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## REVIEW ARTICLE

# Current Status of Supporting Children and Families Needing Home Health Care; From the Viewpoint of a Coordinator

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## ABSTRACT

Despite the fact that advances in Japanese medical technology have saved lives in childbirth, the number of children requiring medical care due to some sort of disorder or disease continues to increase every year. Because children, unlike adults are still growing and developing, educational support and community support are required in addition to medical and nursing care. This study set out to analyze the role and function of coordinators by reviewing papers concerning support for children and families who need at-home medical care in Japan, so as to clarify the current situation and challenges pertaining to them. In terms of research design, the literature review made use of *Igaku Chuo Zasshi* (ICHUSHI-Web), Medical Online, and CiNii Articles. The keywords used were “medical care,” “children,” “at-home,” “coordinator,” and “community” (in Japanese). This resulted in the identification of 189 papers. Of those, 18 papers conforming to the objectives of this study were selected as targets for analysis. The following four groups were generated with regard to support for children in need of medical care: Support for parents and children as well as co-resident family members, Support for integrated healthcare networks, Educational support, and Support for challenges entailed by continuing to live at home. Focusing not only on mothers and children, but also on all co-resident family members provides a deeper understanding of at-home treatments and leads to smoother transition to at-home care. Also, cross-institutional and cross-disciplinary cooperation and collaboration with healthcare and welfare providers, communities, and government agencies is essential for continuing to provide support for children who require medical care at the society and community level. Care manager with the specialty of the child is necessary. Moreover, an educational approach can help families become aware of children’s developmental challenges and foster an awareness of roles within the family unit.

### <Key-words>

medical care, child, at home, coordinator, nursing

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## I. Study Background and Purpose

Japan has become a “super-aging society” with an increasingly declining birthrate. The proportion of heads of household aged 65 or older is projected to increase to over 30% in 2030, and to exceed 40% in 2040.<sup>1)</sup> Furthermore, the rate of population aging (the ratio of the population aged 65 or older to the total population), which is 26.6%, is projected to reach 36.8% by 2045, when it is estimated that approximately 4 in 10 people will be elderly.<sup>1)</sup>

Conversely, with regard to the declining birthrate, as of June 2020 the annual number of births in Japan was 865,234, which was 53,166 less than the previous year (2018), and the lowest number ever recorded since surveys began in 1899. The total fertility rate (TFR, calculated as the number of children a woman is expected to have over the course of her life) was 1.36.<sup>2)</sup> This has also decreased over the previous year.

The number of individuals who, although born safely, require ongoing postnatal medical care due to some sort of disorder or disease is increasing year after year. It is thought that this is because advances in medical technology have made possible the survival of children who might previously have died. However, while the number of elementary and junior high school students who, though their lives were saved, require constant medical care, was 5,901 in 2006, this number rose to 8,750 in 2014. Moreover, the number of cases requiring at-home artificial respirators rose from 812 in 2010 to 2,126 in 2013.<sup>3)</sup>

Japan’s Ministry of Health, Labor and Welfare (MHLW) defines children in need of medical care as “children with severe disabilities who, in the context of advances in medical technology, after being hospitalized in a NICU for an extended period, make continued use of devices such as artificial respirators or gastrostomies and require ongoing medical care such as the suction of sputum or tubal feeding.”<sup>3)</sup>

Thus, as a measure to address the increasing number of children in need of medical care, the Collaborative Base Project for Children’s At-Home Medical Care was launched in 2013.<sup>4)</sup> This project was aimed at expanding services at medical institutions overseeing at-home medical care for children and others, the construction of a collaborative system for medical care, welfare, and education in the community, and the establishment of a coordinator function able to provide welfare services in cooperation with medical care. Furthermore, the “Law to Partially Amend the Act on the Comprehensive Support for the Daily and Social Life of Persons with Disabilities and Child Welfare Act” came into force in June 2016.<sup>5)</sup> Under this amendment, local governmental bodies are expected to liaise and coordinate with various professions and institutions to improve the system so that children in need of medical care will be able to receive appropriate support in a variety of related fields including health, medical care, disability welfare, childcare and education in accordance with their physical and mental situation.

This study set out to analyze the role and function of coordinators from papers concerning support for children and families who need at-home medical care in Japan, so as to clarify the current situation and challenges pertaining thereto.

