



# Characteristics of Home-Visit Nursing Stations that Accept Children Requiring Long-Term Medical Care after Discharge from Neonatal Intensive Care Unit

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Many cultures are witnessing high-risk births due to the increasing trend of delayed childbearing. This has resulted in a higher proportion of children requiring long-term medical care (CLTM). The number of home-visit nursing stations available for pediatric patients should increase to provide care for CLTM at home. Through a questionnaire-based cross-sectional survey of 338 home-visit nursing station managers, this study aimed to identify the determinants of the acceptance of CLTM by analyzing the characteristics of the stations, managers, staff, and registered children, and the volume of home visits. Chi-squared tests and logistic regressions were applied to determine the independence of the variables of acceptance and analyze their significance, respectively. The response rate was 14.6%, the number of pediatric patients registered in the past was 914, and the average number of registered pediatrics was 2.7. The results indicate a correspondence between the increase in home visits by nursing staff and the number of CLTM accepted for home-visit nursing services after discharge from neonatal intensive care units. Additionally, stations whose managers have three or more years of pediatric care experience accept more CLTM, and their employees are better equipped to facilitate these acceptances. Nonetheless, the number of facilities with pediatric departments has declined; thus, nurses will face increasing difficulty gaining pediatric work experiences. Therefore, enhanced seminars and training on pediatric medical care for managers and nurses, as well as strengthened collaboration/coordination with pediatric wards, clinics, and multidisciplinary occupations should be implemented as countermeasures. Our findings illustrate issues and strategies for acceptance.

**Keywords:** community health nurses; house calls; parent-child relationship; postnatal care; social welfare  
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## Introduction

Japan's declining birthrate remains a long-standing issue and has led to considerable change in the country's demographic structure. In 2018, the number of births fell to a record low of approximately 918,000, and the total fertility rate was 1.42 (Ministry of Health, Labour and Welfare 2019). Despite the declining fertility rate, there has been an increase in high-risk births due to the advanced age at which many women now give birth: in 2017, the average age of first-time mothers was 30.7 years, and the proportion of women bearing their first child at the age of 40 or older was 36.7% (Health, Labour and Welfare Statistics Association 2019). However, as medical science has

advanced, children born with serious congenital diseases and extremely low birthweight can now be saved. This has resulted in a higher proportion (as well as a higher number) of children requiring medical care, an increased need for medical equipment such as respirators and oxygen supply devices, and a rapidly increasing number of children who are dependent on the use of these medical devices for survival (Kusuda 2017). The increased number of infants requiring medical care has simultaneously resulted in an increased demand for neonatal intensive care unit (NICU) facilities (Kusuda 2017) and an increasing number of children requiring long-term medical treatment and the use of medical equipment such as ventilators.

Children who require medical care, such as the use of

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mechanical ventilation, gastrostomy tube-feeding, and suction of sputum, are described here as children requiring long-term medical care (CLTM; also, for “a child” requiring long-term medical care). [The Japanese term for this is *Iryouteki kea ji*, which has been used in other studies (Tamura 2016; Sato 2018). However, a consistent English translation of this term is not available. Therefore, we use the term “children requiring long-term medical care”]. Accordingly, Tamura (2016) reported an increasing trend in the number of children requiring medical care, estimated at approximately 17,000 in 2015. Furthermore, the long-term hospitalization of children has been identified as an obstacle to the growth and development of those children and the development of parent-child relationships (Narama 2013). Homes or medical facilities for children with disabilities have been identified as the best places for CLTM to live after their discharge from the NICU. Medical facilities for children with disabilities provide treatment and daily living support for those with severe intellectual and physical disabilities. However, these facilities are limited; thus, children who are not accepted have to receive care at home.

