

Care Procedures Performed by Nurses during Long Home Visits as Respite Care Services

A Time Study of a Child with Medically-dependent Severe Motor and Intellectual Disabilities Requiring Home Mechanical Ventilation –

Machiyo IKUTA

Department of Nursing, Faculty of Health Sciences, JUNSHIN GAKUEN University

Abstract:

Aim: The purpose of this study was to clarify the care procedures performed by visiting nurses for a medically-dependent severe motor and intellectual disabilities child using home mechanical ventilation in regular long home-visit nursing and the duration of each procedure.

Methods: A time study was conducted by a visiting nurse for the families of a child undergoing home mechanical ventilation therapy, and the contents and durations were aggregated and analyzed.

Results: Among all care procedures, [observation/monitoring] accounted for the largest part both at night and during the day (46.8 and 16.4%, respectively). The mean durations of [care to promote expectoration], such as tracheal suctioning, drug inhalation, and pulmonary physical therapy (night 11.4%; daytime 24.1%) and [mechanical ventilator management] (6.6 and 7.8%, respectively) were the second longest. [Playing with the child] also accounted for a large part (night 5.7%; daytime 16.9%).

Conclusion: As nurses care for pediatric patients longer during long home-visit nursing than during standard services, it may be necessary for them to deepen their knowledge of child development and play, in order to enhance risk management and provide daily life support, including developmental support, in addition to improving the quality of medical care.

Key words: Child with Medically-dependent Severe Motor and Intellectual Disabilities, Home Mechanical Ventilation, visiting nurse, Respite Care Services, Time Study

1. Introduction

The advancement of pediatrics and medical technologies has increased the number of children saved, leading to a decrease in child mortality. However, this is also raising the number of children saved but left with various disabilities. In particular, the number of pediatric patients requiring continuous advanced medical care and using home mechanical ventilation (HMV) systems reached 4,178 in 2018, revealing a nearly 10-fold increase in 10 years¹⁾.

Care for children with HMV increases physical, mental, and financial burdens, and it has a marked impact on families²⁻³⁾. Respite care for caregivers is necessary to reduce these burdens and the negative impact of care, and there have been many reports supporting its usefulness⁴⁻⁶⁾. Respite care provides

short-term child care services for the parents/families of children (adults) with disabilities, with a view to offering temporary relief from fatigue due to care for children (adults) with disabilities and opportunities for rest. Respite care services (RCS) are provided by daycare and short-stay service facilities or by substitute home caregivers. In the case of pediatric patients, a shortage of facilities providing RCS and some families hesitating to use RCS systems have been reported⁷⁾.

In home-visit nursing, the number of home visits per week is generally limited to 3, but it is allowed to make 4 or more visits and up to 3 long visits (exceeding 90 minutes per visit) a week for children with medically-dependent severe motor and intellectual disabilities (MD-SMID) and sub-MD-

92 Machiyo IKUTA

SMID, who require higher-level nursing care. A previous study examined the actual length of stay per visit in FY2009, and reported a mean of 1.4 hours each day⁸⁾. Nowadays, as some home-visit nursing facilities collaborate with home-visit care service providers, and/or also provide optional home-visit services, visiting nurses increasingly make long visits and spend many hours caring for patients in their homes.

This suggests that care procedures performed by visiting nurses for children with HMV during long home visits and their durations are different from those during standard home visits. Previous studies noted that mothers are concerned about care procedures and the quality of care when they use RCS⁹⁻¹¹⁾. Another report revealed that visiting nurses are anxious about visiting children with disabilities¹²⁾. Considering such a situation, it is important to clarify differences in the care procedures performed by visiting nurses for these children during long and standard home visits.

Previous surveys on care procedures for MD-SMID children and their durations examined the services provided by facilities for SMID children (adults) ¹³⁻¹⁵⁾, analyzed the characteristics of home-visit nursing facility users based on the direct/indirect service time ratio ¹⁶⁾, and calculated the time families spend caring for school-age children with HMV¹⁷⁾. However, none examined the care procedures performed by visiting nurses for these children during home visits as part of RCS or their durations.

