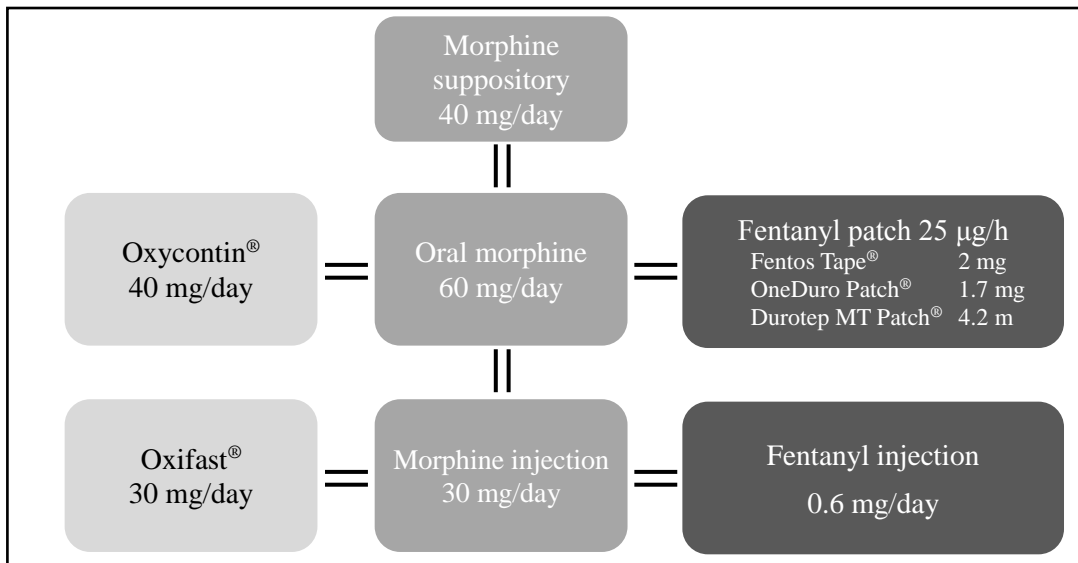
When the analgesic effect is insufficient, the dose is increased by 30%–50%. However, it should be kept in mind that fentanyl patch is a highly sustained-release formulation; therefore, detailed dose adjustment is difficult. Also, fentanyl has a weaker analgesic effect compared to morphine or oxycodone. At higher doses, an increase in the level of analgesic effect may not match the level of dose increase. Therefore, in cases with an unsatisfactory effect of Fentos Tape® 8 mg, opioid switching or combination with adjuvant analgesics should be considered rather than a simple dose increase.

In home care practices, it is sometimes seen that a dose of fentanyl patch is rapidly increased for an attempt of pain control by fentanyl patch alone. As previously described, in consideration of the properties of fentanyl and the characteristics of patches, the sudden dose increase should not benefit patients. When dose increase is considered, the effect should be assessed for at least 72 h without increasing the dose. To resolve pain during the time, an effective use of rescue dose is recommended, which is described below. The author recommends a week as an interval for dose increase.

(d) Rescue dose

For rescue dose, morphine hydrochloride or oxycodone is used. From 2014, transmucosal immediate-release fentanyl has been available as a rescue dose of fentanyl. However, it has difficulty in dose adjustment. Thus, prior to the use of this drug product, it is desirable to establish the dose after consulting a palliative care expert under hospitalized conditions. When using morphine hydrochloride or oxycodone, a rescue dose is determined based on the conversion calculation that fentanyl patch 25 µg/hr (fentanyl 0.6 mg/day; Fentos Tape® 2 mg) is equivalent to oral morphine 60 mg (Figure 2).

Figure 2. Table of Opioid Potency



(3) Oxycodone

In terms of ADR classification, oxycodone is positioned close to morphine. However, the hepatic metabolites are not pharmacologically active. Thus, in cases with decreased renal function, oxycodone is a first-line choice. Also, oxycodone has a slightly higher effect on neuropathic pain than morphine. A fast-acting formulation of Oxinorm® and a sustained-release formulation of Oxycontin® are available.

(a) Dosage

After administration of Oxycontin®, a relatively immediate effect is obtained, and the effect lasts for 12 h. The dose can be set from a low dose (5 mg tablet); therefore, initiation from the second step is available. After the treatment start, the dose is gradually increased by assessing the effect. For switching from other opioid, Figure 2 should be referred. For a rescue dose, the fast-acting Oxinorm® should be used at about 1/6 of daily oxycodone dose.

(b) ADRs

A lower frequency of queasy and sleepiness has been reported than in morphine. Though a low frequency of constipation, once the patient suffers constipation, the handling may be more difficult than in morphine. For prophylactic measures against constipation, administration of magnesium oxide or stimulant laxative is necessary at all times.

(4) Methadone

Methadone (Methapain®) is one of the opioid analgesics for the fourth-stage cancer pain treatment. Methadone is cheaper than other opioids and has low cross-resistance to other opioids.

Also, it has an N-methyl-d-aspartate (NMDA) receptor antagonistic action and is effective on neuropathic pain. In contrast, it has a long half-life with individual differences, having a risk of accumulation in the body. Also, it may induce ADRs, including cardiotoxicity. Therefore, it should be used in cooperation with a palliative care specialist.

d. Adjuvant analgesics

Pain from cancer infiltration around the nerve (neuropathic pain) may be difficult to control only by opioids. In such cases, drugs called adjuvant analgesics are used. Adjuvant analgesics are not analgesics in the original indication but are drugs that, under certain conditions, exhibit an analgesic effect in combination with analgesics. Adjuvant analgesics are roughly classified into anticonvulsants, antidepressants, antiarrhythmics, and NMDA inhibitors.

(1) When neuropathic pain is observed

When patients complain “stabbing, gripping, or electric-shock-like pain,” neuropathic pain should be considered, and concomitant treatment with adjuvant analgesics should be considered.

(2) Anticonvulsants

Anticonvulsants are known as relatively effective on sudden electric-shock-like pain. Na-channel blockers, such as sodium valproate (Depakene®), sodium valproate (Valerin®), and clonazepam (Rivotril®/Landsen®), and Ca-channel blockers, such as gabapentin (Gabapen®) and pregabalin (Lyrica®), are used. Common dose ranges are 400–1000 mg for sodium valproate, 0.5–1 mg for clonazepam, 200–2400 mg for gabapentin, and 50–600 mg for pregabalin.

(3) Antidepressants

Tricyclic antidepressants are said to be effective for persisting gripping pain. amitriptyline (Toryptanol®) and amoxapine (Amoxan®) are commonly used. A dose range is 10–75 mg. Frequently reported ADRs of tricyclic antidepressants include thirst, hoarse voice, hypogeusia, and sleepiness, and caution should be exercised for development of these ADRs. Also, tricyclic antidepressants have an anticholinergic effect and QT prolongation effect; therefore, special caution should be taken for the use in patients with cardiac diseases.

(4) Antiarrhythmics

Oral dosage form of antiarrhythmics, such as mexiletine (Mexitil®) and flecainide (Tambacor®), are commonly used. Many reports have been published about the efficacy on both lancinating pain and persistent pain.

The dose of the antiarrhythmics is almost equivalent to that used for treatment of arrhythmia. A common dose range of mexiletine is between 150 and 300 mg.

A standard dosage regimen of flecainide is 200 mg/day twice daily. Compared to mexiletine, flecainide has a longer effective duration and a stronger effect. However, flecainide has a negative inotropic effect on the cardiac function; therefore, caution should be exercised for the use in patients with decreased cardiorespiratory function.

(5) NMDA inhibitors

Ketamine (Ketalar®) responds to various types of neuropathic pain. In home palliative care, an intramuscular injection of Ketalar50® is continuously injected subcutaneously. Due to skin irritancy, betamethasone (Rinderon®) 2 mg (0.5 mL) is added to ketamine, or ketamine is diluted with saline or morphine. Though large individual differences, strong floating feeling (e.g., feeling like flying in a swinging plane, feeling of out-of-body experience) may be induced in some cases; therefore, a small dose of midazolam (Dormicum®) may be concomitantly administered. During treatment with ketamine, caution should be exercised for development of intracranial hypertension.

(6) Steroids

Steroids are also effective adjuvant analgesics. The author often uses Rinderon[®] 2–4 mg. In home palliative care, the duration of steroid treatment is not so long in many cases; therefore, issues of ADRs are not likely to arise.

e. Pain caused by bone metastasis

Pain from metastases to bone is also difficult to control only by opioids. Radiotherapy is one of the most effective measures. However, in home palliative care practices, many patients have already received the maximum permissible dose of radiation.

At first, the combination of NSAIDs and opioids is necessary. Then, in many cases, steroids are also concomitantly administered. By suppressing the action of osteoclasts, inflammation surrounding the bone reduces, showing the effect of supporting pain relief.

zoledronic acid (Zometa[®]) is one of the bisphosphonates and is said to be effective for pain caused by bone metastasis by suppressing osteoclasts' activities. Zoledronic acid 4 mg is infused over at least 15 min at 4-week intervals. denosumab (Ranmark[®]), a therapeutic drug for bone lesions, is also effective for pain caused by bone metastasis. Ranmark[®] can be subcutaneously injected; therefore, it is easier to use at home than Zometa[®]. However, Ranmark[®] is likely to induce hypocalcemia, requiring administration of calcium preparations and monitoring of serum calcium levels. Both Zometa[®] and Ranmark[®] have a risk of osteonecrosis of jaw. Therefore, caution should be exercised when either of these products is repeatedly administered to patients with dental caries.

C. Dyspnea (Suffocation)

a. Causes of dyspnea

Various causes of dyspnea exist, including those caused by cancer itself, such as reduced respiratory surface, airway obstruction and stenosis, pleural effusion, disturbance in gas exchange represented by carcinomatous lymphangitis, and those associated with cancer, such as pneumonia and respiratory convulsion.

b. Treatment of dyspnea

(1) Approaches depending on the cause

For pleural effusion, puncture and drainage is available even at home. The author's method is as follows. A puncture site is determined using ultrasound. After disinfection, local anesthesia, and puncture, the effusion is drained using transfusion route of liquid medicine. During drainage, attendance of a nurse or physician is necessary. The drainage completes in 1–2 h.

For increased sputum during the terminal stage, continuous subcutaneous injection (or subcutaneous injection at 4- to 6-hour intervals) of anticholinergics, such as scopolamine (Hysco[®]) and butyl scopolamine (Buscopan[®]), is effective.

(2) Oxygen administration

Home oxygen therapy (HOT) is initiated. Oxygen concentration produced by an oxygen concentrator is around 90%. Some reports indicate that liquefied oxygen that can offer 100% oxygen concentration is more effective for dyspnea associated with respiratory cancer.

(3) Drug administration (MTS treatment)

MTS treatment is basically a treatment with morphine (M), tranquilizer (T), and steroid (S).

Morphine has a strong antitussive action and also relieves dyspnea. Morphine dose of approximately 30%–50% of that used for pain relief often shows the effect.

Steroid relieves inflammation of the respiratory tract and lung parenchyma and has an improvement effect on respiratory convulsion and lymphangiopathy.

Tranquilizer has effects on anxiety and panic symptoms induced by dyspnea. During night time, when dyspnea aggravates and no particular changes are observed in respiration findings,

minor tranquilizer, such as mitazolam (Dormicum[®]) or diazepam (Horizon[®]), is intravenously administered as needed.

(4) Sedation

In patients with refractory unbearable suffering, sedation may be used under certain conditions as the ultimate treatment option for relief. One of the common sufferings is dyspnea. The use of sedation is considered in patients with a short remaining life time (≤ 1 week in many cases), and when no other treatments can relieve the suffering. Prior to the use, informed consent must be obtained from the patient or family, and sedation must be carefully used.

Depending on conscious level, conscious sedation and deep sedation are differentiated. Conscious sedation is a condition in which a patient comes to consciousness when being called and can have a talk. Deep sedation is a condition in which a patient does not awake even if strong stimulations are given. Regarding drugs, Dormicum[®] has been commonly used, because it is useful to control depth of sedation. At a dosage of 20–40 mg/day, moderate sedation can be achieved in many cases; however, large individual differences are identified. For conscious sedation, 10% phenobarbital (Phenobal[®]) is used. In the elderly, sufficient sedation can be often achieved also by Serenace[®], an antipsychotic.

“Guidelines for sedation to relieve sufferings”⁴⁾ should be referred for application of sedation, ethical considerations, and necessary procedures in the processes to provide sedation.

D. Palliative Care for Gastrointestinal Obstruction

For lower gastrointestinal obstruction, octreotide (Sandostatin[®]), a somatostatin analog, is used. Even in cases with intestinal obstruction, the symptoms can be controlled to some extent without inserting an ileus tube.

A daily dose of 300 μ g (3A 3 mL) is administered by continuous subcutaneous injection. Relief of abdominal pain and vomiting is expected in many cases. Depending on the obstruction site, the effect on queasy may vary. In cases with severe queasy, an antiemetic drug, such as Serenace[®], is added.

In cases with upper gastrointestinal obstruction, satisfactory effects may not be obtained. In thorough consideration of the stage and medical conditions, gastrostomy placement and nasogastric tube insertion should be considered as decompression treatment.

E. Queasy and Vomiting

Gastrointestinal prokinetics, such as metoclopramide (Primperan[®]) and domperidone (Nauzelin[®]), have been commonly used. For relief of central queasy/vomiting, Novamin[®], Serenace[®], or atypical antipsychotics (e.g., risperidone, olanzapine) are more likely to be effective. For symptoms considered as induced by gastrointestinal obstruction, Sandostatin[®] is administered.

F. Inappetence, General Malaise, and Listlessness

Patients with inappetence or general malaise may show a complete response to steroid for its improvement. The effect lasts for about 1–2 months. After elimination of the effect, the patient is likely to die within a relatively short period of time. Rinderon[®] 2–3 mg or Predonine[®] 20–30 mg should be orally administered.

G. Control of Ascites (Pleural Effusion)

In home medical care, ascites and pleural effusion can be also treated. Temporal relief may be obtained by diuretic treatment; however, the effect is of limited duration. Puncture and drainage of ascites can be conducted also in home care. In the same manner as pleural effusion, a puncture site is determined using ultrasound and punctured. When puncture and drainage is expected to be required in a frequent basis due to a high accumulation rate of ascites, a catheter (14GCV catheter with a side hole) is inserted and placed in the peritoneal cavity or pleural cavity, and

ascites is drained every few days by opening the catheter. In this case, the catheter is fixed by purse-string suture to prevent leakage of ascites or pleural effusion from the puncture site.