Tamura (2016) categorized the types and prevalence of care provided to CLTM at home, with tube feeding being the most prevalent at 64.0%, suction at 55.6%, combined tracheostomy and ventilator use at 17.4%, and combined home oxygen therapy and respiratory equipment use at 13.0%. The severity of the affliction suffered by CLTM may vary from some level of walking to being bedridden. Therefore, based on the severity, and given that the necessary medical services for CLTM at home are often provided by the parents, such caregiving may place a heavy burden on these parents, especially the primary caregiver, who in many cases is the mother. Moreover, it has been reported that caregivers are often unable to provide appropriate support for their other children’s growth and development (Fujioka et al. 2014). Parents of CLTM tend to be so engulfed in providing medical care to their ailing children that it becomes difficult for them to interact with their other children; for example, they have less time to talk and walk with their other children, or cuddle and provide physical contact as is usual with healthy children. Moreover, caregiving provided at home has the potential to trigger other family issues. For example, 55.7% of people who provide medical care to their CLTM are not working, and yet 61.4% of them do wish to work (Kobe City 2018). Such a situation can easily result in economic problems and tension in the family.

Furthermore, although the Long-Term Care Insurance Law requires designated “care managers” to prepare care plans and coordinate care for the elderly, there is no such designation available for children. Parents must independently obtain medical care, comprehend the social system, and coordinate home-visit nursing. Thus, there is an obvious need to provide support to the parents of CLTM so that there is a smooth transfer of the children from hospital- to home-based care (Sato 2018). Furthermore, families for

CLTM often request nursing consultations to check their child’s health status, receive advice on medical care, learn what to do in an emergency, how to handle medical equipment, and coordinate services, among others. This suggests the need for replete nursing services and the importance of home-visit nursing consultation for these families.

Home-visit nursing for children, including children requiring medical care, was positioned as a medical insurance service according to the “Vision for Reform of the Medical Care System” (Ministry of Health, Labour and Welfare 2003) in 2003. Such care plays an important role in providing the necessary services to children and their parents during the preparation, transition, and stabilization phases of those children’s lives. Thus, the introduction of home-visit nursing services supports the discharge of CLTM from hospitals. However, despite the introduction of home-visit nursing for children, a survey of children requiring medical care in Kobe city reported that mothers remained the most prominent providers of medical care at home (92.0%), followed by fathers (58.5%), while home-visit nursing stations accounted for only 22.2% (Kobe City 2018).

Similarly, in March 2019, the Saitama prefectural government conducted a survey of home-visit nursing stations in the district (Saitama Prefecture Department of Public Health and Medical Services 2019). The results showed that 52.4% of these establishments accepted and treated children, while 45.2% did not (2.4% did not respond); 32.5% of the nursing stations that did not accept children cited “lack of nursing staff with experience and skill” as the reason for not treating children in their visiting program. Similarly, Ohnishi and Ishida (2019) found that home-care nurses face challenges while providing home care for CLTM, including inexperience and a general lack of knowledge. Moreover, home care nurses need to build trust with the child’s mother to help solve their problems. There are also specific issues regarding the management of medical care, family nursing, developmental support, and the care system itself. All these contribute to the hurdles home-visit nurses face in providing medical care to CLTM.

The results of these surveys highlight the need to increase the number of home-visit nursing stations that can accept CLTM to promote the successful transition of these children to home-based care. To do so, it is important to clarify the determinants of the acceptance of CLTM in home-visit nursing programs; however, to the best of our knowledge, no study has done so till date. “Acceptance” here is defined as receiving a referral from a health-care facility and an agreement to start home nursing. Thus, our research question was “What determines home nursing stations’ acceptance of CLTM after being discharged from NICUs?” Therefore, the aim of this study is to identify the determinants of the acceptance of CLTM by home-visit nursing institutions. By doing so, this study provides recommendations that can facilitate the acceptance of more CLTM into home-visit nursing programs.

## Material and Methods

### Study participants

We surveyed home-visit nursing service managers nationwide to identify the reasons behind a home-visit nursing station's ability to accept and treat CLTM once discharged from the NICU along with the characteristics of home-visit nursing programs that were able to provide care to CLTM.