## II. Research Methods

### 1. Study design:

Literature survey

### 2. Criteria for document selection:

We used ICHUSHI-Web, Medical Online, and CiNii Articles, eliminating any duplicate results. In terms of the search window, we restricted the search to original papers, case studies, and review articles published before 2020 and after it was announced in 2013 that a coordinator function was to be established to carry out support tailored to individuals for child patients and families in conjunction with institutions affiliated with the MHLW's Collaborative Base Project for Children's At-Home Medical Care.<sup>4)</sup> The search terms "medical care," "children," and "at-home" (in Japanese) returned 106 hits, "coordinator," "community," and "children" 78 hits, and "medical care" and "coordinator" 5 hits. A total of 189 papers were extracted. Of these, 18 papers conforming to the objectives of this study were selected as targets for analysis.

### 3. Method of analysis:

The materials selected for analysis were classified by title, author, publication, objective, subject, method, and results in order of the year of publication. For analytical perspective, the content of research results from Japan were coded after extracting passages relating to support for children requiring medical care and their families and coordinator functions and roles. Codes were classified, named, and grouped based on similarity. The selection of target documents, creation of summaries, classification of codes, and naming were determined after investigation by the researchers.

### 4. Ethical considerations:

Data collected from the literature used in this study adheres to copyright and is clearly attributed in the reference literature and citation literature.

### III. Results

#### 1. Extraction of targets for analysis

A total of 189 articles were extracted based on the literature selection criteria. Of these, 18 papers conforming to the objectives of this study were selected as targets for analysis.

#### 2. Results of analysis

##### 1) Results from analysis of the target papers

The extracted materials were divided according to purpose, target, content relating to specific interventions, and results and future challenges (Table 1).

From these, 3 reports were found to deal with the improvement of parent-child and family relationships and continuation of appropriate at-home medical care in interventions for post-discharge mothers and children<sup>14,23)</sup> and cohabitating family members.<sup>24)</sup> There were 2 reports concerning the success of post-discharge support by demonstrating management functions in the construction of community medical systems<sup>16,19)</sup> and 4 reports concerning the enhancement of community coordinator activities and the role of coordinators.<sup>15,22,26,28)</sup> There was also 1 study of care time for children with severe disabilities requiring medical care<sup>18)</sup>, 1 paper describing a pre-discharge approach for the families of children with infant spinal muscular atrophy<sup>25)</sup>, and 2 reports on the current situation for children with severe physical and mental disabilities requiring at-home medical care.<sup>29,30)</sup> In terms of papers concerning challenges in the construction of support systems, the training of coordinators, and the need for administrative measures, 1 article described the current situation of at-home medical care for newborn infants<sup>20)</sup>, and 3 articles described the current situation with regard to community-based support.<sup>21,27,31)</sup> One paper concerned a survey of mothers of children requiring at-home care with reference to coping behavior in times of disaster.<sup>17)</sup>

