

Current Situations and Problems of Home Care for Children*¹

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Introduction

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

Background

In 2006, a pregnant woman died in Nara Prefecture. This death was reported by media under headlines such as “emergency acceptance of a pregnant woman rejected by 19 hospitals.” After this case, various measures were taken with the aim of resolving difficult acceptance of mothers and neonates by hospitals, under the presumption that prolonged hospitalization of neonates in the neonatal intensive care unit (NICU) was the major underlying cause.²⁻⁴ As a result, in

major 5 hospitals in Osaka, the rate of discharge within 2 years after NICU admission increased from 63% in fiscal 2008 to 94% in fiscal 2010.³ Along with this increase, the number of children receiving advanced medical care at home also increased. According to the data from healthcare centers in Osaka, the number of children on a mechanical ventilator at home has increased 5.4-fold over the past 7 years (**Table 1**).

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

Problems Surfaced from a Questionnaire Survey

The Osaka Pediatric Association conducted a

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

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

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

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

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

Table 2 Coordinating organizations for care after discharge

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

(n = 32)

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

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

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

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

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

Case

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

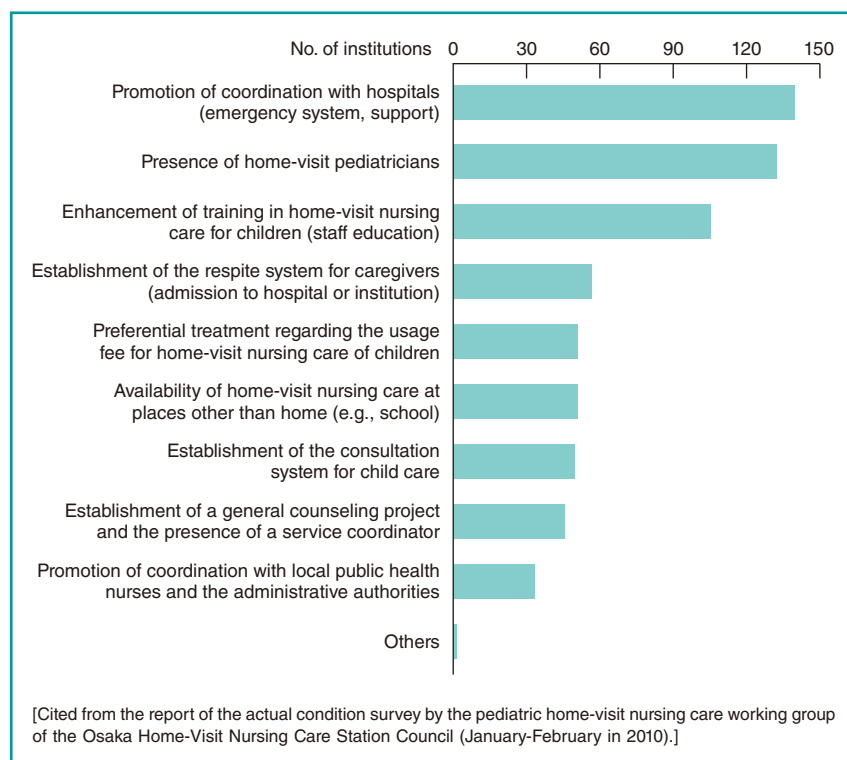


Fig. 1 What is considered necessary for promotion of home-visit nursing care for children?

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

Process to home medical care

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

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

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

Course after discharge

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

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

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

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

Claimable points before discharge are:

[1] Collaborative guidance at discharge 1 (600

points + special management guidance addition, 200 points) $\times 2 = 1,600$ points

Claimable points after discharge are:

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

For actual individual medical actions:

[3] Written direction for home-visit nursing care: Direction for home-visit nursing care, 300 points

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

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

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

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

Basic points are as follows:

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

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

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

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

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

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

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

Table 3 Role sharing between clinics and hospitals

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

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

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

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

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

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

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

Home-care pediatric patients often require specialized medical services, necessitating coordination between hospitals and home-care providers. Role sharing by hospitals and clinics (**Table 3**) is important for reducing the burden on the clinic side.^{8,9} The division of roles should be confirmed

before discharge of the patient. If this procedure is definitely followed, the barriers hindering the participation of general pediatricians in home medical care would likely be lowered.

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

Conclusion

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

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

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

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