H. Tumor Associated Fever

Basic treatment for tumor associated fever is administration of NSAIDs or acetaminophen. Among NSAIDs, Naixan[®] has relatively a low risk of gastrointestinal disorders, and the efficacy is demonstrated. The dosage is 600 mg/day.

When the fever is uncontrollable even by the above treatment, concomitant treatment with steroids should be considered. Rinderon[®] 1–2 mg or Predonine[®] 10–20 mg is effective in many cases. Caution should be exercised not to overlook infection.

I. Hypercalcemia

For hypercalcemia, bisphosphonates and steroids are effective. Zometa[®] is intravenously infused over about 15 min. A common frequency of treatment is 4 weeks. However, a serum calcium level may decrease within less than 4 weeks post-infusion depending on cases. In such cases, a shorter dosing interval is selected.

J. Skin Troubles Associated with Cancer

Pressure sore is frequently observed at the terminal stage; however, it is described in the separate section. Therefore, the following issues associated with tumor-related ulcer are presented.

Tumor on the body surface, which is self-destroyed and formed ulcer, is called as cancerous skin ulcer or malignant ulcer. Basically, they are handled in the same manner as pressure sore. The specific measures include handlings of hemorrhage, bad smell, and effusion.

For treatment of hemorrhage, alginate dressing is used in a basic manner, and compression is applied to achieve hemostasis. However, arterial or oozing hemorrhage may be difficult to achieve hemostasis in a desired manner. Though no evidence has been obtained, the methods attempted by the author are presented below.

One is dry ice cooling hemostasis. A small amount of dry ice is placed on the bleeding tumor. Removal of the dry ice in a forced manner may cause tumor rupture. The dry ice should be allowed to stand until the evaporation finishes. A possibility of pain and frostbite in the surrounding tissues remains, and a possibility of re-hemorrhage is not low.

The other is local injection of absolute alcohol, using an as-thin-as-possible local injection needle. Removal of the needle immediately after injection causes hemorrhage; therefore, the needle should be placed in the site for a few minutes. About 1 mL of absolute alcohol per injection site often shows the effect. Injection may be associated with pain.

For cases with diffuse and oozing hemorrhage from the ulcer surface, external application of hydrophilic ointment mixed with a 0.001% concentration of Bosmin[®] may be effective.

Regarding measures against odor, control of effusion and corruption of necrotic substances is needed. Basically, sufficient washing is effective. Some reports recommend the use of 0.8% metronidazole ointment (per 100 g, metronidazole 0.8 g + macrogol 400 20 g + macrogol ointment 69.2 g + Xylocaine Jelly[®] [lidocaine jelly] 10.0 g). A commercial product of 0.75% metronidazole (Rozex Gel[®]) is also available. However, the base is relatively easy to dry, so caution should be exercised to prevent bleeding when removing the gel.

Using a similar idea, effusion can be adsorbed, using povidone-iodine preparations. The author often uses Cadex Ointment[®]. It is also effective to cover the lesion with diapers or film materials.

K. Anemia and Transfusion

Various opinions are expressed regarding transfusion during the terminal stage. Except for emergency transfusion, the use of erythropoietin is reported to be effective. In consideration of the remaining life time and performance status (PS), the indication should be considered. A crossmatch should be conducted, and a physician or nurse should be attended during transfusion.

L. Delirium

Delirium is a symptom induced by a depressed level of consciousness. Therefore, it is often observed after considerable progression of medical conditions. If it is left untreated, family members' anxiety increases; therefore, it should be treated as immediately as possible. The first-line choice is Serenace®. In cases with severe anxiety or cases with increased activity, a benzodiazepine preparation may be concomitantly used. However, when delirium is tried to be treated using a benzodiazepine preparation alone, the symptoms may be aggravated.

After the symptoms subside, the medication may be switched to atypical psychotropics (e.g., risperidone [Risperdal®], quetiapine fumarate [Seroquel®]).

M. Fluid Infusion in Home Palliative Care

The recent research revealed that, in patients close to the terminal stage, fluid infusion even at 1000–1500 mL per day increases adverse reactions, such as edema, pleural effusion, ascites, delirium, and increased airway secretion. Therefore, reduction or discontinuation of fluid infusion towards the terminal stage has been widely recognized in the field of palliative care.

Still, intravenous hyperalimentation has a positive sense for patients with difficulty in oral intake due to gastrointestinal stenosis. At the terminal stage, negative sense of fluid infusion may increase. However, if the patient or family has a strong preference, the fluid infusion may be provided in home care practices. In recent years, subcutaneous transfusion has been drawing attention to be provided for such cases.

(Hiroshi Suzuki)

References

- 1) 恒藤暁：最新緩和医療学。最新医学社，25，1999。Tsuneto S.: Most current palliative medicine. Saishin Igaku, 25, 1999.
- 2) 世界保健機関：鎮痛薬の使用法。がんの痛みからの解放 —WHO 方式癌疼痛治療法—。金原出版，17，1996。World Health Organization: Method of use of analgesics. Cancer pain relief—Cancer pain therapy proposed by the WHO—Kanehara & Co., Ltd. 17, 1996.
- 3) 蘆野吉和：上手なオピオイドの使用法。消化器外科 28 (13) : 1871-1878, 2005。Ashino Y.: Appropriate methods of use of opioids. *The Japanese Journal of Gastroenterological Surgery* 28(13): 1871-1878, 2005.
- 4) 日本緩和医療学会緩和医療ガイドライン作成委員会 編：苦痛緩和のための鎮静に関するガイドライン 2010 年版。金原出版，2010。Guideline preparation committee for palliative medicine, Japanese Society for Palliative Medicine (Ed). Guidelines for sedation to relieve sufferings 2010. Kanehara & Co., Ltd., 2010.

3. Home Palliative Care for Noncancer Diseases

Two of three people requiring palliative care suffer noncancer diseases. Palliative care is “fundamental care offered to all people at all places.” Home care physicians have a basic role to relieve suffering of patients with various noncancer diseases, such as dementia and respiratory failure, and families and to support their ways of living (decision-making).

Introduction

In 1990’s, the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) in the United States and the Regional Study of the Care for the Dying (RSCD) in the United Kingdom were conducted. The results revealed that sufficient palliative care had not been offered to patients with noncancer diseases. In this century, the Western developed countries have started widespread practices of palliative care for noncancer diseases.

In Japan, palliative care for noncancer diseases has drawn attention in the fields of home medical care and geriatrics from 2000; however, its practices and researches have delayed from those of the Western developed countries. Starting from the “Statement for end-stage cardiovascular care” (The Japanese Circulation Society) in 2010, the academic societies of each specialty have presented ideal medical care for the terminal stage one after another also in Japan, showing a notable change.

Currently, two of three people requiring palliative care have noncancer diseases. Palliative care has been offered not only to cancer patients but also to patients with noncancer diseases and pediatric patients. Also, the place of practices has spread from palliative care units to homes, acute-phase wards, intensive care units (ICUs), and facilities. In this diversifying history, palliative care has re-established the universal value of “fundamental care offered to all people at all places,” and it has also developed a new basic philosophy of “palliative care as a human right” (Prague Charter, 2012).

Trajectory Characteristics and Prognostic Prediction of Noncancer Diseases

Lynn, et al. classified the trajectory of the terminal-stage disease into three models of “cancer,” “organ system failure, such as cardiopulmonary diseases,” and “dementia/frailty.”¹⁾

The characteristics of cancer include that relapsed cancer is incurable in most cases, and that the overall function rapidly decreases in the last 1–2 months; therefore, prognostic prediction is relatively simple.

In contrast, in the organ system failure model, including respiratory diseases and cardiac diseases, the condition gradually aggravates with repeated acute exacerbations and reliefs, and differentiation between the terminal stage and acute exacerbation may not be easy. In the dementia/frailty model, the function slowly decreases like descending a slope.

However, the actual trajectory of noncancer diseases is not such a simple one but wide-ranging with little common features. Because, in many noncancer diseases, the basic medical conditions is deterioration caused by cell necrosis and regressive changes, and the site and organ of the reduced function and the way and speed of disease progression vary depending on diseases and individuals. Furthermore, in noncancer diseases, the trajectory and prognosis considerably vary depending on “whether or not the standard treatment and care have been provided,” and “whether or not the patient chose life-prolonging treatment.” For these reasons, prognostic prediction on a monthly or weekly basis available for cancer patients is difficult for patients with noncancer diseases.

Though accurate prognostic prediction for noncancer diseases is difficult, support of decision-making has become considered as possible, and various methods have been attempted worldwide.

The following three prognostic prediction models have been presented: (1) prediction model based on the course of underlying disease, (2) prediction model based on the systemic symptoms (conditions), and (3) subjective model. The British gold standard framework (GSF) has introduced an algorithm of the subjective model with a high effect (sensitivity) of discovery first to detect patients requiring care at an early stage. Specifically, a GP asks a question that “Would you be surprised if this patient were to die in the next few months, weeks, days?” (surprise question) to detect candidate patients of palliative care regardless of diseases. Then, the answer is shared with the patient in an open manner, and advanced care planning is prepared.

Detailed Explanation of Trajectory of Noncancer Diseases

It is very important that health care providers should have knowledge of disease trajectory and insights into uncertain and unsure trajectory of terminal-stage noncancer diseases to provide information that may lead patients’ and families’ way of living and to have consultations how they are going to live their lives.

A. Trajectory of stroke patients

Within 30 days post-stroke, 20%–30% of patients die. In contrast, 21% of stroke patients live over 10 years.²⁾ After the stroke, 40% of patients suffer moderate impairment, and 15%–30% of patients suffer severe impairment. Also, prognosis varies depending on primary diseases. Cardiogenic embolism has the worst prognosis, followed by arteriosclerotic stroke, and lacunar infarction. Cerebral hemorrhage, including subarachnoid hemorrhage, has a high mortality rate at first-ever stroke; however, patients survived from the first-ever stroke have a relatively favorable vital prognosis.

Once a patient has gone through the acute phase of stroke, he or she dies not from the attack but from relapse or various complications. The major causes of death in patients with sequelae of stroke are recurrent stroke, complication of cardiovascular disease, and pneumonia aspiration; therefore, prevention of these conditions is important. In post-stroke patients, it has been indicated that undergoing gastrostomy may be associated with prognostic improvement, which means that the choice of gastrostomy may have an effect on the trajectory.

B. Trajectory of Chronic Obstructive Pulmonary Disease (COPD) Patients

At the terminal stage of COPD, the overall function gradually decreases due to repeated acute exacerbations. The mortality rate of admissions due to acute exacerbation of COPD is 5%. The 1-year readmission rate is 45%, and the 1-year mortality rate is 13%. In COPD patients, the larger the number of readmissions is associated with poorer prognosis.

Known factors of poor prognosis of COPD include severity of COPD, use of home oxygen, readmission, aging, extreme thinness, and decrease in ADL. Acute exacerbation is highly likely to be prevented by optimal treatment and management and undergoing comprehensive respiratory rehabilitation. Appropriate management also has an effect on the trajectory.

C. Trajectory of ALS Patients

In a few months to around a year after the onset of amyotrophic lateral sclerosis (ALS), patients begin to have difficulty in working and performing everyday activities. Eventually, the patients suffer quadriplegia, respiratory muscle paralysis, and paralysis of the swallowing muscles. Without the use of a respirator and feeding tube, the patients’ lives cannot be maintained. The mean survival of nonrespirator-supported ALS patients is 36.4 ± 30.6 months.³⁾ The most common cause of death in nonrespirator-supported patients is respiratory failure caused by pneumonia aspiration, etc.

Treatments to improve the prognosis of ALS are mechanical ventilation including noninvasive positive pressure ventilation (NPPV), tube feeding including gastrostomy, and the internal use of Riluzole®. Riluzole® prolongs the mean life expectancy of ALS sufferers by 25% to 30%. Nearly half the patients are tolerant to NPPV. Except for patients with severe bulbar palsy symptoms, NPPV may improve vital prognosis of ALS for ≥ 1 year. In Japan, the mean survival of respirator-supported patients is 57.0 ± 42.3 months, with a 3-year survival rate of 41.2% and 5-year survival rate of 17.5%.⁸⁾ In patients on tracheostomy positive pressure ventilation (TPPV), further prolongation of survival can be expected.

In ALS patients, gastrostomy is effective for the maintenance of body weight and prolongation of survival, and gastrostomy placement at an early stage of diagnosis is desirable.

D. Trajectory of Patients with Chronic Cardiac Failure

Patients with chronic cardiac failure experience multiple acute exacerbations over time, by which myocardial cells are damaged, resulting in a rapid reduction of cardiac function. After passing through the acute phase of the disease, cardiac function partially recovers. However, the next acute exacerbation will further worsen cardiac function significantly.

A method to predict the prognosis for chronic cardiac failure has not been established primarily because sudden deaths from arrhythmia and cases with unexpected acute exacerbation are not unusual.

Poor prognosis factors include age of ≥ 75 years, reduced SBP (< 115 or < 120 mmHg), increased BUN (≥ 43 mg/dL), increased Cr (≥ 2.75), and hyponatremia (< 135).⁴⁾ Increased BNP levels of ≥ 100 pg/mL are also associated with an increase in the mortality rate by 35%.⁵⁾ Prognosis is considerably poor in patients with increased BNP levels of ≥ 500 pg/mL and extremely poor in those with ≥ 1000 pg/mL.

E. Trajectory of Patients with End-stage Renal Failure

In patients with end-stage renal failure not receiving dialysis, survival after a reduction in eGFR to ≤ 10 mL/min is between 1 and 22 months, with a mean survival of 11 months.⁶⁾ Based on blood data, a rough prognosis can be expected.

Prognosis for elderly people requiring care after the initiation of dialysis is poorer than that of juveniles on dialysis. After dialysis initiation, only 13% of elderly dialysis patients requiring care maintained their predialysis renal function. This finding showed that dialysis initiation is likely to cause rapid functional deterioration. The 1-year mortality rate after dialysis initiation is 58%.⁷⁾

F. Trajectory of Dementia and Palliative Care

The clinical course of dementia varies depending on the underlying diseases and individuals. The 4 major dementia subtypes accounting for most cases of dementia are Alzheimer's dementia (AD), vascular cerebrovascular dementia, Lewy body dementia, and frontotemporal lobar degeneration. All these subtypes are associated with progressive functional deterioration in the course of a few to 10 years.