&lt;Table 1&gt; Analysis of the literature

consecutive number	object	subject	method	Result & future implication
1	Family support of the nurse for the medical neglect	A mother and a 11-year-old girl with mild intellectual disability who goes to the school with special support	Nurses focused on the skin trouble which was one of the causes that deteriorated the mother and child relationship. They also supported both mother and kid, the suitable way of how the mother treats the kid and the bridging care between hospital and community during the discharge period.	Parent-child relationship had improved, and appropriate medical care was provided seamlessly after the discharge.
2	Research about a role, the function of the local coordinator for the "period for integrated study" activation	The local coordinator and school personals in 748 public schools in Niigata Prefecture	Questionnaire survey	228 responses were obtained (response rates 31.4%, valid response rate 30.5%). The improvement of activities of local coordinators has related to the activation of the "period for integrated study". Local coordinators connect public school needs and activities to communities, and vise versa. These coordination skills and the ability to manage with local teachers can lead to the activation of the "period for integrated study". In addition, the critical role of local coordinators were found; sharing the human resource information in community with neighbor schools and planning on the "period for integrated study" at the beginning of the year so securing the human resources throughout a year without shortness.
3	Characteristic of the participation of the public health center health nurses in community-based integrated care systems construction in comparison with that of other professionals	Public health nurses and other professions among 372 public health centers across Japan who are in charge of duties relating to community-based integrated care system	An anonymous questionnaire was conducted by mail. It compares the involvement of public health nurses and that of other professions into the creation of community-based integrated care system and consists of 32 items including the participants' attributes and which duties they are in charge of.	148 public nurses and 163 other professionals responded, and there are no significant differences on the age and the length of experience between two groups. The most common duty those two groups involved in was the duty relating to the middle term construction of the community-based integrated care system, followed by the beginning term among public health nurses whereas the end term among other professionals. Public health nurses engaged significantly more than the other professionals on 12 items ( $p < 0.001$ ), and specifically public health nurses showed the great significance with the item on the education for the community professionals, with the moderate significance on the management role for the community-based integrated care system, and the low significance on the collection and distribution about the related information.
4	Coping actions at the time of the disaster such as a home care child and typhoon of the family to need medical care	Seven mothers of the home care child who need medical care	An interview with the analysis of the KJ method was conducted	92 pieces of unit labels were gained, and after seven phases of group formation, six labels were generated and the relations of those six labels were mapped. Specifically, six male and two female home care children at age of 1-18 living in Okinawa Prefecture participated. Six children experienced blackout, One kid experienced evacuation to the hospital, another evacuated to the hill. As for the coping actions at the time of typhoon, the important point was placed in security and securing power supply. It was showed that they need the detailed support along the disaster cycle.
5	Medically dependent severe motor and intellectual disabilities: Time study of medical care	33 ward staff taking care of seriously ill mind and body child with a disability (SMID)	The study carried out every minute for 48 hours. It compared the data between SMID patients who need medical care on a daily basis and who do not	As for the time of caring, those for SMID depending on the medical care and general SMID were about the same, while it was 10 times longer than the latter the time of the medical care. As for the duties about the time record and the exchange of the information on care, the SMID depending on medical care needed four times more frequently than the general SMID patients.
6	Report about the discharge support of the child and mother needing respirator management by the tracheotomy and nourishment management by gastrostoma	A mother and kid who was born as asphyxia neonatorum, and need respirator with tracheostomy and nourishment management by gastrostoma	A case study which analysed the conversation between the mother and visiting nurses	A period required for discharge adjustment was six months and was shorter compared with conventional intervention. What is more, there was no re-admission due to the lack of the support and the education for the skills aquirement by mothers. The discharge support team provided mental supports through interviews to the families. Moreover, with the cooperation with visiting nurses, they organized cares needed at home, which lead to the assurance among the families. The cooperation with other professionals and building the support system resulted in successful discharge.