### Method

In February 2016, potential participants were randomly chosen from 4,842 home-visiting nursing stations nationwide listed as members on the National Visiting Nursing Business Association webpage. We distributed questionnaires to 2,500 managers of home-visit nursing stations, other than those specializing in elderly care, with the aim of obtaining responses from at least 1,455 managers (i.e., 30% of the total number of visiting nursing facilities nationwide).

The content of the questionnaire was as follows:

- a. Characteristics of the home-visit nursing stations' staff, registered users, and the volume of visits:
  - 1) Number of employees (total, full-time, part-time, and full-time equivalent)
  - 2) Staff composition (public nurses, nurses, midwives, associate nurses)
  - 3) Total number of registered users and number of children using the service per month
  - 4) Total number of visits per month; total number of visits to children
  - 5) Number of registered children by disease or condition
  - 6) Number of visiting nurses who have experience providing pediatric home-visit nursing services
  - 7) Number of children accepted directly from NICUs in the past year
  - 8) Number of children accepted in the past year who had not been in NICUs
- b. Background of the station manager
  - (1) Age
  - (2) Acquisition of non-nursing related qualifications
  - (3) Years of experience working as a nurse
  - (4) Years of working experience as a home-visit nurse
  - (5) Years of experience as a pediatric home-visit nurse
  - (6) Years of experience in pediatric nursing
  - (7) Years of experience as a home-visit nursing administrator
  - (8) Number of cases the manager had been involved in regarding the acceptance of children admitted to the NICU in the past year

### Survey period

The questionnaires were administered and collected from February to April 2016.

### Data analysis

We compared the characteristics of the home-visit nursing stations that accepted CLTM from NICUs with those that did not. Each group was divided into three categories based on the number of nurses at each station (1-4, 4-9,  $\geq 10$ ); the independence of each category was then analyzed using the chi-square test. We also divided the "accept" and "do not accept" groups into three categories according to the managers' years of experience as pediatric administrators (< 1, 1-3, or > 3 years) because these data were not normally distributed; the independence of each category was also analyzed using the chi-square test.

Then, a logistic regression analysis was performed using those items that were supposedly associated with the acceptance of CLTM. Thus, the association between home-visit nursing service characteristics and the acceptance of CLTM transferred from NICUs was further investigated using SPSS Statistics 25 (Windows version) for statistical analysis; a *P* value of 0.05 or low was determined to be significant.

### Ethical considerations

Information on the significance, purpose, method, disadvantages, and dangers of the study and the steps taken to ensure the anonymity of all persons and institutions that participated—including storing data on an external hard drive in a secure location accessed by key and processing data without using the Internet—was provided in the questionnaire. Questionnaires were completed anonymously and returned in sealed envelopes. Participation in the study was voluntary, and the return of a completed questionnaire was deemed as willingness to participate in the study. This study was approved by the Ethics Committee of the University of Occupational and Environmental Health (No. H28-198).

## Results

Of the 2,500 home-visit nursing station managers solicited, 364 responded (14.6%); the number of valid responses was 338 (92.5% of the returned surveys). Table 1 shows the characteristics of health professionals and frequency of visits from home-visit pediatric nursing stations. The average number of staff was 9.5 (full-time staff: 5.5, part-time staff: 3.9, and full-time staff equivalent: 5.8). The average number of staff for each job category was 0.2 for public health nurses, 6.6 for registered nurses, and 0.4 for Licensed Practical Nurses. The average number of users registered with a home-visit nursing station in the previous month was 75.8, of which 2.7 were pediatric patients. The average number of monthly visits was 417.8, of which 17.9 were child-focused. In total, 46.7% of all home-visit nursing stations registered children, and the total number of children registered was 914.

Table 2 shows the characteristics of children receiving home-visit nursing services. Regarding the state of registered children, the average number of children who received

Table 1. Characteristics of health professionals and frequency of visits from home-visit pediatric nursing stations in Japan.