AD is representative of dementia diseases. It is a degenerative disease, and the core symptoms develop in a constant order. Following onset, AD patients die within 10 years in average. The symptoms become severe about 7 years after onset. Then, urinary incontinence and fecal incontinence develop followed by gait disturbance. Around the last 6 months to 2 years before death, patients are likely to be bedridden. Around the beginning of the severe stage, the swallowing reflex starts to weaken, followed by an increase in the onset and frequency of pneumonia. In the advanced stage, the swallowing reflex disappears. When patients become unable to swallow, they often start to suffer recurrent treatment-resistant pneumonia aspiration. If a life-prolonging treatment is not selected after the objective confirmation of the disappearance of the swallowing reflex, end-of-life care needs to be provided.

Finucane, et al., published a report of tube feeding in patients with advanced dementia.⁸⁾ Following the publication of the report, it has been considered that tube feeding should not be basically implemented in advanced-stage dementia patients in European countries and the United States because notable survival prolongation cannot be expected. The invasive life-prolonging procedure imposes greater suffering on patients and therefore should not be conducted for only a slight prolongation of the life span.

Characteristics of Suffering in Noncancer Diseases

The basic medical condition of noncancer diseases is deterioration along with cell necrosis and regressive changes. Depending on the disease and individual, affected sites and deterioration speed varies. In the terminal stage of the disease, the respiratory and swallowing functions that are indispensable for a living body are affected, and the patient is likely to suffer dyspnea, dysphagia, and inappetence.

Among noncancer diseases, the individuals suffering from organ failure should be provided standard treatment for their respective diseases till the end of life, and the standard treatment also serves as palliative care. Also for symptom relief, aggressive treatment of the primary disease should be continued. In addition to standard treatment and care, palliative care procedures, such as opioid treatment, are often provided. Especially for dyspnea, a low dose of morphine as well as oxygen therapy can be effective.

In patients with cerebrovascular disease, dementia, and senility, the main symptoms are dysphagia and inappetence. Thus, dietary support or implementation of artificial alimentation such as fluid infusion is required. Management of the following symptoms is also important: infection-induced pyrexia, secretions such as sputum and saliva, and various symptoms associated with disuse syndrome, such as pressure sores due to long-term recumbency.³⁾ In actual palliative care practices, sufficient observation and careful nursing are important.

Noncancer diseases include many diseases with self-regulation impairment such as dementia. Until the end of life, the possibility of improvement remains; therefore, decision-making as to what extent treatment should be given is a difficult task. As well as appropriately supporting decision-making, comprehensive and well-balanced treatments for improvements and palliative care are required.

Detailed Explanation for Suffering and Palliative Care for Noncancer Disease Patients

A. Stroke Patients' Suffering and Palliative Care

Dysphagia occurs in $\geq 50\%$ of patients with acute phase stroke. Patients who had experienced pneumonia in the acute phase have a high risk of pneumonia thereafter. In addition, for terminal-stage patients with sequelae of stroke, adjustment to the eating environment, training in swallowing, and oral care are important aspects of palliative care. Effective care for respiratory secretion includes sputum removal, regular sputum aspiration, anticholinergic inhalation such as oxitropium bromides, and sublingual administration or continuous subcutaneous injection of scopolamine hydrobromide.

Respiratory discomfort induced by repeated pneumonia is treated by oxygen therapy or antimicrobial treatment. For severe dyspnea or terminal-stage pneumonia, continuous subcutaneous morphine injection may be given.

Paralyzed limbs of stroke patients show flaccid paralysis first, with a shift to spastic paralysis over time. Spasm at the time of physical exercise induces pain. Also, patients with disturbed consciousness or motor dysfunction, such as severe hemiplegia, are likely to suffer pain due to

disuse muscle atrophy and joint contracture. For spasm and contracture, treatment with baclofen or botulinum toxin type A (BOTOX®) should be considered, as well as analgesics, such as NSAIDs. Central pain including thalamic pain is intractable and causes a burning sensation, spontaneous pain, or allodynia in the extremities with decreased sensation. NSAIDs and opioids are ineffective, but antidepressants and anticonvulsants are often used. However, no proven treatment has yet been established.

Due to abnormal protrusion of the sacrum induced by contracture and gluteal muscle atrophy, pressure sores are likely to occur, and pressure-sore-associated pain may develop. To relieve such suffering associated with paralysis or muscle atrophy, the following should be instructed: positioning, benign position, prevention of contracture by ROM training, initiating rehabilitation (such as stretch and massage) from the early stage, and the appropriate use of orthosis, welfare equipment, and pressure distribution apparatus.

In the chronic phase of stroke, 15% to 30% of patients experience dysuria, including urge incontinence and pollakiuria. With a decrease in ADL, bowel problems is also likely to occur, which should be controlled by intake of fluids and dietary fibers and the use of laxatives or enemas.

B. Suffering of COPD Patients and Palliative Care

The most common symptom in COPD is dyspnea. It has been known that dyspnea in the terminal stage of COPD is comparable to that of cancer; however, sufficient palliative care has not been provided. For COPD-related dyspnea, comprehensive respiratory rehabilitation is effective, mainly by lower-extremity exercise therapy. However, exercise therapy becomes difficult as the disease progresses. Thus, while drug therapy such as tiotropium inhalation, oxygen therapy, chest physical therapy, respiratory muscle massage, and nutrition therapy are maintained, palliative care procedures such as the use of morphine and oxygen should be also employed.

Even when a low dose of morphine (30 mg/day on a basis of oral dosage form) is administered to end-stage COPD patients for the relief of dyspnea, it does not affect mortality rates. Opioids should be used for relief of dyspnea in end-stage COPD patients.⁹⁾ The treatment may be started by providing water containing 2 to 3 mg of morphine per dose as needed, or by regular administration of a low dose of morphine (2–3 mg) at 4- to 6-hour intervals. After titration, the formulation is switched to sustained-release medication (not covered by health insurance). Respiratory depression and CO₂ accumulation should be monitored with the help of respiratory rate, capnometer, and blood gas analysis. For severe dyspnea uncontrollable by morphine, the use of sedatives (e.g., midazolam, phenobarbital) should be considered.

In the terminal stage, the oxygen dose should be increased so that the SpO₂ level is maintained at 89% to 92% (60–70 Torr for PaO₂). At the onset of dyspnea, the body should be positioned in the most comfortable way, such as Fowler's position. Sufficient ventilation and face cooling are also effective for the relief of dyspnea.

C. Suffering of ALS patients and palliative care

Morphine is effective in 81% of ALS patients in hospice care for the relief of dyspnea. Ogino et al.,¹⁰⁾ reported the following method for relief of dyspnea in ALS patients: Starting from 2 to 3 mg of morphine hydrochloride per dose as needed basis, the dose is increased without restrictions of use. Upon determination of a daily dose, the formulation is switched to sustained-release medication.

ALS patients often become unable to take medicine orally due to the progression of bulbar palsy. For tube-fed patients, including gastrostomy-fed patients, morphine water or sustained-release granules (Morphes®) should be used. For nontube-fed patients, continuous subcutaneous injection should be given.

The need of palliative care for respirator-supported patients in long-term home care has not been fully elucidated. Common causes of death in long-term respirator-dependent patients

include infection, such as pneumonia and cholecystitis, and cardiovascular complication, such as myocardial infarction. Therefore, it should be kept in mind that complication-related suffering mainly induced by infection should be relieved.

D. Suffering of Cardiac Failure Patients and Palliative Care

For individuals suffering from organ failure including cardiac failure, maintenance of the standard treatment fills the role of palliative care. Also for symptom relief, maintenance of cardiac failure treatment is necessary.

Dyspnea is the most common issue associated with cardiac failure. Efficacy-proven treatments for dyspnea include loop diuretics, nitroglycerines, and a low dose of opioid, followed by cardiogenic agents, respiration training, exercise therapy, and oxygen therapy. For maintenance of the standard treatment, hemodynamics should be assessed to some extent by the combination of physical findings, brain natriuretic peptide (BNP) measurement, and cardiac ultrasonography. For patients who do not chose inpatient treatment, when no improvements are seen even when providing the maximum drug treatment possible including diuretics and oxygen therapy, the condition is determined as terminal. When dyspnea occurs at resting or during night time, a low dose of morphine should be used, as well as the standard treatment for cardiac failure. The efficacy of benzodiazepines on respiratory discomfort associated with cardiac failure has not been established.

Other symptoms to be relieved for patients with end-stage cardiac failure are pain, depressive state, and malaise. Regarding pain, the use of medication according to the cause (e.g., nitrites for anginal pain) and opioids are recommended. For depression, psychological intervention such as cognitive-behavioral therapy and counseling are effective, as well as the use of selective serotonin reuptake inhibitors (SSRIs), serotonin and norepinephrine reuptake inhibitors (SNRIs), and tricyclic antidepressants. For malaise in end-stage cardiac failure, no other treatments are effective other than removing apparent causes (e.g., anemia, infection, sleep apnea); therefore, symptom relief is difficult.¹¹⁾

E. Suffering of Patient with Chronic Renal Failure and Palliative Care

With the progression of uremic symptoms, reduced appetite, queasy, and vomiting start to develop, and the patients start to have difficulty in oral intake. Queasiness and vomiting associated with uremia are mainly induced by stimulation of the chemoreceptor trigger zone (CTZ); therefore, a very small dose of central D2-receptor antagonist (olanzapine) should be used.

As well as oral cavity dryness, mucosal roughness becomes pronounced. Therefore, positive oral care is necessary to relieve thirst and to protect the oral mucosa. In end-stage renal failure, bowel problems and gastrointestinal hemorrhage also occur; therefore, bowel control becomes also important.

Psychiatric symptoms associated with end-stage renal failure include apathy and decreased short-term memory. In the end-of-life stage, uremic encephalopathy and somnolence tendency induced by metabolic acidosis are observed with the progression of medical conditions.

In a period of mild disturbance of consciousness, peripheral neurological symptoms may occur. In particular, restless leg syndrome may develop, which causes listlessness, tingling feeling of the lower extremities, and dysesthesia with pain or suffering even by a slight contact. As one of the neurological symptoms, convulsion may develop, and the possibility of convulsion should be notified to the family members.

In the course of renal failure, the frequency of developing pain is not so high. Still, severe pain may develop due to arthritis, etc. Recommended medications for relief of pain in patients with end-stage renal failure include acetaminophen for Step 1, codeine for Step 2, and strong opioid, particularly fentanyl, for Step 3.¹²⁾

In end-stage renal failure, cellular immunity and humoral immunity decrease, leading to increased susceptibility to infection. Frequent occurrences of pneumonia or urinary tract infection are treated by concomitant antimicrobial treatment.

With the progression of renal failure, urine output decreases followed by the development of pleural effusion, pericardial fluid, and edema due to fluid retention. Then patients complain of severe dyspnea. Especially in the elderly, edema, pleural effusion, pulmonary edema (uremia lung), and ascites are likely to be observed from the early stage. Severe dyspnea under the state of relatively mild disturbance of consciousness should be relieved in a positive manner. While providing oxygen inhalation, diuretic infusion should be given without any unnecessary infusions to decrease excess body fluid. In this way, dyspnea is often gradually relieved. Basically, morphine should not be used in patients with severe renal failure. For patients with strong respiratory discomfort, a single low dose of morphine water (2 to 3 mg per dose) is given (not covered by health insurance). When the frequency of morphine use increases, the use of fentanyl should be considered. When abnormally slow deep respiration is observed in comatose patients, it is considered as Kussmaul's respiration associated with metabolic acidosis. In such cases, the family members should be told that the patient does not feel pain anymore, and meaningless treatment should not be given.

F. Suffering of Advanced-stage Dementia Patients and Palliative Care

Multiple studies have revealed that suffering in advanced-stage dementia patients includes not only dysphagia, inappetence, and dyspnea, but also infection-related symptoms, such as pyrexia and sputum, and disuse syndrome, such as pressure sores, that should be relieved by nursing care.³⁾

Beck-Friis Barbro established the concept of palliative care for dementia patients which that includes the main pillars of (1) symptom observation and relief, (2) team approach, (3) communication, and (4) support of families. The author has added the fifth pillar of (5) dietary support. For dementia patients, detailed observation and careful care fill the role of palliative care.

(Satoshi Hirahara)

References

- 1) Lynn J: Serving patients who may die soon and their families. *JAMA* 285(7): 925-932, 2001
- 2) Hardie K, Hankey GJ, Jamrozik K, et al: Ten-year survival after first-ever stroke in the perth community stroke study. *stroke* 34(8): 1842-1846, 2003.
- 3) 柳澤信夫, 進藤政臣, 桃井浩樹, 他: 筋萎縮性側索硬化症の予後一斑関連施設における全国集計調査一. 厚生省特定疾患「神経変性疾患調査研究班」1995 年度研究報告書, 253-256, 1996. Yanagisawa N., Shindo M., Momoi H., et al.: Prognosis of amyotrophic lateral sclerosis—National survey in group-related facilities—. Specified diseases by the Ministry of Health and Welfare “Research group of neurodegenerative diseases” Research report in 1995, 253-256, 1996.
- 4) Bao CH, Aleksandr R, Michael WR, et al: Longterm Survival in Elderly Patients Hospitalized for Heart Failure 14-Year Follow-up From a Prospective Randomized Trial. *Arch Intern Med* 166(17): 1892-1898, 2006.
- 5) Doust JA, Pietrzak E, Dobson A, et al: How well does B-type natriuretic peptide predict death and cardiac events in patients with heart failure: systematic review. *BMJ* 330(7492): 625, 2005.
- 6) Burns A, Carson R: Maximum conservative management: a worthwhile treatment for elderly patients with renal failure who choose not to undergo dialysis. *J Palliative Med* 10(6): 1245-1247, 2007.
- 7) Manjula Kurella Tamura, et al: Functional status of Elderly Adults before and after Initiation of Dialysis. *NEJM* 361(16): 1539-1547, 2009
- 8) Finucane TE, Christmas C, Travis K: Tube feeding in patients with advanced dementia ,A review of evidence. *JAMA* 282(14): 1365-1370, 1999.
- 9) Abrahm JL, Hansen-Flaschen J: Hospice Care for Patients With Advanced Lung disease. *CHEST* 121(1): 220-229, 2002.
- 10) 荻野美恵子: 侵襲的人工呼吸療法を選択しない ALS 患者さんの緩和ケア. 難病と在宅ケア 12 : 23-26, 2006. Ogino M.: Palliative care for ALS patients not selecting invasive mechanical ventilation. *Home Medical Care for People with Intractable Diseases*, 12:23-26, 2006.
- 11) Adler ED, et al: Palliative Care in the Treatment of Advanced Heart Failure. *Circulation* 120(25): 2597-2606, 2009.
- 12) Levy JB, et al: Supportive care for the renal patient. *Nephrology Dialysis Transplantation* 19(6): 1357-1360, 2004.