Therefore, the present study analyzed these items using data from the author's previous study in 2008, where visiting nurses had regularly made long home visits to provide RCS for the family of an MD-SMID child, and the effects on his mother and other family members were evaluated.

2. Purpose of the Study

To clarify the care procedures performed by visiting nurses for an MD-SMID child with HMV in regular long home-visit nursing and the duration of each procedure as a basis for developing future perspectives on this form of nursing.

3. Outline of RCS provided by visiting nurses during long home visits

Nurses of a home-visit nursing facility regularly made long home visits to provide RCS for the mother of an MD-SMID child. The visiting schedule was determined in consideration of the family's wishes and the facility's business schedule. In the night-time, 1 RCS session was provided every week, and each session lasted for 12 hours from 19:00 to 7:00 the next morning. In the daytime, 1 RCS session was provided every 2 weeks, and each session lasted for 8 hours from 9:00 to 17:00. As part of RCS, the visiting nurses provided care for the child, covering medical care and all daily life support. During each visit, the mother acted freely; she was told that she might either care for the child with the nurse or go out. In the night-time, the nurses were allowed to take a nap at the child's bedside.

4. Methods

4.1 Research Design

A case study adopting a time study design.

4.2 Participants

The subjects were nurses of a facility who provided regular long home-visit nursing services and the family of an MD-SMID child who used RCS.

4.2.1 Situations of the child and his family

The child was a male in late infancy with a congenital metabolic disorder. His scores from the scoring inventory of Suzuki et al. to assess SMID children as a medical care-dependent group (MCDG) and sub-SMID-MCDG¹⁸⁾ were as follows: mechanical ventilator management (with spontaneous breathing; 24-hour ventilator connection): 10, tracheotomy: 8, oxygenation: 5; frequent suctioning (more than once per hour): 8; and fully assisted oral feeding: 3. Thus, his total score was 34, diagnosing him with MD-SMID. As for motor development, he was able to sit, but unable to walk. He was also able to move around by rolling over, and this expanded his range of activity. On the other hand, he often removed his tracheostomy

tube by himself. He had intellectual disabilities, and his speech was limited to some one-word sentences.

The child's family consisted of 5 members: the child, mother in her forties acting as the main caregiver, father, and paternal grandparents. The mother had to care for the child alone, as she could not rely on other family members, even though it was too dangerous to leave the child unattended.

4.2.2 Visiting nurses

Three visiting nurses provided RCS. They had begun to make standard home visits (30-90 minutes/visit) 5 days weekly as part of health-insurance-covered home-visit nursing services 2 years before the initiation of this study. The length of the home-visit nursing experience was 8 years in Nurse A in her forties, 4 years in Nurse B in her thirties, and 4.5 years in Nurse C in her forties.

4.2.3 Survey periods

Among all the RCS sessions provided, we examined 8 night-time and 8 daytime sessions. The survey period was from February to April 2008 in the former and from October 2008 to February 2009 in the latter.

4.2.4 Survey methods

To examine care procedures, the nursing service classification codes developed by Yamamoto et al.¹⁹⁾ were used after selecting and modifying those deemed necessary for pediatric patients with HMV. The care procedures were classified into the following categories, covering medical and daily life care: [personal hygiene], [excretion], [nutrition], [positioning], [drug administration], [care to promote expectoration (suctioning, drug inhalation, and pulmonary physical therapy)], [mechanical ventilator management (such as the management of mechanical ventilators or oxygen inhalators)], [skin care], [observation/monitoring], [support for the mother and other family members], [play with the child], and [rest/nap times for nurses]. [Rest/nap times for nurses] is not a care procedure, but it was added to clarify the situation during each visit.

Furthermore, the child's condition and the time the mother spent outside were also recorded in consideration of their possible influences on the durations of care procedures.

Along with a time study recording form to enter data every 5 minutes, the nurse in charge visited the child's home, performed care procedures, and recorded them. These data were entered in a self-administered style between care sessions.