consecutive number	object	subject	method	Result & future implication
7	The current situation and approach of the home medical care of the newborn baby in the Kinki area	53 hospitals in Kinki area in Japan having Neonatal Intensive Care Unit	A questionnaire was conducted on February in 2015 about 1) the situation of long term admission, 2) present illness and the number of kids treated at home with outpatient department, 3) a person in charge of the expendable supplies, 4) the presence of home doctor, 5) the participants for the discharge conference, 6) the use of respite care, 7) types of respiratory machine used at home, etc.	44 hospitals responded (response rate 83%). 1) 34 patients stayed longer than one year at hospital. 2) 235 patients were using respiratory, 516 were on oxygen, 286 were with gastrostoma, 58 needed nutritional management through a central venous line and 6 required home autoperitoneal perfusion therapy. 3) outpatient nurses and Supply Processing & Distribution staff 4) Seven facilities had home doctor department. 5) Doctors, nurses, medical social workers, public health nurses and home visiting nurses 6) four hospitals responded all the patients use respite care while 29 facilities as occasional and nine hospitals answered infrequently. 7) 32 facilities (57%) responded as using Philips respiratory In short, there is a necessity of improved system construction surrounding the home care for the neonatal infants considering the current insufficient situation.
8	The role of public health nurses and the linkage between maternal and child health and preschool education: the examination about the project and its promotion implemented during the year 2010-2012	Public health nurses for the child with a developmental disability	The middle term revision of a project called "network building for the developmental disability" in town B was conducted. Reviewing the first phase of the project during the year of 2010 and 2012, it was examined the role of public health nurses and the linkage between maternal and child health and preschool education.	As for the new projects, namely, visiting consultation, an overall consultation for development, consultation at the year four and individual support planning, it is found crucial to build the relationship between childcare workers/clinical psychologist and parents. Moreover, it was showed that public health nurses played important role to help constructing relationship indirectly. Tasks for the future are standardising the screening test at one and half years old, three years old and four year old, improving skills of childcare workers and public health nurses and strengthening cooperation among the concerned departments for the continuation of the project.
9	The actual situation of the early support at special support schools: the coordination of early support among related organizations; From the analysis of the inventory survey results to special support schools across Japan	Special support schools across Japan	Questionnaire about the placement of the special support education coordinator, the supported area's actual situation, the cooperation between public health and social welfare	The school area where more than 500,000 people who need special support had few consultation by the visit to a school and patrol consultation by a nursery school and a kindergarten. While the special school which has no special support education coordinator had further fewer ratio of consultation by the visit to a school and patrol consultation by a nursery school and a kindergarten during a year in comparison with the school with at least one special support education coordinator.
10	Support to mother of the child who became the peritoneum dialysis introduction by the postponement of the renal transplantation	A mother of the child whose renal transplantation became the postponement, and chose peritoneum dialysis introduction	Nurses performed support to decision making for the peritoneum dialysis introduction and provided preparation support toward the home care while confirming the psychology situation of mother. Setting a goal with mother, nurses helped them to image life at home affirmatively along with confirming their reactions.	Grasping mothers' psychological situation appropriately and enhancing self-efficacy allows them to assume the positive results. It also enables them to make decisions and raises their motivation. It is found effective to build the cooperative relationship and to work out for the shared goal with mothers as the preparations for the transition to the home care.
11	The at-home shift support for families who have a child treated at NICU and requires medical care	A child with laryngomalacia, congenital hypothyroidism, epilepsy & chronic lung condition, etc Family construction: Parents (office worker & housewife), two female siblings at 3 & 5, grandparents and uncle	A questionnaire about evaluations for the hospitalized nursing practice to the mother one year after the discharge and a semiconstructed-interview based on the answer above questionnaire performed. Nurses performed the at-home shift support that aimed at the whole family who lived together as well as parents soon after the birth of the child and promoted to become attached to the child.	It led the smooth at-home shift for nurses to have approached at the whole family who lived together as well as parents for the care.

consecutive number	object	subject	method	Result & future implication
12	Support for the discharge adjustment of the child needing medical care in the home care: One consideration of the process until a discharge and the approach to a family	A 1-year-old girl who rehospitalized for preparations of home care and the family: A baby who had diagnosed as spinal cord-related amyotrophy and underwent tracheotomy in other facilities before the hospitalization	The parents almost acquired the necessary medical care after four months during the hospitalization. After two times of in-hospital staying out with medical facilities and at home, they discharged after six months	As for the support before the discharge including when to discharge, nurses' initiated supports were effective. The adjustment of the schedule on the basis of the life rhythm of the family and the instruction of the care method suited at home during hospitalization were also effective. In addition, it is found crucial to confirm the necessity care with families before the discharge.
13	The current situation and problem of discharge support for children at NICU	The 167 cases that perinatal support coordinators consulted from May, 2012 to April, 2013 were analyzed	By the introduction of the perinatal support coordinator, the cooperation between NICU, obstetrics and pediatrics were gained and they introduced the screening to all hospitalization child at the time of hospitalization	By the introduction of the coordinator, the cooperation between other professionals and the regional alliances were forged. In addition, the screening to all hospitalization children at the time of hospitalization enabled to properly select the patients in need and to clarify their necessary supports, which in turn, lead to the early intervention.
14	Problem for a medical practitioner to support children needing home medical care: Findings from a questionnaire in Tokyo	Pediatricians in Tokyo	Questionnaire about the home medical care	For the conduct of at-home medical treatment, it needs to be more organized 1) the cooperation with related hospitals and nighttime medical service 2) the construction of the backup system for doctors including substitute personnels 3) the maintenance of training system for nurses 4) the maintenance of medical care materials' supply
15	The way of pediatrics nursing at outpatient department	40 members of the families of children who need home medical care and travel to a outpatient department	Questionnaire based on "a family life ability assessment scale"	About 50% of the respondents answered that they assess children's health status "frequently" or "often", and about 90% of the respondents replied that they are dealing with children's change in their status "well" and "fairly". Approximately 20% of respondents did not have the confidence about home medical care knowledge, and about 30% responded that they did not have confidence regarding home medical care skills. Only about 30% of families answered they use local social resources. Overall, as for the outpatient nursing care in the future, it would be important that nurses properly assess the need for supports along with the children's developmental stage and their families' situation, and that nurses play a role of coordinator to consult children and their family to the appropriate support decision.
16	The current situation of the children with severe motor and intellectual disabilities (SMID) at-home medical treatment	29 serious case of SMID children during at-home medical treatment who hospitalized shortly to a ward for pupils with disability called Himawari during July, 2011 to June, 2012	Questionnaire about the age, sex, disease severity, mean hospitalization, the underlying disease in conjunction with SMID, main medical care of the childrens with SMID	The average age was 10.1 years with 15 boys and 14 girls. Eleven (38%) were at severe status, 13 (45%) were quasi-supercritical and the average length of stay was 4.2 days. the underlying disease in conjunction with SMID were fetal brain injury in 12 cases (41%), perinatal/neonatal brain injury in 13 cases (45%), and acquired brain injury in 4 cases (14%). The main medical cares were tracheotomy management in 18 cases (62%), artificial ventilation support in 11 cases (38%), gastrostomy nutrition in 23 cases (79%), and tube feeding in 5 cases (17%).
17	Coping strategies and difficulty of a child and the family at home medical care	A family who has a 4-year-old girl needing home medical care (at-home oxygen therapy & intratracheal suction)	An interview about the use of daily goods for care, the way of supplies and management of necessity equipments, the purchase of the medical tools, difficulty by the house space and its coping strategies and the limitation among family members by giving care during the period from July to August of 2011.	Various difficulties and coping strategies were talked and it was found that all the care provision and judgement were incharged by the family. Medical staff should provide the necessity information for families with kids at home medical care in order to secure their safety and quality of life. Moreover, they should also suggest the safe environment suited at each home by observing childrens' action in a bathroom, living room, bedroom, etc.