Chapter V References

1. General Introduction of Home Palliative Care

2. Home Palliative Care for Cancer Diseases

- (1) 木澤義之, 森田達也, 新城拓也, 他 編: 3 ステップ実践緩和ケア. 青海社, 2013. Kizawa Y., Morita T., Shinjo T., et al. (Ed): Three-step practices of palliative care. Seikaisha Co., Ltd., 2013.
- (2) 平原佐斗司, 茅根義和 編: チャレンジ! 在宅がん緩和ケア (改訂2版). 南山堂, 2013. Satoshi H., Chinone Y. (Ed): Challenge! Home palliative care for cancer (Revised edition 2). Nanzando Co., Ltd., 2013.
- (3) 日本緩和医療学会緩和医療ガイドライン委員会 編: がん疼痛の薬物療法に関するガイドライン(2014年版). 金平出版, 2014. Guideline preparation committee for palliative medicine, Japanese Society for Palliative Medicine (Ed): Guidelines for drug therapy of cancer pain (2014). Kanehara & Co., Ltd., 2014.
- (4) 日本緩和医療学会緩和医療ガイドライン委員会 編: 苦痛緩和のための鎮静に関するガイドライン (2010年版). 金原出版, 2010. Guideline preparation committee for palliative medicine, Japanese Society for Palliative Medicine (Ed): Guidelines for sedation to relieve sufferings (2010). Kanehara & Co., Ltd., 2010.

3. Home Palliative Care for Noncancer Diseases

Chapter VI.

Home Medical Care for Children

Home medical care is most likely to be considered as care for the elderly. However, an increasing importance of home medical care has been also placed on the pediatric field. This is due to an increase in disabled children requiring advanced medically-related care related to increased neonatal survival rates and declining birth rates. However, pediatric home medical care has numbers of issues. The most common issue is the fragility of medical and social foundations. Short-term care facilities and helper offices to support children's community lives are insufficient in terms of both quality and quantity. Visiting nurses and physicians are not enough. Development and growth are the core part of care for children. Therefore, it is extremely important to prepare the foundation of home medical care to assure that children can live with their families.

(Hirotoishi Maeda)

The Yuumi Memorial Foundation for Home Health Care website has a section providing a listing of medical facilities dedicated to home medical care.

Please contact our executive office if you are interested in signing up for the listing.

Note) The website only provides names with contact information of the physicians and medical facilities, which are not intended for recommendation.

1. Issues and Views of Pediatric Home Medical Care

Currently, Japanese society is facing a significant hurdle—namely, declining birth rates and aging. In the medical field, two major issues exist. One is the various issues faced in the field of adult medical care with initiation of increasingly elderly society. The other is the sudden increase in the number of highly medically dependent children, which pediatricians have faced.

Changes in the Total Fertility Rate in Japan

For the maintenance of the population, a total fertility rate (the average number of children that would be born to a woman over her lifetime) of 2.07 is required. In Japan, the total fertility rate dropped below 2.07 in 1975 and kept decreasing to a nadir of 1.26 in 2005. In 2012, it slightly increased to 1.41. One of the important pillars against the declining birth rate is child-rearing support, and it requires enhancement of perinatal and pediatric medical care.

Reduction in Child Deaths in Japan

In Japan, advancement in medical technology has contributed to a decrease in child deaths from disease. The number of recent child deaths is below 1/3 of that in 1985 (**Table**). This value also includes deaths from accident. This indicates that a lower number of children died from disease. Japan has become a nation with low child mortality.

Currently, 1 in 10 newborns are low birth weight babies in Japan, and the proportion is the highest among developed countries. Also, the average childbearing age for women has risen. For expectant mothers over 30, the rate of newborns with chromosomal aberration increases. None the less, the newborn mortality rate has kept decreasing in Japan. Based on the WHO's statistic result, only 1 in 1000 newborns dies in Japan, giving Japan the highest infant survival rate in the world. With the advancement of techniques in pediatric medical care and the increased survival rate, an unexpected situation has arisen, that is, emergence of children dependent on medical care and equipment, such as respirators.^{Note)} The children stayed in the neonatal intensive care unit (NICU) for a long term, causing no vacancy in NICUs. Then, the children have started shifting from hospitals to communities.

Table. Reduction in Child Deaths

	Deaths in the age of 0–19 years
1985	18488
2001	8069
2010	5836

Rapid Increase in Children Requiring Home Medical Care

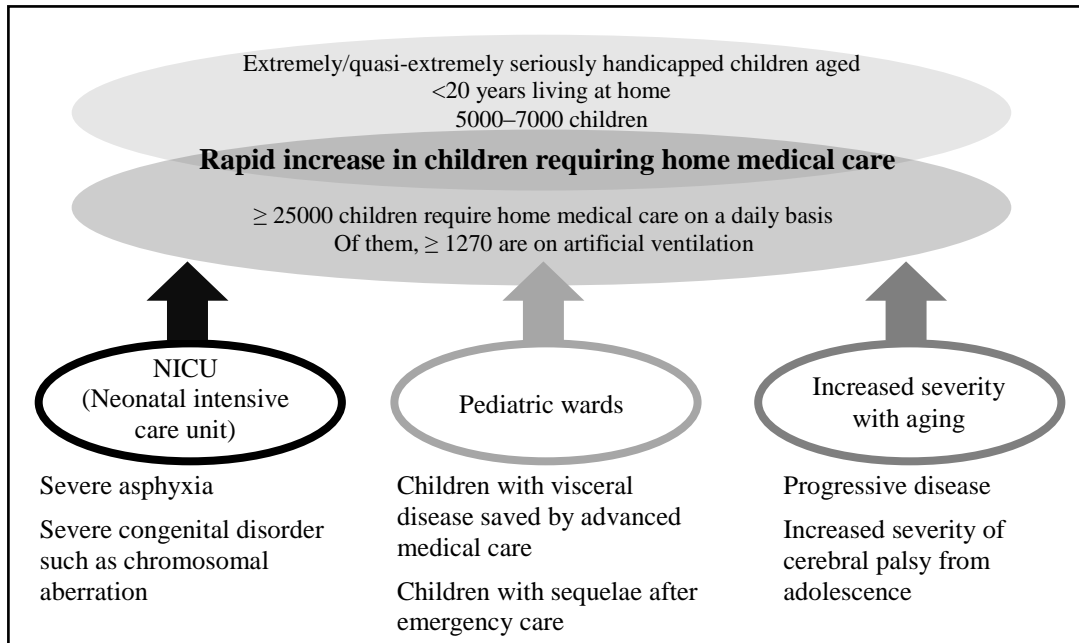
Currently, the number of children requiring medical equipment and care on a daily basis has been rapidly increasing in the community (**Figure**). Regarding this situation, three factors are involved. The first is the transition of children requiring medical care from NICUs to the community. The second is that children under similar conditions have been transferred from pediatric wards to the community. Not only in the field of neonatal medical care, but also in the field of pediatric medical care, lifesaving techniques have kept improving. An increasing number of children's lives have been saved that would have previously been lost, including those with very complicated congenital cardiac diseases and severe congenital anomalies in the trachea, esophagus, or digestive organs, and their long-term survival has become possible. These children cannot live without medical equipment and care. The third is severely mentally and physically disabled children originally not requiring medical care living at home or in the community begin to require medical equipment and care as they age. Seriously handicapped children born 20 to 30 years ago whose lives were saved with the help of the pediatric medical techniques that had started to develop around their birth dates did not need medical equipment or care even when they were unable to walk or talk. With support, they could even eat meals by themselves. However, the physical function of these children declines faster than in their parents and they start to require medical care, such as tracheostomy or tube feeding. These children are often cared for only by their parents. Multiple tragic news have been reported recently that, due to the sudden death of a family member who had cared for a handicapped child, the child was also found dead from hunger. Such incidents may rapidly increase in the future.

The Characteristics of Children Requiring Home Medical Care

The characteristics of children requiring home medical care are as follows:

- (1) Highly dependent on medical care
 - Use of multiple medical devices
 - Airway control (e.g., tracheostomy) is important for respiratory control.
- (2) Changes in medical conditions in seriously handicapped children with growth, such as secondary disability
- (3) Communication with the children is often difficult and identification of abnormalities is also difficult.
- (4) In home medical care of the elderly or terminal-stage cancer patients, caregivers can go out in a short time. However, children with medical devices may die if caregivers take their eyes off the children even for 5 minutes, indicating that 24-hour assistance is required, imposing a heavy burden on caregivers.
- (5) Support is necessary for their growth, in other words, to gain various experiences and to increase what they can do.

Figure. Rapid Increase in Children Requiring Home Medical Care



Widespread Effects of Pediatric Home Medical Care

The progress in the preparation for pediatric home medical care will lead to the following widespread effects:

- (1) Without preparation for pediatric home medical care, maintenance of perinatal care and pediatric emergency care is difficult.
- (2) Due to rapid medical advancement, welfare services have not met present needs. Pediatric home medical care will serve as the foundation to establish the structure for collaboration between the welfare and medical fields.
- (3) The environment will be prepared such that all children can grow up in peace in the community, which will enhance the child-rearing support system, one of the main pillars against declining birth rate.
- (4) Pediatric home medical care contributes to establish the structure for home medical care support for cases with intractable disease and those highly dependent on medical care.
- (5) Reduction of medical cost¹⁾

(Hirotooshi Maeda)

Note) Medical care is defined as care provided by medical professionals, such as physicians and nurses. In contrast, medically-related care indicates care served by those who are not medical professionals, including family members. Even the same procedure, the term differs depending on the career.

References

- 1) Mosquera RA, et al: Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness a randomized clinical trial. JAMA 312(24): 2640-2648, 2014.

2. Regional Cooperation for Pediatric Home Medical Care

Pediatric patients receiving home medical care are highly dependent to medical care, imposing a large burden on their caregivers. Children can grow and develop even with severe disability and can acquire new capabilities. Therefore, people with a wide variety of occupations in each field of medical, welfare, education, care and education, nursing, healthcare, and administration and Rhoiku (medical care and education to enhance development and growth) need to work as a team in the community to support home care.

Community Supporters of Children Receiving Home Medical Care
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A. Medical care

A number of children receiving home medical care are highly dependent on medical care. Therefore, it is essential to assure the children and their families that they have an access to the proper medical care when needed.

(1) Visiting medical care

In a pediatric home medical care system, multiple physicians, such as pediatricians from regional hospitals, visiting care physicians from home care support clinics and private pediatric clinics, are likely to be involved in the treatment of one patient.

It is ideal that the various roles in a treatment are shared among these physicians from different hospitals and clinics who are involved in the treatment: pediatricians in regional hospitals should provide specialized and inpatient treatment when the patient is deconditioned, and visiting care physicians in the community should provide routine home care. Today, only a small number of children receive visiting medical care. In 2013, 127,000 patients aged over 65 years old and 1,207 pediatric patients aged under 19 years old received visiting medical care based on calculations using visiting medical care fee.¹⁾ It is estimated that there are more than 10,000 seriously handicapped children who belong to severe motor and intellectual disabilities-medical care dependent group throughout Japan.²⁾ Even among highly medically-dependent children, only <10% of them receive visiting medical care.

(2) Visiting care

A visiting nurse is an important position to support children and families of children receiving home medical care.

(3) Visiting rehabilitation

Children with severe disorders experience difficulties going outside for they are on multiple medical devices and can easily fall into unstable conditions. Rehabilitation at home by visiting nurses or rehabilitation therapists can stabilize the physical and respiratory condition and prevent the increase muscle tone, scoliosis, and joints contracture. Rehabilitation therapists can give advice on the physical and mental development of children.

(4) Visiting dentist

Oral care is important for the prevention of respiratory infections. Also, disabled children often lack proper eating and swallowing functions and training is required to acquire these functions. It is desirable to have dentists who are available provide visiting medical care for the disabled children.

B. Welfare

(1) Consultation and support specialist

One of the major problems of pediatric home medical care is that the roles of coordinators corresponding to the care manager in the long-term care insurance system have not been clearly established. To establish a support system in the community, role sharing and collaboration between the respective occupations are necessary. Services and Supports for Persons with Disabilities Act established the post of consultation and support specialist who works as a coordinator. The consultation and support specialist prepares the plan for the usage of the welfare service, or the appropriate support for children receiving home medical care. After the approval of the plan, consultation and support specialists contact service offices, works as a coordinator between community supporters, and continuously assesses whether the community services are appropriate for the children and their families who receive them. However, it is currently difficult for a consultation and support specialist to undertake all the roles of a community coordinator because of the inexperience of highly medically-dependent children, the insufficient payment system and lack of linkage of the medical care system and the welfare system for children.

(2) Home help (in-home care/transferred support)

Children who are highly medically-dependent need additional support with daily lives such as bathing and transfer. When children are approved to receive these services, they can utilize Welfare Service for Persons with Disabilities and the in-home care services from helper offices such as transfer support and bathing support. However, only a small number of helper offices provide such services for children receiving home medical care.

(3) Respite care (short-term admission to care facility and daytime temporary support)

The most pressing need of children receiving home medical care and their families is to be able to receive more respite care services. The care for the highly medically-dependent children, which require careful attentions for 24 hours, exhausts the caregivers and makes it difficult for the caregivers to maintain home-care. Respite care is important in home-care system because it gives caregivers time to rest. However, there are not sufficient numbers of facilities that provide the respite care service.

C. Education

All children have a right to education. The number of children requiring medically-related care registered in school is 7,842 in public special needs schools (elementary, junior high, and high schools) and 813 in public elementary and junior high schools. Of them, 6,467 children go to school, and 2,188 receive visiting education.³⁾ In visiting education, teachers visit the children's houses, facilities, or hospitals to offer education for about 6 hours a week. In the special needs schools, (1,354) nurses are placed to provide medically-related care. The guardians of highly medically-dependent children may be required to attend schools with their children, particularly for the off-campus activities such as school trips and excursions.

D. Preschool Education

Day-care centers and kindergartens serve for the enhancement of psychosomatic development of preschoolers and to train adaptation to communal living. By the Development Support Service for Children with Disabilities system, care providers can be assigned for children who need medical care in kindergartens and Children with difficulty in communal living due to developmental delay can attend day care service facilities for child developmental support with their parents. They receive training for everyday activities and training through playing, depending on their developmental stage. A shortage of preschool facilities capable of offering medically-related care remains an important issue.

E. Healthcare

There are community health nurses who are assigned to each community. They visit homes of children who are discharged from hospitals (Visits to All Families with Infants Program) and introduce and coordinate medical care and welfare services in the community.