4.2.5 Analysis Methods

We classified the care procedures recorded on the forms every 5 minutes based on the type of nursing service. When multiple care procedures were listed in the same time frame on the recording form, those performed as direct acts to maintain the child's life or improve his worsened condition were selected. For example, when phlegm suctioning was performed while conversing with the mother to collect information from her, we classified this into [suctioning] as a direct act to improve the child's worsened condition.

The child's condition and the time the mother spent outside possibly influencing the durations of the care procedures were extracted from the recording forms and classified based on the details to total the values.

4.2.6 Ethical considerations

The participants were given oral and written explanations regarding the purpose of the study, and that they were free to not participate, or to discontinue without any disadvantages, and that the names of individuals and facilities would not be identified when the study was presented. All participants signed an informed consent statement prior to participation in the study.

This study was conducted with approval from the Institutional Ethics Committee of Kumamoto University (Approval number: Rin 197 and 268).

5. Results

5.1 The child's condition and the time the mother spent outside

Table 1 shows the child's condition and the time the mother spent outside in the night-time, and Table 2 shows those in the daytime.

The child had wheezing at both times, in addition to occasional nystagmus. During the 7th daytime session, a one-dose anticonvulsant medication was administered to address persistent nystagmus. There was no marked deterioration in the child's condition on the other survey days.

The child's night-time sleep time ranged from 6 hours and 5 minutes to 9 hours and 20 minutes, with a mean of 7 hours and 27 minutes. In the daytime, he slept 45 minutes during the 4th session and 70 minutes during the 6th session.

In the night-time, the mother did not leave the house during the 5th session, and the longest and mean time she spent outside were 4 hours and 30 minutes and 2 hours and 48 minutes, respectively. In the daytime, the

Table. 1 The child's condition and the time that the mother spent outside in night-time

Condition	1st time	2nd time	3rd time	4th time	5th time	6th time	7th time	8th time	average
Body temperature (°C)	36.0-36.9	36.6	36.1-36.5	36.5	37.0-36.7	37.7	35.5-35.7	36.6-36.8	
SPO ₂ (%)	88-99	77-98	94-98	93-98	88-98	94-100	99-100	98-100	
Oxygen dosage (L/min.)	1.0-1.5	1.0-3.0	1.0-1.75	1.0-3.0	1.0-2.0	1.0-1.5	1.0	1.0	
Wheezing	+	+	+	+	2+	+	+	+	
Vomiting	-	+		-		-			
Excretion	-	+	+	-		+			
Convulsions	Occasional nystagmus	Occasional nystagmus	Occasional nystagmus	-	-	-	-		
Time of sleeping	23:15-5:40	21:15-3:30	21:30-5:00	21:40-7:00	21:00-2:00 3:00-6:25	21:30-2:00 2:20-5:00	22:00-5:00	21:50-1:10 2:15-5:00	
Total sleep time	6 h.25 m	6h.15m.	7h.30m.	9h.20m.	8h.25m.	7h.10m.	7h.	6h.05m.	7h.27m.
Time mother spent outside	20:00-0:30	19:15-23:00	21:00-22:30	19:20-23:00	-	19:10-22:30	19:30-23:00	20:20-22:30	
Total time spent out	4h30m	3h45m	1h30m	3h40m		3h20m	3h30m	2h10m	2h48m

Table. 2 The child's condition and the time that the mother spent outside in daytime

Condition	1st time	2nd time	3rd time	4th time	5th time	6th time	7th time	8th time	average
Body temperature (°C)	36.3-36.9	36.5	36.4	36.1	36.2-37.2	35.7-36.7	36.1	35.9-36.5	_
SPO ₂ (%)	98-99	94-97	95-100	92-98	95-97	96-100	94-98	96-98	
Oxygen dosage (L/min.)	-	-	-	-	-	-	-	-	
Wheezing	+	+	+	+	+	+	2+	+	
Vomiting	-	-	-	-	-	-	-	-	
Excretion	+	taking laxatives	loose stool	-	-	-	-	+	
Convulsions	-	Occasional nystagmus	-	-	-	Occasional nystagmus	Persistent nystagmus, taking anticonvulsant drugs	-	
Time of sleeping				14:15-15:00		13:20-14:30			
Total sleep time				45m		1h10m			
Time mother spent outside	10:40-16:00	10:00-16:30	10:20-16:00	12:30-15:50	13:15-15:25	10:00-13:40	9:15-13:00	10:40-11:30	
						14:30-16:00	14:00-16:00	12:25-16:30	
Total time spent out	5h20m	6h30m	5h40m	3h20m	2h10m	5h10m	5h45m	4h55m	4h51m