consecutive number	object	subject	method	Result & future implication
18	The current situation and problem of the local support of the child needing medical care	The subjects of the study were three nurses, three health nurse, four nursery staff, five teacher, one physical therapist, one occupational therapist, one speech clinician (in total 23) who are working in public health centers, nursing facilities & special support schools	The semi-structured interview was conducted for around 30 minutes for each person about how to deal with the increase of the child with medical care and the various needs from diversified families	About the increase of the child with medical care and the various needs from diversified families, it was observed that there is the gap between high family expectation and the role of each professionals and that the staff provide insufficient information about pediatrics and they lack the technical knowledge in the associated facilities. As for the problem of the caring at home support systems in the area, it was inferred more needed the provision of technical information and smooth communication between local facilities and hospitals, upbringing of the coordinator who support continuation of the caring at hospital and home and building networking of the whole area including municipals.

## 2) Support for children in need of medical care

A total of 16 Middle groups making up four large groups were generated as a result of categorizing 62 codes extracted from the target materials (Table 2). The following four groups were generated with regard to support for children in need of medical care: Support for parents and children as well as co-resident family members, Support for integrated healthcare networks, Educational support, and Support for challenges entailed by continuing to live at home, and codes in parentheses. Difficult-to-understand passages are supplemented by words in *italic text*.

Support for parents and children as well as co-resident family members; Support involving (1. approaches that targeted both mothers and children) and (8. the construction of relationships enabling cooperation with affected mothers) (7. led to acceptance and decision-making *by appropriately grasping the mother's psychological situation and increasing her self-efficacy*). In addition, the fact that (9. working *with affected mothers* towards a common goal was effective in supporting preparations for providing at-home care) and (11. led to a smooth transition to being at home by positioning not only parents but all co-resident family members as the focus of care).

Support for integrated healthcare networks; The fact that (15. adjusting schedules based on families' life rhythms from the time of hospitalization was effective) and that (20. the coordination of practical post-discharge care was carried out in cooperation with visiting nurses) (29. demonstrated a management function in the context of building a regional medical care system). Conversely, (26. a discrepancy existed between the roles of individual professionals and excessive expectations on the part of the family at the various institutions with respect to the increasing number of children in need of medical care and the diversification of families' needs). (28. Environmental accommodations surrounding at-home medical care for newborns inside and outside the hospital were insufficient) and (33. there was a demand for detailed support keyed to the disaster cycle).