F. Administration

The welfare divisions for persons with disabilities in municipal governments are in charge of the approval of the applications for the welfare services and the applications for the physical disability certificate and allowances. The child consultation centers watch over the growth and safety of the children. When there is a child-care-related problem, the child is protected by the child consultation center.

Interprofessional Cooperation

It is necessary to establish a support system for children receiving home medical care in cooperation with various fields of medical care, welfare, education, healthcare, administration and Rhoiku in the community. Community coordinator plays the important role in the establishment of the community support system for safe and healthy home recuperation, which is to enhance collaboration between community supporters. In order to prepare for the home recuperation for highly medically-dependent children from neonatal or pediatric intensive care unit and pediatric ward of regional hospital, the cooperation of the medical field personals (e.g., medical social worker, discharge coordinating nurse) and the community coordinators (e.g., community health nurses, consultation and support specialist) is essential. These professionals need to share information and division of the roles at the coordination meeting when the patients are discharged from hospital and the case meeting for home recuperation. As for the home medical care of highly medically-dependent children, clarification of the division of the roles between the regional hospital and visiting care physicians in the community, and assurance of inpatient treatment at the regional hospitals at the time of emergency are also necessary.

(Yasuko Nasu and Kazuko Yamazaki)

References

- 1) Ministry of Health, Labour and Welfare: Program for cooperation of home care pediatrics in fiscal 2014
<http://www.mhlw.go.jp/file/06-Selsakujouhou-10800000-lseikyoku/0000071084.pdf>
- 2) Sugimoto T., et al.: Present condition and issues of medical care for extremely severely mentally and physically disabled children. *The Journal of the Japan Pediatric Society* 112(1): 94-101, 2008.
- 3) Ministry of Education, Culture, Sports, Science and Technology. Survey on medically-related care in special needs schools in fiscal 2013
http://www.mext.go.jp/a_menu/shotou/tokubetu/material/1345112.htm

3. Home Medical Care of Seriously Handicapped Children

Definition and classification of seriously handicapped children are presented below. To comprehend conditions of seriously handicapped children, the status of respiratory control (e.g., medical conditions, respirator support, tracheostomy, chest physical therapy) and nutritional management (swallowing function, tube feeding such as nasal feeding or gastrostomy) should be comprehended.

Definition and Condition of Seriously Handicapped Children

“Seriously handicapped children” is a shorter term for severely mentally and physically disabled children. Children (and adults) with a combination of severe physical disabilities and severe intellectual impairment are called severely mentally and physically disabled children (or patients). This is not a medical diagnostic term but a definition to be used in the field of child welfare administration. Though the definite criteria have not been established, Oshima’s classification (**Figure**) is commonly used. Oshima’s classification presents motor impairments on the x-axis and intellectual impairments on the y-axis using IQ. Children in the range of 1 to 4 in the Figure are determined as severely mentally and physically disabled. Also, those in the range of 5 to 9 are determined as children requiring continuous medical supervision, those in a state of disability progression, and those likely to have complications, and they are called as marginal children.¹⁾

Causes of Seriously Handicapped Children

The causes of seriously handicapped children are classified as follows:

- (1) Prenatal causes: Prenatal infection, chromosomal aberration, congenital disease
- (2) At birth/neonatal causes: Abnormal labor, apparent death, premature labor, low birth weight baby
- (3) Later perinatal causes: Central nervous infection, such as meningitis, encephalitis, and encephalopathy, epilepsy, hypoxic encephalopathy due to surgery, near drowning, or road traffic accident, sequelae of cerebral trauma

Figure. Oshima’s Classification

21	22	23	24	25	70
20	13	14	15	16	50
19	12	7	8	9	35
18	11	6	3	4	20
17	10	5	2	1	2
Able to run	Able to walk	Gait disturbance	Able to sit	Bedridden	IQ

Children in the range of 1, 2, 3, and 4 are determined as severely mentally and physically disabled.
Children in the range of 5, 6, 7, 8, and 9 are called as marginal children.

With the development of perinatal care, fetal diagnosis has become available, which enabled the medical staffs of the obstetrics, pediatrics, and pediatric surgery to cooperate with each other to prepare environments to save children’s lives from the prenatal period. With technological advancement of the neonatal intensive care unit (NICU) and pediatric intensive care unit (PICU), more children’s lives have been saved,

including extremely-low-birth-weight infants born at gestational age ≥ 22 weeks and body weight ≤ 500 g and children with congenital disease, such as complex heart malformation or multiple malformations requiring multiple surgeries.

On the other hand, though the lives are saved, seriously handicapped children require around-the-clock medical care to maintain their lives, such as aspiration of secretions from the oral and nasal cavities and trachea, respirator support, tube feeding, central venous nutrition, urethral catheterization, and enemas. In the current neonatal and pediatric medicine, the first priority is placed on protecting the brain. Therefore, regardless of whether they don't have encephalopathy, motor impairment, and intellectual impairment, children requiring advanced medical care have emerged.

For example, children with tracheomalacia require artificial ventilation and have undergone tracheostomy; however, some of them are able to walk and have a normal intellectual level. Also, some children with Hirshsprung's disease with short-bowel syndrome require central venous nutrition all the times, except for when taking a bath, due to the lack of sufficient intestines to digest and absorb fluids and meals. Some of them go to regular elementary school while on continuous infusion by bringing a knapsack with an infusion set. Such children do not meet the criteria of seriously handicapped children in the traditional Oshima's classification. However, they are highly dependent on medical care, and any trouble in medical care directly threatens their lives. Such children require sufficient medical and welfare services to keep living at home. As a new concept to seriously handicapped children, the score of extremely seriously handicapped children (**Table**) has started to be used.²⁾

Table. Criteria for Extremely Seriously Handicapped Children

The score is counted when the following medical care is required for ≥ 6 consecutive months. Those with a total score of ≥ 25 points are defined as extremely seriously handicapped children, and those with a total score of ≥ 10 points are defined as quasi-extremely seriously handicapped children. (Numbers in the parentheses are the scores.)	
Respiratory control	Respirator (10) Endotracheal intubation/tracheostomy (8) Nasopharyngeal airway (5) Oxygen inhalation or condition of $SpO_2 \leq 90\%$ for $\geq 10\%$ of time (5) At least 1 aspiration in an hour (8) At least 6 aspirations in a day (3) Use of nebulizer for ≥ 6 times a day or regular use (3)
Dietary function	IVH (10) Enterostomy, enteral nutrition (8) Tube feeding (5), oral intake with full support (3)
Digestive symptom	Uncontrollable coffee-ground vomiting (5)
Other parameters	Hemodialysis (including peritoneum perfusion) (10) Regular urethral catheterization, artificial anus (5) Body position exchange for ≥ 6 times a day (3) Hypertonicity requiring a temporary drug (3)

Respirator Management at Home

Two types of respirators are available. One is tracheostomy positive pressure ventilation (TPPV) to be placed under tracheostomy, and the other is noninvasive positive pressure ventilation (NPPV) to be placed through a mask. Recently, the ratio of NPPV has been increasing (146 patients with TPPV and 103 patients with NPPV based on Aozora Clinic's survey up to March 2015).

A. Differences between TPPV and NPPV

Even though there are marked differences of need of tracheostomy and certain or uncertain airway control, both are essentially comparable. The advantages of NPPV include no need of tracheostomy, which promotes convenience of initiating NPPV from the early stage. However, the initiation of NPPV without careful consideration causes discontinuation with only little consideration. Also from the aspect of medical quality and medical economics, it is desirable to follow the initiation criteria.

B. Initiation Criteria of NPPV

Indications of NPPV in pediatric patients have not been fully established. However, in the latest "Guidelines for Noninvasive Positive Pressure Ventilation (NPPV) 2nd Edition,"³⁾ Ishikawa presented the time spent at $\text{SpO}_2 < 94$ and $\text{PCO}_2 > 45$ for daytime and $\text{SpO}_2 < 90$ for nighttime are $\geq 4\%$ of time measured and apnea hypopnea index (AHI) > 10 , which indicates the severity of sleep apnea syndrome for neuromuscular disease only. Data analysis of SpO_2 monitor kept by home-care patients will offer the above measurement data without performing polysomnography under hospitalization. (AHI can be substituted by desaturation index.)

C. Setting of Home Respirator

The terms may be confusing, but parameters to be set are the same in both TPPV and NPPV.

- (1) Upper and lower airway pressure (PIP = IPAP and PEEP = EPAP)
- (2) Presence or absence of a pressure support
- (3) Back-up respiratory rate

The term of ventilation mode also differs depending on manufacturers, causing confusion. However, the difference is only whether the inspiratory time is in a set manner or automatic in most cases, and no practical difference exists.

D. Issues of Tidal Volume

Tidal volume (VT) presented on a home respirator is either inspiratory tidal volume (VTi) or expiratory tidal volume (VTe) that is calculated by a closed formula. For children with a large amount of leakage, these values are not reliable. It is not good to be moved from joy to sorrow by looking at the presented VTs. Instead, whether or not the artificial ventilation is proper should be determined based on auscultation of breath sounds and observation of chest rise, which is the principle of artificial ventilation assessment. In TPPV, whether or not ventilation is appropriate can be surely determined by the positive use of a microcapnometer (Masimo EMMA[®]).

E. Issues of Fraction of Inspired Oxygen

The current home respirator increases the inspiratory flow rate by ≥ 100 L/min to correct a leak, including an intentional leak, inducing a side effect of decreasing in-circuit oxygen concentration. In children with spontaneous respiration, 2 L of oxygen supply in a heat and moisture exchanger increases the oxygen concentration up to 50%. In contrast, even 3 L of oxygen supply in the home respirator, the fraction of inspired oxygen only increases up to about 25%. A manual of previous home respirator presented an equation to predict an oxygen concentration based on an in-circuit oxygen flow rate. However, the current manual may only include information that an

oxygen concentration may reduce depending on ventilation conditions. For patients with pneumonia or atelectasis requiring high oxygen concentrations, the home respirator should be changed to a respirator equipped with a blender that is used in hospitals under admission.

Management of Tracheostomy at Home

It is important to prevent accidents related to tracheal cannula at home. In his former workplace (National Center for Child Health and Development), the author of this article (Kondo) came across 500 pediatric patients with tracheostomy in 20 years. Of them, 8 patients (a little lower than 2%) died at home due to troubles related to tracheal cannula. The troubles related to tracheal cannula include obstruction and accidental withdrawal, and both can be handled by a prompt exchange to a new cannula. Therefore, early detection (using SpO₂ monitor) and family members' acquisition of the cannula exchanging procedure are important.

A. Prevention of Accidental Withdrawal

Periodic exchange of tracheal cannula may be easy. However, a care provider may have difficulty inserting a new cannula of the same size when a child cries or when a certain period of time has passed from accidental withdrawal. Therefore, it is important to always have a stock of thinner cannula by 1 size on hand. The most common cause of accidental withdrawal is loose fixation of the cannula. The fixation band should be tightly fixed so that only 1 finger can be inserted between the band and the patient's skin. In many patients, gauze is used at the surroundings of tracheostomy opening; however, it is likely to cause loose fixation and delay in detection of accidental withdrawal. The gauze increases the risk of accidental withdrawal; therefore, it should not be used. Recently, the Japan Society of Perinatal and Neonatal Medicine recommended a more strict alarm setting to notify care providers when the respirator circuit comes off. However, in terms of technology, it is difficult for the respiratory alarm to ring an alarm right after withdrawal of a thin cannula. Therefore, continuous SpO₂ monitoring is important.

B. Prevention of Obstruction

The major cause of cannula obstruction is either insufficient tracheal aspiration or insufficient heating and humidifying. In fear of injury of the tracheal mucosa, many families are trained to keep insertion of a suction catheter within the edge of the tracheal cannula, which is also proposed in the "Guidelines for tracheal aspiration" issued by the Japanese Society of Respiratory Care Medicine. However, the most current version of "PALS Study Guide" recommends to insert the suction catheter up to ≥ 1 cm deeper than the edge of the tracheal cannula.⁴⁾ When the suction catheter cannot be smoothly inserted to the specified depth and stopped in mid-course, the cannula should be exchanged. Rather than tracheal aspiration, the importance of the use of noninvasive sputum induction equipment (cough-assist) has been recently emphasized. However, adequate positive and negative pressure setting (and target peak cough flow setting) for children is left for future discussion.

Even when following appropriate aspiration procedures, frequent obstruction can be caused by insufficient heating and humidifying. It is necessary to adjust a heated humidifier to maintain temperature at 37°C and humidity at 100%. However, room temperature is unstable at home, and dew condensation and low temperatures in winter are often raised as concerns. Also, in the current home respirator, the intentional leak from an exhalation port increases the in-circuit flow by ≥ 100 L, imposing a burden on the heated humidifier. It may become important to use a higher performance heated humidifier (e.g., HumiCare 900[®], PMH 8000[®]) than those used in hospitals with a constant temperature environment.

Under conditions in which the use of heated humidifiers is difficult, such as when going outside or at the time of transfer, the use of in-circuit heat and moisture exchanger of appropriate size is important. A large amount of leaking induces the condition that the patient's expired air

(a moisture source) does not circulate through the heat and moisture exchanger, reducing the heating and humidifying function of the heat and moisture exchanger. Therefore, when using the heat and moisture exchanger, a small amount of water drops should be always confirmed around the junction of tracheal cannula, which indicates the functioning of heat and moisture exchanger.

A speech valve used for the purpose of phonation in patients with spontaneous respiration is not equipped with the heating and humidifying function; therefore, it is not recommended to use the speech valve for extended periods of time.

Nutritional Management in Seriously Handicapped Children

Soon after birth, newborn babies experience dramatic changes in their environment that require stressful adaptation for their multi-organ functions: circulation, respiration, gastro-intestine, metabolism and nervous systems; while such a severe stress they feel peace of mind by taking the first dietary delight of mother's breast milk. Children whose problems prevent them from starting oral breast milk feeding are forced to be discharged under parenteral nutrition, or enteral tube feeding, arising concerns on emotional development usually nurtured by breast milk feeding which also promote mother-to-children attachment processes. For this reason, nutritional support at home care should be started gradually "from life support toward life style", not only to promote total growth and development by appropriate nutritional intake physiologically and emotionally but also to cultivate a well-being perspective of food intake in children and families.

A. Dietary Delight–Dietary Education, Especially for Seriously Handicapped Children–

Dietary intake is basic activities not only to stabilize physiological conditions but also to achieve feeling of self-esteem such as "enjoying" or "peaceful" through the right brain and limbic system which enhance physiological and emotional developments. It also develops gastrointestinal function by forming rich intestinal flora in order to ferment the various foods. Home nutritional care should be performed in the point of view such as above.