	Item	Range	Mean (standard deviation)
Employees (n)	Total		9.5 ± 6.1
	Full-time	0-31	5.5 ± 3.7
	Part-time	0-34	3.9 ± 4.1
	Equivalent number of full-time staff	0-27.2	5.8 ± 4.5
Employee composition per station	Public Health Nurse	0-16	0.2 ± 1.0
	Registered Nurse	1-33	6.6 ± 4.1
	Midwife	0-1	0.0 ± 0.2
	LPN	0-6	0.4 ± 0.8
	PT	0-15	1.5 ± 2.4
	OT	0-8	0.6 ± 1.1
	ST	0-3	0.1 ± 0.5
	CW	0-3	0.0 ± 0.3
	Other	0-9	0.4 ± 0.8
	<b>Number of new registrants per month</b>	Total registered users	0-367
Children		0-83	2.7 ± 7.4
<b>Total visits per month (times)</b>	Total visits	0-2429	417.8 ± 341.3
	Visits to children	0-800	17.9 ± 61.2

LPN, Licensed Practical Nurse; PT, Physical Therapist; OT, Occupational Therapist; ST, Speech Therapist; CW, Certified Care Worker.

Table 2. Features of children (n = 914) receiving home-visit nursing services.

<b>Medical care received by the child</b>	N (percentage)	Mean number per station (standard deviation)
Respirator-connected	279 (30.5)	0.8 ± 2.4
Home-based oxygen therapy	345 (37.7)	1.0 ± 2.7
Nasal tube feeding	273 (29.9)	0.8 ± 2.1
Gastronomy	328 (35.9)	1.0 ± 2.8
Tracheostomy	358 (39.2)	1.1 ± 2.8
<b>Status of registered child</b>		
Low birth weight infant	211 (23.1)	0.6 ± 2.9
Chromosomal/genetic abnormalities	245 (26.8)	0.7 ± 2.0
Malignant neoplasm	104 (11.4)	0.3 ± 2.1
Congenital metabolic disorder	66 (7.2)	0.2 ± 0.6
Hematologic (blood) disease	13 (1.4)	0.0 ± 0.3
Chronic renal (kidney) failure	40 (4.4)	0.1 ± 0.7
Chronic respiratory disease	189 (20.7)	0.6 ± 2.3
Chronic heart disease	184 (20.1)	0.5 ± 2.5
Other	327 (35.8)	1.0 ± 9.2
Cases discharged directly from NICU per station		0.4 ± 1.1
Cases discharged from departments other than NICU per station		0.6 ± 1.9
Number of staff members with experience in child home care per station		1.9 ± 2.7

Low birth weight infant implies that birth weight is lower than 2,500 grams. NICU, neonatal intensive care unit.

tracheostomy care was 1.1, which was the highest, followed by gastrostomy care (mean = 1.0) and home-based oxygen therapy (mean = 1.0). The average number of children seen directly after being discharged from NICUs was 0.4 per visiting nurse, and the number of non-NICU pediatric cases was 0.6. The average number of nursing staff with experi-

ence in pediatric home visits was 1.9.

Table 3 summarizes the backgrounds of the station managers (n = 338). Their average age was 44.6 years, and 178 (52.7%) had qualifications outside of the nursing field. The average number of years in nursing was 23.9, and the average number of years of home-visit nursing experience

was 9.6, of which pediatric home-visit nursing service experience was, on average, 0.5 years. The average number of years of experience in pediatric nursing other than home-visit nursing was 3.0 years, the average number of years of managerial experience was 6.1 years, and the average number of cases involving home transfer during the past year was 0.7.