Educational support; In other words, (35. The community coordinators connected communities with school needs and initiatives) and (40. the role of community coordinators is to collaborate with teachers and share information about local human resources not only with their own schools but also other schools). Moreover, securing local professional personnel entailed (45. *the necessity of training coordinators to support the continuation of at-home care*).

Support for challenges entailed by continuing to live at home; Even though (22. building a medical care back-up system that includes relief personnel is a challenge *for implementing at-home medical care*) and (50. it is important to identify necessary supports in accordance with the stage of a child's growth and development and family situation), it became clear that (55. there was a lack of information provision and specialist knowledge on pediatric medical care) and that (57. In this situation the determination and implementation of medical care was being left entirely to family members). Furthermore, (58. It is necessary to strengthen systems for collaboration among institutions with regard to the continuation of projects) which entailed (61. *The necessity of creating networks for the entire community, including local government agencies*).

&lt;Table2&gt; support of children needing medical care

NO.	cord
1	Approaches that targeted both mothers and children
2	Approach of suitable how to contact mothers for the child
3	Grasping mothers' psychological situation appropriately
4	Enhancing self-efficacy of mother
5	"Grasping mothers' psychological situation appropriately and enhancing self-efficacy of mother" allows them to assume the positive results
6	"Grasping mothers' psychological situation appropriately and enhancing self-efficacy of mother" It also enables them to make decisions
7	led to acceptance and decision-making by appropriately grasping the mother's psychological situation and increasing her self-efficacy
8	The construction of relationships enabling cooperation with affected mothers
9	Working with affected mothers towards a common goal was effective in supporting preparations for providing at-home care
10	"The bridging care between hospital and community during the discharge period." Parent-child relationship had improved
11	led to a smooth transition to being at home by positioning not only parents but all co-resident family members as the focus of care
12	"The bridging care between hospital and community during the discharge period." appropriate medical care was provided seamlessly after the discharge.
13	Almost organizations in the related were hospitals
14	As for the support before the discharge, the instruction by the nurses in hospital was effective
15	Adjusting schedules based on families' life rhythms from the time of hospitalization was effective
16	The teaching of the care method at home was effective from all over the hospitalization
17	It was important that I performed confirmation of the care that a medical person needed with a family before the discharge
18	By the introduction of the coordinator, the cooperation of Interprofessional Work into NICU, obstetrics and the pediatrics became closer.
19	A discharge support team supported carefully the children's family that concern and a change in discharge by a consultation.
20	The coordination of practical post-discharge care was carried out in cooperation with visiting nurses
21	"The coordination of practical post-discharge care was carried out in cooperation with visiting nurses" It was connected in security and satisfaction to home care
22	Building a medical care back-up system that includes relief personnel is a challenge for implementing at-home medical care
23	SMD which depended on the medical care and SMID which I depended on medical care for in time for medical care of general SMD were longer 10 times than general SMID
24	As for the duties about the time record and the exchange of the information on care, The SMID depending on medical care needed quadruple of more frequently than the general SMID patients.
25	The main medical care in conjunction with the severe psychosomatic disorder was tracheotomy management 18 cases (62%), artificial respiration assistance 11 cases (38%), Nourishment from gastrostoma 23 (79%), tubal feeding five (17%)
26	A discrepancy existed between the roles of individual professionals and excessive expectations on the part of the family at the various institutions with respect to the increasing number of children in need of medical care and the diversification of families' needs
27	A high-risk seriously ill child was managed at home a lot became clear, the current situation
28	Environmental accommodations surrounding at-home medical care for newborns inside and outside the hospital were insufficient
29	Demonstrated a management function in the context of building a regional medical care system
30	Collecting information and showed a dispatch function
31	Skill up (I need reinforcement) of a childminder, the Public Health nurse
32	As for the coping action at the time of the disaster, an important point was placed in security and the securing of power supply
33	There was a demand for detailed support keyed to the disaster cycle
34	"By the introduction of the coordinator" The regional alliances came to be carried out positively, too
35	The community coordinators connected communities with school needs and initiatives
36	"An area coordinator" I show coordinates function to connect local seeds with a school
37	"An area coordinator" I showed a function to manage with a teacher and participated in activation of the time
38	I put up time a year in a beginning of the fiscal year
39	It is important that the construction of the relationships such as a childminder and a protector, a protector and the psychology person
40	The role of community coordinators is to collaborate with teachers and share information about local human resources not only with their own schools but also other schools
41	"An area coordinator" It is the main point that finds local human resources premeditatedly
42	Showing education of the function of the community specialist jobs
43	The lower the special education support school where 0 people than that where one or more people of full time teachers for community supports the ratio that the consultation at school
44	There was little annual number of times of the consultation by the patrol to a nursery school, a kindergarten, too
45	the necessity of training coordinators to support the continuation of at-home care
46	The maintenance of a cooperation hospital, the hospital accepting a patient by night is a problem
47	For enforcement building a medical care back-up system that includes relief personnel is a challenge for implementing at-home medical care
48	For enforcement, Education for nurses
49	For enforcement, he maintenance of the supply system of medical materials at home, and giving medical care
50	It is important to identify necessary supports in accordance with the stage of a child's growth and development and family situation
51	The medical practitioner knows the invention of the technique that fitted a lifestyle and a child
52	It is necessary for the medical practitioner to give information so that a family needing home medical care can live a high quality life by security
53	Observation of the action of the child in a bathroom, living, the bedroom
54	It is a role demanded from a medical practitioner to tell the need to fix the safe environment of the child to a family
55	There was a lack of information provision and specialist knowledge on pediatric medical care
56	Enforcement and the judgment of the medical care are entrusted all to a family
57	In this situation the determination and implementation of medical care was being left entirely to family members
58	It is necessary to strengthen systems for collaboration among institutions with regard to the continuation of projects
59	The need of the provision of information each other, expert knowledge from the medical
60	The important to carry coordinates position such as leading it to the appropriate window for an affected child, a family to be able to receive necessary support
61	The necessity of creating networks for the entire community, including local government agencies
62	The need of the measures of states