B. Many Gastrointestinal Problems

Seriously handicapped children have often poor gastrointestinal functions subsequently due to severe stresses from multi-organ problems might to be called "chronic gastrointestinal failure". For an instance, cerebral palsy children with spasticity often feel severe somatic pain of joint and muscles and chronic dyspnea due to obstruction of upper airway, which induce the hyper-excitability of autonomic nervous systems resulting hyper-contraction of the stomach, intra-gastric pressure, flaccid sphincter of cardia, gastro-esophageal regurgitation, gastric hemorrhage, or dumping syndrome due to excessive secretion of gastrointestinal hormones. Also they are sometimes affected with gastroesophageal reflux disease associated with acquired hiatal hernia possibly due to highly intra-abdominal pressure of spasticity. There are various approaches for relieving distress and discomfort; environmental psychological approaches, physiotherapy, nutritional support for enhancing fermentation of intestinal microflora, pharmacological treatment with/without opiates and surgery including cardioplasty with gastrostomy; palliative approaches for relieving gastrointestinal distress such as above will promote gastrointestinal function in children which also enhances their growth and development.

C. Improvement of the Digestive Function

Careful attention is needed to long-term usage of semi/totally digested commercially available nutrients alone especially of high GI and osmolality, which may cause poor intestinal flora of fermentation resulting chronic diarrhea or constipation sometimes with malabsorption; in such a case, using low GI and osmolality ones with cereal gruel, ~~or~~ thickened agents or blender food can achieve gradual digestion and absorption and enhancing fermentation of intestinal microflora. It is important for multiple nutrient resources to support appropriate intestinal fermentation.

Intake of Necessary Nutrients

A. Intake of Required Calories

Seriously handicapped children may experience insufficient calorie intake during the course of nutritional management. As well as maintenance of the basal metabolism, nutritional management should be realized in consideration of activities and growth. In tube-fed children, resting energy metabolism differs depending on individuals; however, it correlates well with Harris-Benedict equations. Children with severe hypoxic-ischemic encephalopathy have sometimes low basal metabolisms and are forced to be restricted of calories for body weight at discharge. Energy expenditure fluctuates 10% to 20% from the basal metabolism, which varies in using medical devices, underlying diseases, metabolisms, and digestive functions. It should be noted that growth and activities require increased calories. For an instance, in cases of an exercise load of about 12 hours of sitting (+50%), 20% for maintenance, 50% for growth, and 25% for sitting are summed up, and a total of 95% should be added to the calculation. In such a case, children under extreme malnutrition (20 kcal/kg/day) are highly likely to have an exhausted condition by infectious stress and nutritional assessment is needed.

There are several parameters to be referred for nutritional assessment: albumin, transferrin, transthyretin (pre-albumin), retinol-binding protein, and somatomedin C; formation of free fatty acids and ketone bodies explains a decrease in binding protein and acceleration of lipid metabolism, which is one of the indicators of malnutrition; lymphocyte count can be also used as a parameter: 2000/mcl for mild, 1200/mcl for moderate, and <800/mcl for suspecting severe immunosuppression due to malnutrition. Sufficient protein should be taken. 1.5g/kg for infants gradually decreasing by age to 1.0g/kg body weight about at adulthood. Medium-chain triglyceride (MCT) oil is promptly metabolized to energy without mediation of carnitine, which contributes to assist energy supply, to mitigate catabolism tendency of protein, and to relieve exhausted condition; which should be taken gradually to avoid gastrointestinal irritation.

B. Trace Elements and Vitamins

The trace elements and vitamins should be noted in tube-fed children. Commercially available nutrients are often designed to realize sufficient intake of vitamins and trace elements by feeding at 1000kcal/day. However, tube-feeding less than 1000kcal/day only with commercially available nutrients can cause substantially lower from appropriate trace vitamins and vitamins supplies for children, and sometimes causes deprivation of them in required increase conditions such as infectious stress. Tube-feeding with certain commercially available enteral nutrients alone may induce deficiency in selenium, carnitine, iodine, zinc or copper. It should be noted that zinc supplies alone sometimes cause too lower copper levels competently, which requires both minerals supplies in such a case. It should be noted the required amounts of vitamins may increase in some specific conditions: vitamin A and vitamin C in cases of infection, biotin, vitamin B12, folic acid, and carnitine in cases of under-treatment with drugs containing anticonvulsants, and vitamin A, vitamin C, and vitamin B complex in cases of malnutrition. For bone metabolism, it is important for calcium and phosphate supplies with appropriate vitamin D and K.

C. Making Efforts to Take Various Foods

Management by a single enteral nutrient not promoting fermentation imposes stress of poor intestinal flora and putrefactive bacteria growth on the gastrointestinal tract. As mentioned above, the step-up nutritional strategies of various natural foods intake with digestive nutrients are very important for rich fermentation with microbial flora so that may grow gastrointestinal. The author has experienced following cases: metabolized ammonium salt caused an increase in urinary pH to >8.0, inducing urinary tract infection; even under vitamin D administration, bone collagen still leaked in the urine; immunological tolerance was not obtained in the gastrointestinal tract; and the child had a food allergy. Before starting natural foods for tube-fed children with long-term

commercialized digestive nutrient, it should be surveyed of foods allergy, by which the poor fermentation of intestine causes gastrointestinal intolerance. Gruel of cereal is simple and easy food for starting multiple foods intake; the author (Toya) often uses rice gruel in patients with chronic diarrhea with malabsorption susceptible due to poor growth of intestinal flora with probiotics, which may be a basic medium of microbial flora. Probiotics, such as bifidus bacteria, lactic acid bacteria, saccharifying bacteria, aspergillus, butyric acid bacteria, Also, fermented foods for probiotics, such as yogurt foods with bifidus bacteria, lactic acid bacteria, saccharifying bacteria, soybean paste with aspergillus oryzae, butyric acid bacteria, and other probiotics are considered to promote growth of intestinal flora in the small and large intestine. At the same time, the intake of dietary fibers and vitamins from vegetables and fruits enhances the intestinal environment. Cranberry juice is useful for acidification of urine, mostly by inhibition of the above putrefactive bacteria. The following should also be noted: seaweeds for iodine sources, foods of vitamin K sources, appropriate animal proteins as sources of carnitine, and if available, appropriate amounts of yellow eggs for cholesterol and selenium.

Viewpoint of Eating

The right brain and the limbic system, including sense of taste, is mainly developing until about the age of 3 years. The author has experienced a 7-year-old child with a severe bowel disorder, who does not start tasting without medication until the age, he doesn't feel the normal tasting, in which he said the sweet cake is bitter, and the bitter medication tastes sweet, which suggests that the tasting development is the acquired competency by oral feeding habits limited by the early maturation of right brain and limbic systems. Thus the early efforts of oral feeding/tasting for non-nutritional purpose is very important for achieving the sense of taste and the emotional development including mother to child attachment even if the children whose swallowing function is not sufficient.

For feeding several points should be noted; 1) The oral feeding as a total physiological movement; easy to breathe and keep relaxed body muscles with comfortable seating, positioning and appropriate reclining for easy to swallow. 2) The assessment of lingual movement; the observation of movements of tongue and muscles around the laryngopharynx should be performed if available by a speech-language-hearing therapist and visual assessment of swallowing including VF, which may suggest what kind of foods applicable. 3) The choice of foods; for an instance, smooth bilateral movement of tongue can sort materials to chew the non-uniform foods, which should be assessed for stepping up from uniform to non-uniform foods. 4) The importance of tasting; the author has experienced a case that had good effects on development through the experiences of tasting simple sweetness, hotness, sourness, and good flavor by the effective use of filtered juice or broth and by preventing aspiration with simultaneous oral cavity suction; such attempts for oral intake to experience tastes are still controversial, however the multipotent possibilities of "developing palliative biological function of eating that promotes growth and development" of non-nutritional feeding should not be excluded for severely handicapped children. 5) The disadvantage of nasogastric tube feeding and consideration to step up to gastrostomy tube feeding; nasogastric tube interferes with smooth laryngeal function causing aspirations; further, with the development of function, the hypersensitivity of nasopharynx and difficulty to insert nasogastric tube can also occur; for such a case, it is recommended of placement of gastrostomy as a support for oral intake. 6) The gastroesophageal reflux assessment on placement of gastrostomy; the level of reflux should be assessed using 24-hour esophageal pH monitoring and upper gastrointestinal radiography; if esophageal hiatal hernia or gastroesophageal reflux disease are found, surgical treatment should also be considered.

Total Parenteral Nutrition (TPN)

For cases in which a low gastrointestinal function impedes sufficient nutritional intake, including those with Hirschsprung's disease, TPN should be considered; it should be evaluated of the appropriate supplies of trace elements and vitamins, as well as a well-balanced caloric intake. The author has experienced a case that had developed seriously impaired liver function due to carnitine deficiency with the administration of fat preparations without carnitine to relieve malnutrition. It is always important to evaluate and supply vitamins and trace elements, apart from nutrients and calories.

Nutritional management at the terminal stage

Nutritional management that matches the decreased gastrointestinal function should be considered. For a long-term management of decreased nutrition in the end of life care, exhaustion can occur due to deprivation of vitamins and trace elements. In the last several days of a children's life, it should be noted for the overall exhaustion with multi-organ dysfunctions; the deteriorating circulatory, respiratory, and renal functions can induce gastrointestinal dysfunctions; in such a case, a gradual step-down of fluid intake with limiting medications should be considered of if necessary; reduction of fluid intake to about 0.5 to 1.0 L/m² of body surface area (BSA) will contribute to maintain dry condition, relieving suffering from decreased respiratory clearance at the terminal stage. For relieving gastrointestinal distress, the prescription of opiates should be considered; the author uses the buprenorphine, morphine and fentanyl if needed; it should be kept in mind that fentanyl has a low cholinergic effects but no effects for relieving dyspnea. The importance of palliative role of bathing improving peripheral circulation and easing the autonomous hyper-excitability should be noted for relieving of the multi-organ including gastrointestinal distress and emotional distress with/without malnutrition, Many children with advanced-stage cancer often suffer from changes in taste, for whom the well-tasting approaches can be considered in the end of life.

(Erika Okano, Yoichi Kondo, and Takeshi Toya)

References

- 1) Hiramoto H.: Diagnosis and assessment of severely mentally and physically disabled children, Habilitation manual for persons with SMID–Severe motor and intellectual disabilities, 2nd Edition. Ishiyaku Pub, Inc. 18-27, 2005,
- 2) Okano E.: What kind of children requires home support? Guidebook for discharge coordination & home care starting from NICU. MEDICUS SHUPPAN, Publishers Co., Ltd. 13-15, 2013.
- 3) Guideline preparation committee for NPPV, Japan Respiratory Society: Guidelines NPPV, 2nd Edition. Nankodo Co., Ltd. 2015.
- 4) Miyasaka K.: Japanese PALS Study Guide, Revised edition. Elsevier Japan, 416, 2013.

4. Supporting Early Discharge from NICU

While vital prognosis has been improving with the progress of neonatal medical care, infants requiring medical care are increasing by the year. To support early discharge from a neonatal intensive care unit (NICU), efforts such as drawing up schedules from an early stage of hospitalization and creating individual guidelines are important. Collaboration by interprofessional team members who support the child and parents is also indispensable to home medical care after discharge.

NICU and Home Medical Care

According to our study conducted in Saitama Prefecture,¹⁾ in home-cared children with serious illnesses, 51% of the basic diseases occurred before birth (chromosomal abnormality, congenital anomaly, etc.), 13% at birth (severe apparent death, etc.), and 23% in the neonatal stage (chronic lung disease, necrotizing enteritis, meningitis, etc.), indicating that the perinatal period accounts for 87% of the onset stage. It was also brought to light that the rate of infants with severe illness occurring in NICU is high. Because many of these infants need to stay in NICU for a long time, many hospitals are not able to take in neonates requiring acute medical care, and this is becoming a social problem. As a result, efforts aiming to transfer infants from NICU to home medical care are drawing interest. The number of infants being discharged from the hospital while still receiving medical treatment is increasingly growing.²⁾

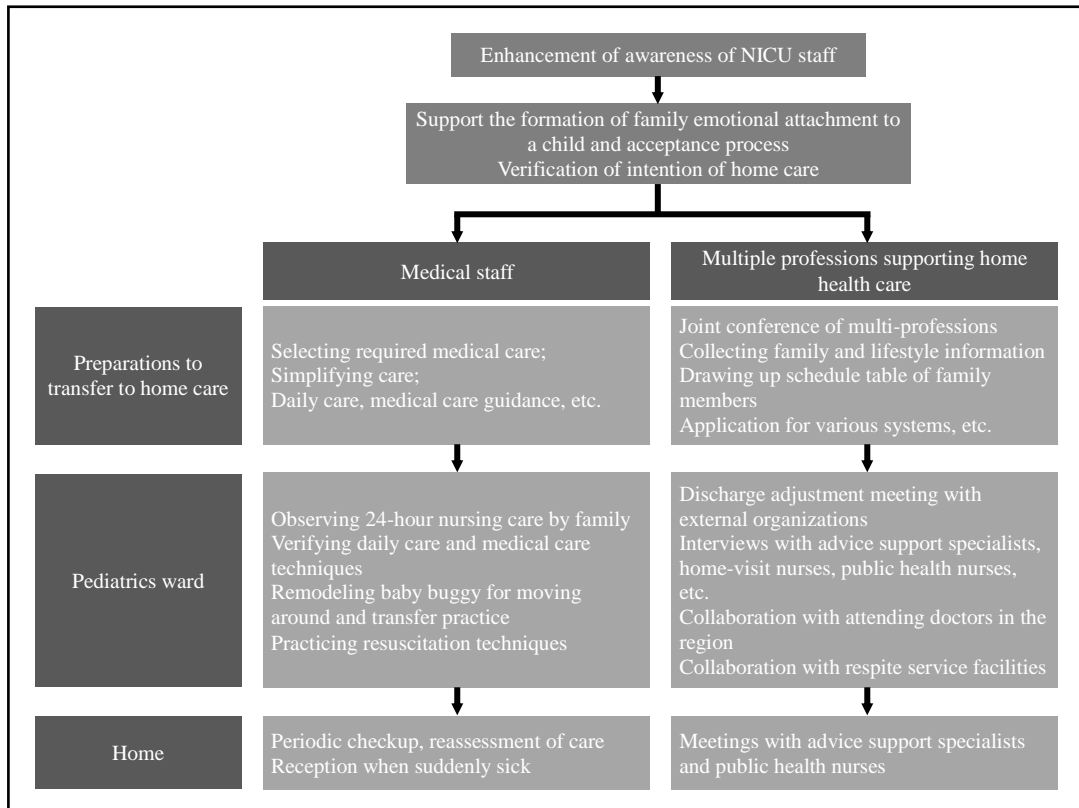
Long-term hospitalization at NICUs can also affect emotional attachment between parent and child, with parents having difficulty receiving the infants as a member of the family and picturing them living and growing up in the community. For this reason, efforts to plan home medical care from an early stage of NICU hospitalization are important.