Table 4 shows a comparison between home-visit nursing stations that accepted CLTM transferred from NICUs and those that did not. Of all home-visit nursing service stations, 56 (16.6%) accepted CLTM transferred from NICUs, while 282 (83.4%) did not. Home-visit nursing stations were categorized according to the number of staff (including midwives and public health nurses) into the following groups: 1-4, 5-9, and 10 or more. The  $\chi^2$  test indicated that the difference in the number of nursing staff between the groups was significant at  $P < 0.001$ . Of the staff managers in stations that did not provide nursing services to CLTM, 146 (51.8%)—compared to 46 (82.1%) at stations that accepted CLTM—had pediatric work experience. The managers' pediatric work experience was categorized into three categories:  $< 1$  year, 1-2 years, and  $\geq 3$  years. A cross-table of acceptance versus no acceptance

was made and a  $\chi^2$  test was conducted, indicating the differences between managers' pediatric experience as significant at  $P < 0.001$ . However, no significant correlations were found between a manager's average years of overall experience and whether or not a station accepted CLTM.

A logistic regression analysis was used with the above-mentioned items as explanatory variables and home-visit nursing services' acceptance of CLTM discharged from NICUs as the objective variable. The results were based on a 95% confidence interval, and the calculated odds ratios are shown in Table 5. Odds ratios were calculated using both home-visit nursing stations with fewer than five employees and managers with more than one year of pediatric work experience as standards. The odds ratio was 3.83 for home-visit nursing stations with five to nine nursing staff and 9.71 for those with 10 or more nursing staff, indicating a significant difference between these groups. There was no significant difference between home-visit nursing stations with managers having more than one year and those with managers having less than one year of pediatric work experience, but the odds ratio for home-visit nursing stations with managers who had more than three years of pediatric work experience was significantly different, at 4.54.

## Discussion

This study aimed to identify the determinants of home-visit nursing stations' acceptance of CLTM. An important result highlighted by the logistic regression analysis is that the greater the number of home-visit nursing staff, the greater the acceptance of CLTM transferred from NICUs. It is also noteworthy that, in 2015, nearly half (approximately 46%) of the home-visit nursing stations nationwide had fewer than five employees. In 2009, the proportion was 55% (Ministry of Health, Labour and Welfare 2017), indicating an increasing trend in the number of employees in recent years. Additionally, the number of home-visit nurs-

Table 3. Background of home-visit nursing station managers (n = 338).

Qualification	Mean (standard deviation)
Age	44.6 ± 8.1
Non-nursing qualification	178 (52.7%)
Years of experience in nursing	23.9 ± 8.9 <sup>a</sup>
Home-visit nursing experience	9.6 ± 7.8 <sup>a</sup>
Pediatric home-visit nursing experience	0.5 ± 0.5 <sup>a</sup>
Pediatric nursing experience	3.0 ± 5.3 <sup>a</sup>
Managerial experience	6.1 ± 6.0 <sup>a</sup>
Home-transition experience	0.7 ± 1.7 <sup>a</sup>

<sup>a</sup>Average number of years

Table 4. Comparison between home-visit nursing services accepting vs. not accepting children from neonatal intensive care units.

	Number	No acceptance from NICU (N = 282)		Acceptances from NICU (N = 56)		Chi-square test P-value	T-test
		n (%)	Mean (SD)	n (%)	Mean (SD)		
Number of nurses (n)						< 0.001	
	1-4	102 (36.2)		5 (8.9)			
	5-9	137 (48.6)		27 (48.2)			
	$\geq 10$	43 (15.2)		24 (42.9)			
Manager with home-visit nursing experience		146 (51.8)		46 (82.1)		< 0.001	
Manager's average years of experience in home-visit nursing			6.2 (6.0)		5.8 (5.8)		0.65
Manager's years of experience as pediatric administrator						< 0.001	
	< 1 year	145 (51.4)		10 (17.9)			
	1 year-3 years	54 (19.1)		9 (16.1)			
	$\geq 3$ years	83 (29.4)		37 (66.1)			

NICU, neonatal intensive care unit.

Table 5. Odds ratios of items related to home nursing stations' acceptance of neonatal intensive care unit patients.