time she spent outside ranged from 2 hours and 10 minutes to 6 hours and 30 minutes, with a mean of 4 hours and 51 minutes. When she was out, she visited her parents, had a meal with her friends, went shopping, or visited a public office for formalities.

5.2 Care procedures performed for the child and the duration of each procedure

Tables 3 and 4 show the care procedures performed

for the child and the mean duration of each procedure in the night-time and daytime.

The time for [observation/monitoring], including staying close to the child without providing any particular care, was the longest: 337.5 ± 107.3 minutes (46.8%), followed by: [care to promote expectoration], including tracheal suctioning, drug inhalation, and pulmonary physical therapy: $81.9 \pm$

Table 3 Care time for the child during night -time respite serviceCare

Care content	1st time	2nd time	3rd time	4th time	5th time	6th time	7th time	8th time	average	SD
Personal hygiene	25(3.5)	10(1.4)	25(3.5)	5(0.7)	30(4.2)	15(2.1)	15(2.1)	15(2.1)	17.5 (2.4)	8.5
Excretion	15(2.1)	20(2.8)	25(3.5)	25(3.5)	30(4.2)	20(2.8)	20(2.8)	20(2.8)	21.9 (3.1)	4.6
Nutrition	40 (5.6)	15(2.1)	60(8.3)	15(2.1)	50(6.9)	0(0)	15(2.1)	60(8.3)	31.9 (4.4)	23.4
Positioning	25(3.5)	25(3.5)	35(4.9)	30(4.2)	45 (6.3)	25(3.5)	50(6.9)	60(8.3)	36.9 (5.1)	13.3
Drug administration	10(1.4)	5(0.7)	10(1.4)	5(0.7)	10(1.4)	10(1.4)	15(2.1)	20(2.8)	10.6 (1.5)	5.0
Care to promote expectoration	105(14.6)	50(6.9)	95(13.1)	55 (7.6)	75(10.4)	60(8.3)	105(14.6)	110(15.3)	81.9 (11.4)	24.8
Mechanical ventilator management	30(4.2)	75(10.4)	35(4.9)	90(12.4)	35(4.9)	55 (7.6)	35(4.9)	25(3.5)	47.5 (6.6)	23.6
Skin care	0(0)	15(2.1)	0(0)	5(0.7)	10(1.4)	10(1.4)	0(0)	0(0)	5.0 (0.7)	6.0
Observation/monitoring	205(28.4)	400(55.5)	385 (53.4)	420(58.3)	395 (54.7)	465 (64.6)	230(31.9)	200(27.7)	337.4 (46.8)	107.3
Support for the mother and other family members	60(8.3)	60(8.3)	25(3.5)	20(2.8)	5(0.7)	10(1.4)	50(6.9)	45(6.3)	34.4 (4.8)	22.1
Play with the child	65(9.0)	45(6.3)	25(3.5)	25(3.5)	35(4.9)	50(6.9)	60(8.3)	20(2.8)	40.6 (5.7)	17.0
Rest/nap times for nurses	140(19.4)	0(0)	0(0)	25(3.5)	0(0)	0(0)	125(17.4)	145(20.1)	54.4 (7.5)	68.9
Total time (%)	720(100)	720(100)	720(100)	720(100)	720(100)	720(100)	720(100)	720(100)	720 (100)	

Unit: minutes

% in ()