Flow of Discharge Support and Key Points

A. Planning to Switch from Hospitalization to Home Care

For infants expected to face difficulty in long-term NICU hospitalization and switch to home care, it is important for the medical staff to take into account switching to home medical care from an early stage in their care efforts.³⁾ First, it is important for NICU staff to support the formation of family's emotional attachment to a child and acceptance process. While building this bond, NICU staff will talk to the parents about the potentials of recovering at home and check the parent's consent to home medical care. The doctors will evaluate the child's conditions and select the required medical care. Once the child's condition stabilizes and the directions for transferring to home care become visible, preparations to move to home care are started on a full scale.

Figure. Process of Transfer to Home



B. Preparations to Transfer to Home Care

Interprofessional joint conferences are held with the participation of NICU doctors, pediatric ward doctors, NICU nurses, pediatric ward nurses, outpatient nurses, discharge adjustment nurses, physical therapists, medical social workers, clinical psychologists, and clinical engineers to share information on the conditions of children, their family, their lifestyle, and social resources as well as to discuss problems. While their child is hospitalized at the NICU, family members slowly acquire skills in daily care and medical care.

C. Simplifying Care and Drawing up Lifestyle Care

The skills required at NICU are 24-hour intensive care and consist mainly of sterilization procedures requiring measures against infections. However, at home, the skills required are for a single child, and strict hygiene procedures are usually not required at home. Simplification of care (while disposable tracheal suction tubes are used in NICU, they are reused at home by wiping with alcohol) is a very important process for home transfer. As parents will get confused if the techniques performed in NICU and pediatric ward after transfer from NICU differ, staff must make sure they teach the same skills to parents. It is also important to prepare checklists and share information on progress.

Since NICU care services are provided around the clock, families often find that they are given everyday schedules that are very difficult to continue (have to feed milk 7 to 8 times/day, have to give medicine late at night, etc.); thus, there is a need to draw up 24-hour timetables that parents can get used to easily once home care starts.

D. From Transferring from NICU to Pediatric ward to Discharge

After the child is transferred from NICU to the pediatric ward, staff will check the care skills of the parents while the parents continue accumulating experience to care for their child full time. Parents may also remodel buggies (wheelchairs) and mount respirators or hang irrigator poles for tubal feeding. It is also important for family members and medical staff to meet the people in the community who will be supporting the child and families (advice support specialist, home-visit nurses, public health nurses, etc.), in the same manner as finding an attending doctor in the region. When discharge approaches, discharge adjustment meetings attended by multiple professionals inside and outside the hospital will be held.

The main caregiver at home is the mother. Chronic lack of sleep and mental and physical exhaustion are anticipated. Collaboration with respite care facilities is thus important.

Doctors may also contact the fire station to notify that a child wearing a respirator will be returning home, or nurses, physiotherapists, and clinical engineers may visit the child's home before the discharge to prepare the environment for the child to live in. In addition, medical social workers may make adjustments of social resources, etc.

E. Support after Transferring to Home Care

After transferring the child to home care, there will be a need to change care and support according to the growth of the child and lifestyle of the family. The involvement of interprofessional teams will become even more important. Ideally, support meetings should be held mainly by regional advice support specialists and public health nurses when required. To provide reliable home medical care service, reception by hospitals in times of acute illnesses is also important.

Conclusion

The continuous collaboration of interprofessional teams supported by core hospital staff and the regional municipality is important for supporting the discharge of infants requiring advanced medical care and their families. The construction of a system that aims not only for the happiness of the infant, but also for family members to lead full lives is sought.

(Eiko Takada)

References

- 1) Koichi Moriwaki, *et al.*: Survey of infants requiring home medical care in Saitama Prefecture. 2011 to 2013, Regional Medical Infrastructure Development Promotion Research Project, Research Report: 28-31, 2013
- 2) Koichi Moriwaki, *et al.*: Survey of discharged infants younger than one-years old requiring artificial respiration tubes from NICU/GCU, 2011 to 2013, Regional Medical Infrastructure Development Promotion Research Project, Research Report: 69-78, 2013
- 3) Hisanori Sobajima: Flow from NICU hospitalization to discharge, *Perinatal medicine* 43 (11): 1335-1339, 2013

5. Palliative Care for Children at Home

In Japan, it is rare for sick children to spend their last moments at home, whereas in the UK, an advanced nation of palliative care, 70%–80% of the children with cancer are reported to die at home. Being able to spend one’s last moments with family at home has profound significance, especially in the case of children. WHO’s definition of palliative care for children contains one sentence mentioning that palliative care should be provided at home, pointing out the importance of palliative care at home for children.

Subjects of Palliative Care

According to WHO’s definition of palliative care, the subjects of palliative care are patients facing various problems due to life-threatening illnesses and their families.

In children, palliative care is provided if their clinical conditions have a high risk of premature death with little hope of a cure. Such conditions are generally called life-threatening illnesses. The judgment is recommended to be made according to clinical conditions rather than medical diagnosis, which include four states of illness: (1) illnesses for which radical treatments are effective; (2) those in which premature death cannot be avoided, but life can be extended by treatment; (3) those that are progressive and treatments are limited to the alleviation of symptoms; and (4) those that are nonprogressive but accompanied by irreversible severe disorders (**Figures 1 to 4**).¹⁾ Prognosis is not limited to six months. Both malignant and nonmalignant diseases are included.

For children, their “family” has more complex structure than for adult patients. The age and role of family members are diverse, including parents, grandparents, and siblings. Relations with the region and school, etc. must also be considered. Taking the depth and extension of sadness into consideration, the target of care cannot be set down uniformly.

Figure 1. State of Illnesses for Which Radical Treatments Are Effective
(e.g., pediatric cancer, heart diseases)

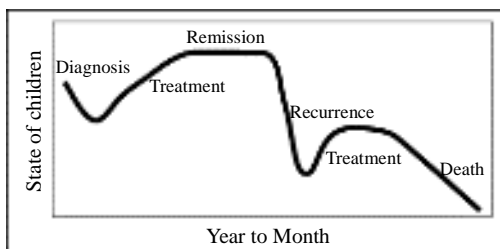


Figure 2. State of Illnesses in Which Premature Death Cannot Be Avoided, but Life Can Be Extended by Treatment
(e.g., Neuromuscular Diseases)

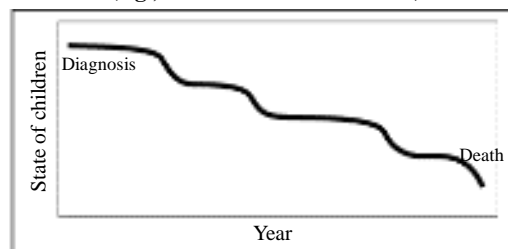


Figure 3. State of Illnesses That Are Progressive and Treatments Are Limited to the Alleviation of Symptoms (e.g., Metabolic Diseases, Chromosomal Aberration)

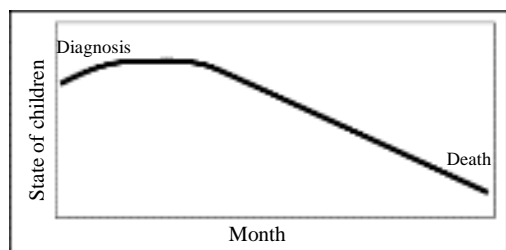
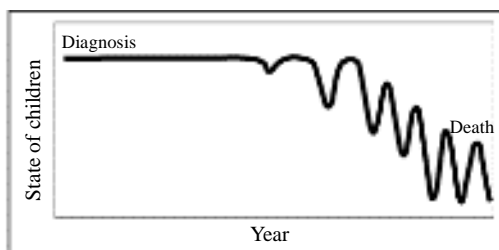


Figure 4. State of Illnesses That Are Non-Progressive but Accompanied by Irreversible Severe Disorders (e.g., Severe Cerebral Palsy)



Why Is Special Palliative Care Required for Children and Family?

The following table includes the common points and differences of palliative care between adults and children.

The spirit of palliative care is shared by the two parties. It includes the quality of life of patients, control of symptoms, psychiatric care, family care, and multidisciplinary collaboration. On the other hand, palliative care differs between adults and children as follows.

A. Death of Children Is Rare

Unlike the death of adults, that of children is rare. Especially in advanced countries, death of children is rare because of the progress of medical technology. In Japan, 1.3 million adults die in a year, but the figure drops to 4,000 in the case of children. Medical practitioners witness the death of adults on a daily basis, but the chances of witnessing the death of children are slim even for doctors and nurses. Moreover, the death of children is illogical and unnatural and cannot be accepted easily. Above all, the sadness and trauma involved are profound and cause various problems.

B. Types of Pediatric Diseases and Prognosis

Those involved in palliative care for adults are able to determine prognosis relatively accurately with experience. However, in case of children, there are many types of life-threatening illnesses and many rare congenital diseases, making it difficult to predict prognosis accurately. Progress also differs by patients. Often, there are children who appear to not have much time left but are able to live for a longer time in well state and then suddenly die. The accurate prediction of prognosis serves as important material for making judgements regarding what should be said to the patient and family, how the surrounding environment should be prepared, and how care should be provided. In the case of children, the prediction of prognosis is difficult, making it also difficult to plan palliative care suited to the patient and family.

C. Palliative Care Supporting the Growth and Development of Children

Children are constantly growing, progressing, and changing. This is the same regardless of what illness or disorder the child has. Growth and progress bring tremendous joy and encouragement to the people around them and their families. For this reason, palliative care for children needs to support this growth and progress.

In adults, normally palliative care is not required to support growth and progress.

This is because the time required for palliative care in the lifetime of a person differs between children and adults (**Figure 5**). Adults become sick after having lived for some time, fall into a state that cannot be cured, and receive palliative care. Even though palliative care is now started

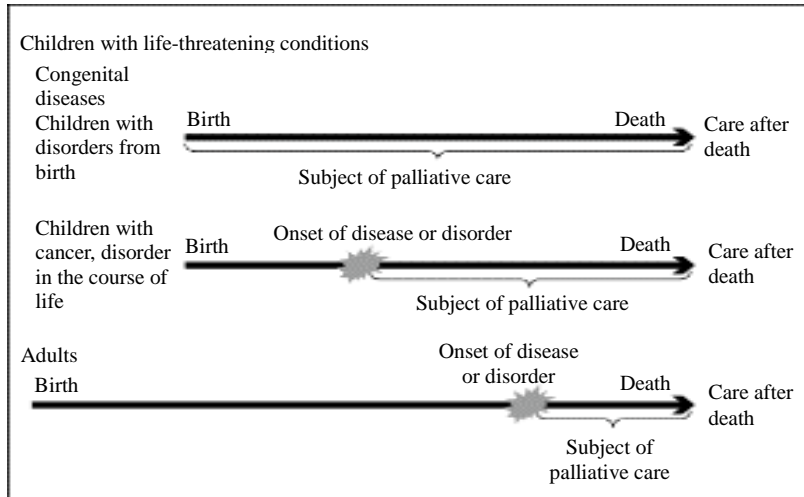
from the time of onset, the time of receiving palliative care is merely less than 10% of their lifetime for many patients. However, many children have to live with life-threatening illnesses for most of their lifetime, during which time, they require palliative care. There are children diagnosed with life-threatening illness from birth such as severe chromosomal aberration, etc., who have to live with the illness for the rest of their lives. There are also children who die after spending more than half their short lifetime fighting cancer. To such children, palliative care serves as an important lifelong partner to their daily life.

Consequently, palliative care for children differs from adult in that it must support the changes in the children’s life stages as well as their development and progress.

Table. Common Points and Differences of Palliative Care between Adults and Children

Common points
<ul style="list-style-type: none"> • Life prognosis of patients is limited • Importance of QOL (quality of life), importance of home care • Importance of controlling symptoms • Importance of mental care • Importance of family care • Multidisciplinary collaboration is required
Differences
<ul style="list-style-type: none"> • <u>Death of children is rare</u> • <u>There are more types of diseases for children; many are rare, progress is different, and some progress rapidly and prognosis is difficult.</u> • <u>Development and progress must be considered for children.</u> • Care for children with intellectual or communication disorders requires special skills • Family care is broad (e.g., siblings, grandparents) • Sadness felt by family is profound • Ethical consideration (e.g., right for child to make own decisions) • More occupations are involved (e.g., school, community, hospital) • Psychological burden of involved staff is huge • <u>Decisively important for children to live at home</u>

Figure 5. Comparison of Period Requiring Palliative Care



D. Communication with Children

For most adults, doctors and nurses are able to determine to what extent patients understand the life-threatening illness they have through communication when providing mental care to them. Patients can tell them what they want to do, how they want to lead their lives, how they want to die, and other wishes.

However, children do not have sufficient ability for such communication. Often, they are not even capable of communication because of intellectual disorder, etc. In such states, it is difficult to provide palliative care in which communication with the patient serves as an important pillar. Often, the parent communicates on behalf of the children, but the parent's will be not always the same as that of the children. There is also a need to give consideration to ethical aspects such as to what extent should the child's decision be acknowledged.

E. Family, Home, and Other Environment

The family members surrounding children are diverse compared to adults. In environments where the parents are naturally caring for their sick child and their interest tend to concentrate on the child's illness, siblings are often hurting deeply. Care for these siblings is an important theme. Care for parents as well as grandparents are also necessary. The sadness of family members towards a child's death is especially profound, and huge psychological burden is also experienced by the medical practitioners who have to face such situations and people in the community, schools, etc. providing support to such families.

It is especially important for sick children to live at home. The importance given to care at home and not in a facility may have significant implications on the surrounding environment of the children, such as family and schools.

Pain Assessment

The most important symptom in palliative care is pain. Pain is assessed by self-report, observing behavior, or by assessing physiological changes. Generally, self-report is most used. Self-report consists of visual analogue scales (VAS), in which patients mark the location on a 100-mm line corresponding to the intensity of the pain experienced, numerical rating scales (NRS), in which patients express the intensity of their pain using numbers 0 to 10, and face scales, where the patients use facial expressions to indicate different levels of pain.