Item	Odds ratio	95 % confidence interval	P-values
Number of home-visit nurses (ref: 5 or fewer)			
< 10 persons	3.83	1.38-10.60	0.01
≥ 10 persons	9.71	3.35-28.16	< 0.001
Manager's experience in pediatric home-visit nursing	1.93	0.84-4.46	0.122
Number of years of managerial experience	0.97	0.91-1.02	0.223
Number of years of manager's pediatric nursing experience (ref: < 1 year)			
1-3 years	1.71	0.62-4.72	0.297
≥ 3 years	4.54	1.95-10.54	< 0.001

ing stations is also on the rise (Ministry of Health, Labour and Welfare 2017). This is a desirable situation for promoting home-visit nursing stations' acceptance of CLTM discharged from NICUs.

Additionally, the presence of managers having three or more years of experience in pediatric nursing had a significant effect on the acceptance of CLTM. Since the presence or absence of pediatric nursing experience in stations' nursing staff and the managers' number of years of overall experience did not have significant effects on acceptance, it is likely that more experienced managers are able to impart some knowledge and skills gained from their time spent specifically in pediatric care to their employees; thus, the manager's guidance and advice facilitate their employees' acceptance of CLTM discharged from NICUs. Nonetheless, the number of facilities that claim to possess a pediatric department declined from 3,015 in 2007 to 2,592 in 2017, and their percentage among general hospitals also decreased from 38.7% in 2007 to 35.3% in 2017 (Ministry of Health, Labour and Welfare 2018). This trend is expected to continue, and nurses are expected to face increasing difficulty in gaining pediatric work experience.

Pediatrics is a broad discipline that covers emergency medical care, cancer, and intractable diseases in children. Moreover, the relatively rapid and significant changes in the growth and development of children compared with adults require careful comprehension, acquisition of knowledge and skills, and care that is suitable for the pediatric patient. While such training is considered important for the acceptance of CLTM by home-visit nursing stations, a decrease in such opportunities can adversely affect the acceptance of CLTM for home-based care. Enhanced seminars and training on pediatric medical care for home-visit nursing managers and nurses, as well as strengthened collaboration/coordination with pediatric wards, pediatric clinics, and multidisciplinary occupations can be implemented as countermeasures. For example, Gyoda (2018) launched the Pediatric Home Care Support Project in collaboration with newborn/pediatric wards, outpatient units, and medical support centers, to connect the wards to outpatients and the community. Regular meetings are held once every two months, medical treatment and care pamphlets are offered, methods for providing necessary information on long-term

care are investigated, support activities for learning are carried out, and public meetings are held where different opinions are gathered by using a home-visiting nurse's experience as an example. These various activities provide continuous interactions and exchanges within the communities and are thought to positively impact the future acceptance of CLTM by home-visit nursing stations. It is also important to collaborate with schools and welfare facilities to support children in accordance with each child's development, with home-visit nursing staff required to have knowledge about the relevant laws and institutions. However, when it comes to the care of children living in the community, the long-term care insurance system does not make provisions for the role of a coordinator, such as a care manager, which makes interactions with schools and welfare facilities difficult. Therefore, the training of coordinators of care for CLTM is also necessary and recommended. Another approach to be considered is the introduction of courses on pediatric care, including long-term care, in nursing educational institutions.

There are research limitations. Although we conducted a nationwide survey of home-visit nursing services, the response rate was low (14.6%); thus, interpretation of the results requires caution as low response rates make it difficult to generalize them. Home-visit nursing stations that do not accept children may have been less motivated to respond to the survey. Additionally, as the survey only assessed the acceptance of CLTM and did not explore the reasons behind it, further qualitative analyses using interviews with managers are necessary for the expansion of home-visit nursing stations that accept CLTM.

In conclusion, the number of CLTM is predicted to increase in the future, as is the number of children receiving long-term medical care at home. In this context, home-visit nursing services play an important role in reducing stress in parents who are the primary caregivers for CLTM, providing support and guidance, as well as enhancing the well-being of their children. Hiring administrators with experience in NICUs and pediatric care, as well as providing more education to all nurses caring for CLTM, is an important initial step toward increasing access to home-visit nursing services for CLTM, which is an urgent issue that requires effective strategies.

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## Conflict of Interest

The authors declare no conflict of interest.

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