Table 4 Care time for the child during daytime respite service

Care content	1st time	2nd time	3rd time	4th time	5th time	6th time	7th time	8th time	average	SD
Personal hygiene	35 (7.3)	50(10.4)	50(10.4)	50(10.4)	25(5.2)	35(7.3)	40(8.3)	30(6.4)	39.4(8.2)	9.8
Excretion	10(2.1)	10(2.1)	30 (6.4)	10(2.1)	20(4.2)	10(2.1)	15(3.2)	15(3.2)	15.0(3.2)	7.1
Nutrition	40(8.3)	25 (5.2)	35 (7.3)	35(7.3)	65(13.4)	45(9.4)	35(7.3)	50(10.4)	41.3(8.6)	12.2
Positioning	15(3.2)	0(0)	5(1.0)	20(4.2)	5(1.0)	5(1.0)	0(0)	5(1.0)	6.9(1.4)	7.0
Drug administration	20(4.2)	20 (4.2)	20(4.2)	15(3.2)	0(0)	25(5.2)	20(4.2)	0(0)	15.0(3.1)	9.6
Care to promote expectoration	100(20.8)	105(21.9)	130(27.1)	105(21.9)	110(22.9)	120(25.0)	130(27.1)	125(26.0)	115.6(24.1)	12.1
Mechanical ventilator management	35 (7.3)	70(14.6)	35 (7.3)	35(7.3)	30(6.4)	30(6.4)	25(5.2)	40(8.3)	37.5(7.8)	13.9
Skin care	5(1.0)	5(1.0)	5(1.0)	0(0)	10(2.1)	5(1.0)	5(1.0)	5(1.0)	5.0(1.0)	2.7
Observation/monitoring	70(14.6)	65(13.4)	60(12.4)	105(21.9)	80(16.6)	115(23.9)	95(19.8)	40(8.3)	78.8(16.4)	25.0
Support for the mother and other family members	40(8.3)	5(1.0)	25 (5.2)	55(11.3)	10(2.1)	50(10.4)	40(8.3)	40(8.3)	33.1(6.9)	18.1
Play with the child	100(20.8)	95(19.8)	85(17.7)	45(9.4)	110(22.9)	40(8.3)	50(10.4)	125(26.0)	81.2(16.9)	32.3
Rest times for nurses	10(2.1)	30 (6.4)	0(0)	5(1.0)	15(3.2)	0(0)	25(5.2)	5(1.0)	11.2(2.4)	11.3
Total time (%)	480(100)	480(100)	480 (480)	480 (100)	480(100)	480 (480)	480(100)	480(100)	480(100)	

Unit: minutes

96 Machiyo IKUTA

24.8 minutes (11.4%); [mechanical ventilator management], including mechanical ventilator application/removal, removal of dew condensation water in the water trap and corrugated tube of the mechanical ventilator, and tracheotomy tube management: 47.5 ± 23.6 minutes (6.6%); [play with the child], including approaches to promote development and play for a change: 40.6 ± 17.0 minutes (5.6%); and [positioning]: 36.9 ± 13.3 minutes (5.1%).

In the daytime, the time for [care to promote expectoration] was the longest: 115.6 ± 12.1 minutes (24.1%), followed by: [play with the child]: 81.3 ± 32.3 minutes (16.9%), [observation/monitoring]: 78.8 ± 25.0 minutes (16.4%); [nutrition], including assistance with meals, preparation for tube feeding, feeding, and cleaning the tube: 41.3 ± 12.2 minutes (8.6%); [personal hygiene], including assistance in washing, grooming, oral hygiene, and dressing: 39.4 ± 9.8 minutes (8.2%); [mechanical ventilator management]: 37.5 ± 13.9 minutes (7.8%); and [support for the mother and other family members], including conversations with and consultations for the mother and other family members: 33.1 ± 18.11 minutes (6.9%).

6. Discussion

6.1 Situations of the child and his mother

There was no marked deterioration in the child's condition at the time of the survey, and the mother was able to go out for 2 hours 48 minutes in the nighttime and 4 hours 51 minutes in the daytime on average. Many mothers of children with disabilities hesitate to leave their children with others due to a poor quality of care provided by medical professionals or because the children do not like to be left⁹⁾. In such a situation, the mother was able to go out, possibly for 2 reasons. As shown in previous studies examining the emotions of mothers who received respite care similar to this study, a trust-based relationship had been established between her and the nurses who provided care, as she expected^{5, 7, 10)}; and the nurses cared for the child on a one-to-one basis as part of RCS at home, and this also

promoted her sense of security⁷⁾. With regard to RCS use, Yamamoto et al.⁶⁾ reported that the services enabled mothers to make the most of their time and work on their own physical and mental recovery, consequently increasing their motivation and peace of mind for continuous care at home. Indeed, in the present study, RCS enabled the mother to make the most of her time during each session.