## IV. Discussion

### 1. Support for parents and children as well as co-resident family members

With regard to support for children in need of medical care, by positioning not only mothers and children but all co-resident family members as the focus of care, we can deepen the understanding of at-home medical treatment, which will lay preparations for at-home medical treatment and facilitate a smooth transition to at-home care. Miyata<sup>6)</sup> points out that at-home medical care for children, in comparison with the adult case, necessitates an understanding of the diversity of illness and changes that arise with growth. This demonstrates that parents require support characterized not only by an understanding of their children's disease and disability, but which also takes into account their children's growth and development. In particular, in support for families with siblings, there is a need to understand that the parents' gaze may tend to dwell on the child in need of medical care, and thus to clarify roles in the family in order to help siblings live their lives free of anxiety or confusion. It is thus necessary to help mothers find time to be involved with siblings, as well. Moreover, in order to lighten the burden of nursing care, it is necessary to provide support that makes it possible to consider the use of social resources when necessary, such as respite care and care that involves night-time suction of sputum and postural management.

Also, it is important to continue providing support so that mothers and co-resident family members will be able to achieve emotional and psychological stability in the context of daily care. When family members experience emotional or psychological instability, this is likely to be transmitted to the child and elicit a reaction. Yoshimi et al.<sup>7)</sup> reported that it was possible to help children and families by holding discussion until both parties were satisfied, facilitating "self-determination", and setting nursing life goals for both the child and family members. Hosoi<sup>8)</sup> suggests the need for an all-encompassing or holistic form of pediatric medical care that takes an overall view of the child, one that takes a bird's eye or comprehensive perspective that includes environmental and social factors. It is necessary to stay in close contact with families and undertake cross-institutional and cross-disciplinary collaboration with healthcare, welfare providers, educators, and the like in order to provide support that enables self-determination while ascertaining the needs of children, their mothers, and other co-resident family members. Beyond the medical care aspect, there is a need for a nursing care lifestyle that has a view of the child's growth and development as well as interactions with non-family members and participation in the local setting that are tailored to the child's age. Moreover, we believe that there will be an increasing demand for a coordinating role that will engage in such cross-institutional and cross-disciplinary collaboration will be increasingly required.