Most children have difficulty with self-report, and pediatric pain profile (PPP) is an assessment method based on observing behavior for such cases and children with several psychological and physical disorders. PPP consists of 20 items for observing behavior.²⁾ It cannot be used for children requiring artificial breathing management or having paralysis. There is also the FLACC pain scale used for children between 2 months and 18 years old who have difficulty in language communication. This scale assesses pain using five categories face, leg, activity, cry, and consolability.

Pain Control

A. Key Concept of Pain Treatment in Children

The WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses include the following four key concepts of pain treatment in children:

(1) Two-stage strategic drug treatment

First, acetaminophen or nonsteroidal anti-inflammatory drugs (NSAIDs) are used (e.g., ibuprofen). If insufficient, strong opioids (e.g., morphine hydrochloride or oxycodone) are used. There is not the weak opioid stage for children.

(2) Dosing at regular interval

As in adult patients, pain is managed by regular administration instead of as-needed use when pain appears.

(3) Using the appropriate route of administration

Oral administration is ideal. In many cases children are unable to take their medication properly, in which case some other means of administration must be devised.

(4) Adapting treatment to the individual child

As the amount of pain medication taken differs according to the individual, there is a need to set the best amount for each patient. There is no limit to the dosage amount of opioid for children. The balance between the effect of pain control and the adverse reactions should be appropriately evaluated. If the adverse reactions cannot be tolerated, a change of medication must be considered.

B. Specific Mode of Pain Medication Administration

First stage acetaminophen is effective for four to six hours. The minimum amount when pain-killing effects are expected is 10 mg/kg. Consequently, in many cases, continuous pain relief effects cannot be acquired with the dosage amount (10 mg/kg × 3–4 times/day) administered for fever by pediatric departments in Japan. It is therefore administered in large dosages while paying close attention to liver disorders, etc.

Acetaminophen administration method:

10–20 mg/kg per 4–6 hours

If acetaminophen does not work, second stage strong opioid is used immediately. The first-line drug is morphine hydrochloride.

Initial dose of morphine:

3–6 months: 0.5 mg/kg/d in 4–6 divided doses

> 6 months: 0.5–1 mg/kg/d in 4–6 divided doses

> 12 years: 20–60 mg/kg/d in 4–6 divided doses

Regular and as-needed strong opioids must be prescribed for constant and sudden pain. The dose amount for the treatment of a sudden pain is 1/4 to 1/6 that of the daily dosage, which is the amount per administration.

There is no limit to the dose of strong opioid. If pain is felt with the initial dose, then the opioid is added on as-needed basis. Then the regular dose of morphine is increased according to the required amount (titration). It is easier to determine the appropriate dose of morphine in titration if a quick-acting medicine is administered in an increasing-dose schedule every four hours compared to sustained-release drug.

(Hirotooshi Maeda)

References

- 1) Goldman A, et al: Oxford Textbook Palliative Care for Children. Oxford University Press, 2006.
- 2) Hunt A, Goldman A, Seers K, Crichton N, Mastroiannopoulou K, Moffat V, Oulton K, Brady M: Clinical validation of the Paediatric Pain Profile. *Developmental Medicine and Child Neurology*. 46 (1): 9-18, 2004.

6. Social Programs for Pediatric Home Medical Care

Welfare service for persons with disabilities was drastically revised in April 2012. With responsible organizations relocated from prefectures to municipalities, efforts that match the actual situation of the region and are familiar to the local community are expected.

Welfare Service for Persons with Disabilities Available for Children
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A. Types of Services

The following **Table** summarizes the types of services available. Whether they can be actually used depends greatly on the infrastructure of the region. The counseling and support center (counseling and support specialist) plays the role of combining the services effectively, sharing the characteristics of children requiring the services with service providers, and negotiating flexible means of using the services with the local government, etc.

B. Counseling and Support of Disabled Children

The counseling and support center prepares plans and provides disabled children with support for using the services. However, due to the lack of counseling and support specialists and because patients have the option to apply for the services by themselves, the guardians and family members of patients often consult the local government regarding welfare services instead of consulting and receiving the support of these centers. This poses as a major task in the future. Welfare service for persons with disabilities consists of counseling and support for disabled children and continued counseling and support for disabled children.

(1) Counseling and support for disabled children

Individual support meetings are held and liaison and coordination with service providers are made to provide information on the use of counseling, assessment, etc. service for living in general and to develop a use plan and service use plan.

(2) Continued counseling and support for disabled children

Individual support meetings are held and liaison and coordination with service providers are made to support the procedures for continued use of consultation, monitoring, and reassessment of living in general, and change a usage plan.

Table. Welfare Service for Persons with Disabilities That Can Be Used by Children

*Differs according to municipalities, as these are community-assisted living services

	Service (basis laws and regulations)	Outline	Applicable age
Day care	Development support for children (Child Welfare Act)	<ul style="list-style-type: none"> ○ Center for development support for children ○ Development support service for children <ul style="list-style-type: none"> - Development support for children - Medicine-based development support for children 	Basically pre-school children and children not going to high school
Day care	After school day service (Child Welfare Act)	After school and long holiday leisure activities	Child with disabilities enrolled in elementary, junior high school, and senior high school
Day care	Visiting support at day care centers, etc. (Child Welfare Act)	Visits by specialist staff such as nursery teachers and nurses, etc. to children of nurseries, kindergarten, care for school children outside school hours, etc. to provide care support	From preschool children to elementary school children
Place other than home	Temporary day support (Services and Support for Persons with Disabilities Act)	Temporary care	From preschool children to adults(*)
Home	Home nursing (Services and Support for Persons with Disabilities Act)	Physical care, housework, assistance with hospital visits (procedures for hospital visits, at public organizations, touring of facilities, etc.)	From preschool children to adults
Home	Behavioral assistance (Services and Support for Persons with Disabilities Act)	Persons with behavioral disorders	From preschool children to adults
Home	Transport assistance (Services and Support for Persons with Disabilities Act)	Can also provide assistance in guiding to destination, transportation, using vehicles.	From preschool children to adults(*)
Admitted	Short-term admission (Services and Support for Persons with Disabilities Act)	Temporary admission service during emergency situations of guardians and families or for them to rest <ul style="list-style-type: none"> ○ Welfare-based short admission service ○ Medicine-based short admission service 	From preschool children to adults
Admitted	Residential care (long term admission) (Child Welfare Act)	Provides long-term admission service when home care becomes difficult. <ul style="list-style-type: none"> ○ Welfare-based short admission service ○ Medicine-based short admission service 	Up to 20 years old

C. Flow to Usage of Service

As the subjects of counseling and support of disabled children specified in the Child Welfare Act are the users of day care support for disabled children (development support for children or after school day service), they also need to receive planned consulting service support (Services and

Support for Persons with Disabilities Act) to use the home care prescribed by the Services and Support for Persons with Disabilities Act and other services. The School Education Act also applies to children going to school. There is a need to further review what support is required to enable use of the diverse services available under the many different laws.

The flow to service usage is outlined in the **Figure**.

Child Rearing Support Service

A. Day Care Center for Children (Child Welfare Act)

Some day care centers accept children with severe mental or physical disabilities and children needing medical care according to the region. Some accept only disabled children whose conditions are mild. Additional staffing and increased operational grants are expected when disabled children are admitted. Some day care centers also provide temporary care service and care for children recovering from illness.

B. Kindergarten (Basic Act on Schools, School Education Act, School Health and Safety Act)

Though very few in number, some kindergartens have in-house nurses.

C. Family Support Centers (Child Welfare Act)

Membership charged volunteer service. The fees paid by the user differ according to the municipality. Some regions invite nurses as support members.

D. Helper Service

Consists of pre- and post-delivery support helpers (Ministry of Health Birth and Child-Rearing Support Help Service) and single-parent home helper (Act on Welfare of Mothers with Dependents and Widows).

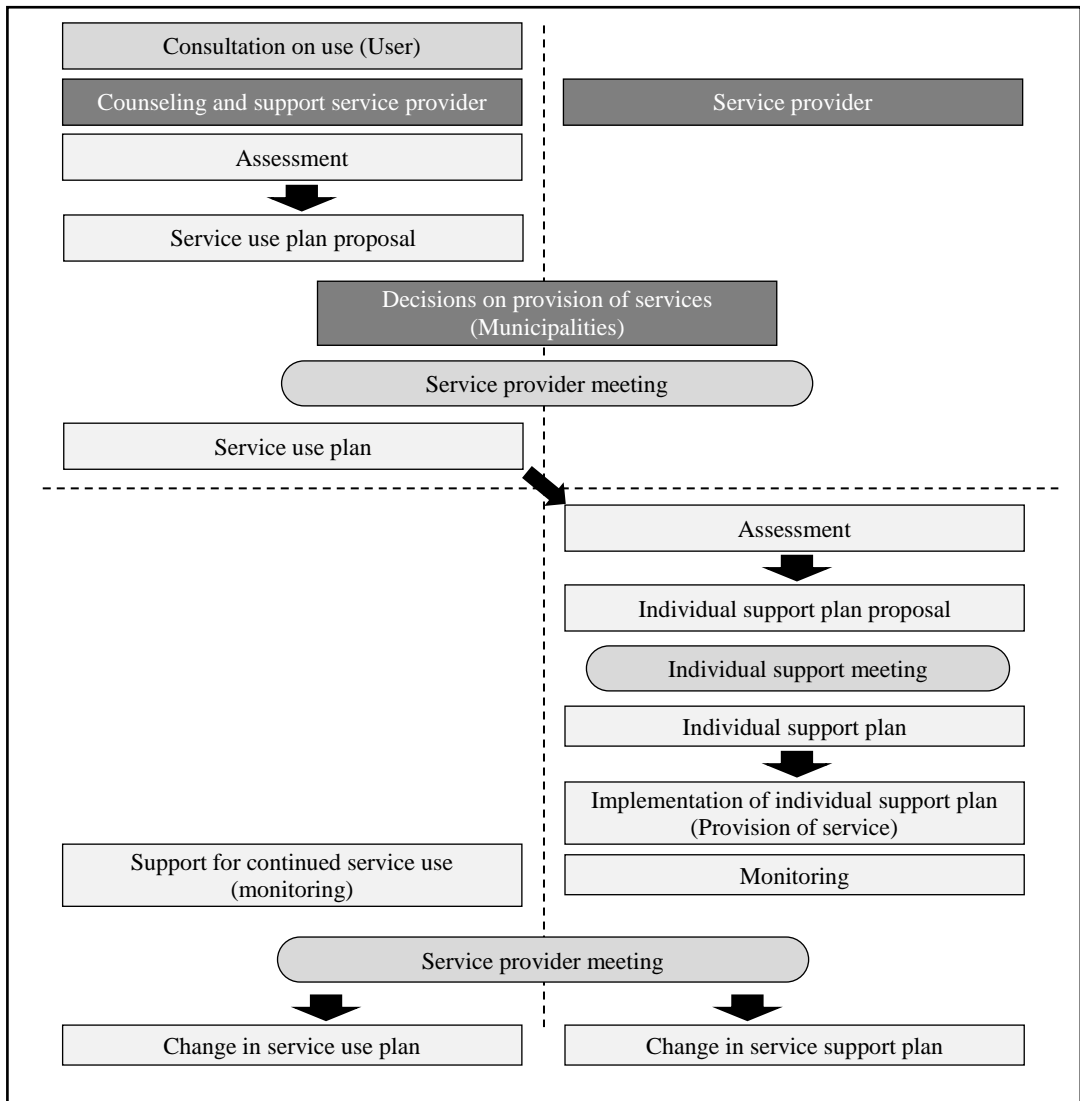
E. Infant Homes/Orphanages (Child Welfare Act)

These are intended for children who do not have guardians, who are abused, or whose guardians are disabled. While there are increasing cases of abused disabled children using facilities for disabled children, there are also many disabled children in orphanages. With the growing number of crossover cases, more and more facilities are facing various issues.

F. Family Homes and Self-reliance Support Home (Child Welfare Act)

Care services and living assistance after starting work are provided in relatively small-scale homely environments.

Figure. Relation between Designated Specific Consulting Support Provider (in Charge of Planning) and Welfare Service for Persons with Disabilities



G. Foster Care System (Child Welfare Act)

Provides child support services in which foster parents look after children with no guardians or who are abused. They are called special foster parents.

H. Maternal and Child Livelihood Support Facility (Child Welfare Act)

Accepts both mother and child and provides livelihood support services for them to become independent.

Independent Support Service for Children with Chronic Pediatric Diseases

A. Purpose of Service

On the basis of the Child Welfare Act, this service provides information required for counseling children and their families to promote the wholesome growth and independence of children

requiring long-term recuperation because of chronic diseases or contacts and makes adjustments with related organizations. Responsible organizations are prefectures, designated cities, and core cities. They can subcontract services to appropriate service providers.

B. Details of Services

- (1) Required services: Support by independent support staff of counseling and support services for children with chronic pediatric diseases.
- (2) Optional services: Child support services, mutual interchange support services, employment support services, care provider support services, and other independent support services.

Community-Assisted Living Services

Services intended for children under 18 years of age whose disorders are caused by intractable diseases or special diseases that restrict continuous daily life or social life to a great extent.

A. Municipal Services

(1) Counseling and support, (2) adult guardian system use support, (3) mutual understanding support, (4) provision of devices/equipment for daily living (adaptive equipment), (5) movement assistance, (6) temporary day care and support, and (7) others (community-assisted activities support center, understanding promotion training, enlightenment, and spontaneous activities support).

B. Prefectural business

(1) Counseling and support for special cases; (2) services that can provide extensive support; (3) personnel development; and (4) training and dispatching of persons to provide special support for mutual understanding, liaison and coordination, and coordination of personnel dispatch.

There are many social resources that children can use at home; however, it takes time for service providers to use such resources effectively, sympathize with the hardships faced by families or the children, and provide support suited to growth and development of the children. There is a need to build a community that can look after children in long-term care.

(Atsuko Kajiwara and Hirotooshi Maeda)

Chapter VI References

1. Issues and Views of Pediatric Home Medical Care
 2. Regional Cooperation for Pediatric Home Medical Care
 3. Home Medical Care of Seriously Handicapped Children
 - (1) Ekvall SW, Ekvall VK: Pediatric Nutrition in Chronic Disease and Developmental Disorders. Oxford University Press, 2005.
 - (2) Wolfe J, Hinds P, Sourkes B: Textbook of Interdisciplinary Pediatric Palliative Care. Saunders, 2011.
 4. Supporting Early Discharge from NICU
 5. Palliative Care for Children at Home
 6. Social Programs for Pediatric Home Medical Care
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