6.2 Current status of care in long home-visit nursing and implications for the future

On totaling the durations of all care procedures, [observation/monitoring] accounted for the largest part in both the night- and daytime, at 46.8 and 16.4%, respectively. It seems to be natural that the duration of [observation/monitoring] increased in the night-time, as the child slept for 7 hours and 27 minutes on average, the mother also went out, and care at midnight was provided while all family members slept. Furthermore, the child who had difficulty in recognizing danger sometimes attempted to roll over to move while sitting, and this markedly increased the risks of falls and bruising. The risk of self-removal of the tracheostomy tube was also high. Therefore, [observation and monitoring] from the perspective of risk management to ensure safety was also required, and it took the longest of all care procedures. In standard daytime home-visit nursing services, nursing care is generally provided, combining care procedures, mainly medical care procedures, within a limited time frame of 30 to 90 minutes. However, in the case of long home visits, [observation and monitoring] that is not a direct act of intervention may become more important.

The duration of [care to promote expectoration] such as tracheal suctioning, drug inhalation, and pulmonary physical therapy (mean rate in the night-time: 11.4%; daytime: 24.1%) and [mechanical ventilator management] (6.6 and 7.8%, respectively) were the second longest. During long home visits, the child had persistent wheezing. As the mechanical ventilator was connected, he also required secretion suctioning, drug inhalation, and pulmonary physical

therapy in the night-time. Drug inhalation and preventive measures against self-removal of the tracheostomy tube may also have taken time in the daytime. The duration of such respiratory care is markedly influenced by airway secretion accumulation levels and other breathing conditions, but the above time is likely to have been average for the child, as there was no marked deterioration in his condition during the survey period. Hosaka et al. 15) examined the durations of support approaches in facilities for children (adults) with severe conditions, and reported that the duration of suctioning was 50 minutes per day, which was the longest of all care procedures for MD-SMID children. In another survey by Miyatani et al.¹⁷⁾ to calculate the durations of various care procedures for school-age children with HMV performed by their families, tracheal suctioning took 66.3 minutes per day. It is unclear whether these surveys also investigated drug inhalation and care to promote expectoration as the present study did, but the duration of respiratory care was longer in the latter. Nursing care for the child was provided on a one-to-one basis. To prevent worsening of symptoms and to improve symptoms in the child with respiratory disorders, the care possibly aimed to detect even slight changes and promptly respond to them. This may also have increased the duration of this procedure.

[Playing with the child] also accounted for a large part, at 5.7% in the night-time and 16.9% in the daytime. Asano²⁰⁾ noted the importance of deeply understanding child development through play, using formulating play activities according to the levels of physical dysfunction and intellectual disabilities, and continuously assessing play in nursing. By guaranteeing appropriate play in consideration of each child's developmental stage and physical/psychosocial situation, it becomes possible to promote his/her growth and development, such as developmentally appropriate play for sensory motor stimulation, picture book reading, and play for hand fine motor skill development. In the present study, the visiting nurses actively used these play activities, possibly aiming to support the motor and cognitive development of the child in late infancy with intellectual disabilities. Long home-visit nursing makes it possible to formulate play activities that are effective to promote development, and provide them during regular and long home visits. Based on this, it may be important for visiting nurses to support children with deeper knowledge of child development and play.