## 2. Support for integrated healthcare networks

Engaging in cross-disciplinary collaboration to coordinate post-discharge care will facilitate a sense of security and satisfaction for at-home medical treatment. Nakamura<sup>9)</sup> notes the importance of governmental cooperation in building systems for providing children with at-home medical care. He suggests the necessity of establishing a strong coordinator function to develop and link medical care with welfare services, and also suggests that building infrastructure for providing children with at-home medical care is a project that should be sustained in the future. Also, Shimabukuro<sup>10)</sup> suggests that this is not only medical care, but at heart an engagement with lifestyle infrastructure, and that what is necessary are social and community initiatives that involve not only mental and psychological perspectives, but encompass education, leisure, and government, as well.

In order to accommodate and support children in need of ongoing medical care in society and the community, cross-institutional and cross-disciplinary collaboration and cooperation between healthcare, welfare, communities, and governments will be essential. The current situation is dire, with insufficient resources for everything to be handled solely by medical and welfare personnel. We believe that the provision of support by capturing the professionalism not of care managers who provide support to the elderly, but people like educators, nursery teachers, and regional medical professionals in a multifaceted way from the perspective of children (i.e., the growth and development of their physical and mental health) and their parents would arguably facilitate more comprehensive support. Further, we believe that it will be necessary to establish venues for the regular sharing of information through cross-institutional and cross-disciplinary collaboration so that policies will not be biased toward either children or parents.

In the future, we believe higher expectations will be placed on coordinators who play a coordinating role and function specialized for children who require medical care.

## 3. Educational support

Children in need of medical care require educational support from the perspective of still being in the process of growing and developing. Hoshino<sup>11)</sup> noting the increasing transition to at-home care for children in need of medical care, points out that a societal response is therefore required, and that the training of coordinators in relation to children in need of medical care is desirable. In the context of at-home support after discharge from hospital, there is a perceived need for coordinators who will be able to provide a reassuring point of contact and consultation, which includes being a point of contact for local consultation as well as arranging admittance into medical care in the case of emergency. In addition, we believe there will be a demand for roles and functions that connect community seeds with schools and manage them together with teachers, and which create links with community professionals to coordinate medical care and educational support. It may also be necessary for potential medical staff (including alumni and those still able

to work) and educators in the community to proactively push forward with measures to connect childcare, medical care, and welfare services.

This manner of educational approach will help to foster families with an awareness of the developmental challenges their children face, as well as to cultivate a sense of roles within the family unit. We also believe that it can be expected that families will discover effective and economical methods from their own experience of daily care.

#### **4. Support for challenges entailed by continuing to live at home**

The development of an integrated system of cooperating and admitting hospitals, as well as medical staff and medical materials has been pointed to as the current state of at-home medical care. Miyata<sup>12)</sup> notes that with the diversity of disease, the extent and burden of medical care is significant, which results in a high degree of nursing. In addition, because institutional and community systems are as yet poorly developed, there is a dearth of both support and cooperation, and the reality of the situation is that at-home medical care and services are not keeping up with demand. In particular, she points out the relatively small number of medical institutions and home-visit nursing stations responsible for overseeing at-home medical care for children, and the fact that the training and participation of personnel remain a challenge. Also, Maeda<sup>13)</sup> has pointed out that despite the fact that the welfare coordinators who provide lifestyle support for children receiving at-home medical care are counseling professionals, unlike care managers in the long-term care insurance system, they face systemic difficulties making connections with medical care.

Based on the above, it seems that support for children in need of medical care has a need for comprehensive support measures on the part of medical care, welfare services, education, and society that involve not only medical care but also education as well as local government. Moreover, it will be necessary to train coordinators to provide support for children in need of medical care. Currently, medical coordinators are people like physicians, nurses, and care support specialists who obtain their own certifications from non-profits and other professional bodies to become medical coordinators, but there is no national certification. Another challenge is that the quality of individual coordinators is only evaluated by the qualifications for coordinating comprehensive support measures on the part of medical care, welfare services, education, and society.

Finally, because the determination and elimination of medical care are currently left to families, medical practitioners feel that mothers require parental education with regard to the observation, treatment, and response to their children's symptoms. Regardless of the degree of competence of professional cooperation, parents will always be involved with their children on a passive footing. We argue the need for a perspective on training parents that is oriented to fostering knowledge and independence to the extent that they will be able to deal with their children's symptoms even in the absence of medical personnel.

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