With regard to home respite care services in the current home-visit nursing system, several municipalities, including Bunkyo-ku²¹⁾ and Setagayaku²²⁾ of Tokyo, Fukuoka City²³⁾, and Kitakyushu City²⁴⁾, launched the Home Respite Care Project for Children Requiring Medical Care in 2021. The duration of each session is 2 to 4 hours, with the annual total limited to 96 hours in Bunkyo-ku, whereas there is no time limit per session, and the services are available for up to 48 hours per year in Fukuoka City and Kitakyushu City. Thus, home respite care services as part of home-visit nursing have expanded since the time of the present study. However, in a previous study, visiting nurses provided these services with anxiety about building relationships with families, the details of care, and how to spend their time²⁵⁾. Understanding the differences between long and standard home visits may help reduce such anxiety in nurses.

In summary, in long home-visit nursing, not only medical care, such as care to promote expectoration and mechanical ventilator management, but also observation, monitoring, and developmental support are important nursing acts, and a shift from medical care-focused procedures to daily life support, including developmental support, takes place. The results suggest that nurses also need to change their mindset accordingly.

7. Limitations of the Study

As a limitation of this time study, the data entered on self-administered recording forms every 5 minutes may not have been a perfect representation of actual times. However, they clarified some tendencies regarding the duration of care.

In addition, many years have passed since the data

were collected. Compared to those days, the types and amounts of social resources for MD-SMID children, such as daycare services, have increased. The numbers of home-visit nursing facilities providing long home-visit services and other facilities providing long home-visit nursing care as an optional service are also increasing, suggesting some possible changes in care procedures. Nevertheless, as real data had not been available, the present study provides useful data for long home-visit nursing.

8. Conclusions

To clarify the care procedures performed by visiting nurses for an MD-SMID child with HMV in regular long home-visit nursing and the duration of each procedure as a basis for developing future perspectives on this form of nursing, a time study was conducted. Among all care procedures performed during long home visits as part of RCS, [observation/monitoring], [playing with the child], and [care to promote expectoration] accounted for higher rates, and nursing to manage risks in the child and promote his development was actively practiced.

As nurses care for pediatric patients longer in long home-visit nursing than in standard services, it may be necessary for them to deepen their knowledge of child development and play, in order to enhance risk management and provide daily life support, including developmental support, in addition to improving the quality of medical care.

Acknowledgments

The author would like to express our sincere appreciation to the families and home nursing stations that cooperated in this survey.

Part of this study was presented at the 29th Annual Conference of Japan Academy of Nursing Science.

This work was supported by the Yuumi Memorial Foundation for Home Health Care Subsidy 2006, and by JSPS KAKENHI Grant Number JP20390563.

Declaration of interest

The author has no competing interests to disclose.

References

- 1) New challenges for pediatric home health care beginning with the NICU. Definition of children with medical care and yearly trends. Perinatal Medicine. 50(5): 752-7, 2020
- Social Welfare and War Victims' Relief Bureau, Ministry of Health, Labour and Welfare. Preliminary results of a "Survey on children in need of home health care, FY 2015", 2023-10-16
 - https://www.mhlw.go.jp/content/12200000/000365983.pdf.
- Ikuta M. The present situation and issues of caring for children with home mechanical ventilation in prefecture A: Based on the results of interview surveys of mothers. Journal of Japan Society of Nursing Research. 30(3): 183,2007.
- 4) Ikuta M, Miyazato K. The influence of Overnight stay Home - visit Nursing Service on a Mother of Home Mechanical Ventilation (HMV) child - In Providing Home - Based Respite Care-. Journal of Japanese Society of Child Health Nursing. .20(1): 40-47, 2011.
- Ikuta M. Experience of mothers with children undergoing home who received periodic home-based respite care and its significance. Journal of Child Health. 72 (2): 289-97.
 2013.
- 6) Yamamoto T. Mothers' perspectives on respite care for children with special needs. Journal of Seirei Society of Nursing Science. 4(2): 1-6. 2014.
- 7) Ikuta M. Case study about experiences of the mothers of children under home-mechanical ventilation who have received periodic home-based respite care. Journal of Japanese Society of Child Health Nursing. 21 (2): 55-63, 2012.
- 8) Status of support for transition to community life for critically ill children at home. The National Association for Visiting Nurse Service (ed). FY 2009 Ministry of Health, Labour and Welfare, Health and Welfare Promotion Project for Persons with Disabilities (Research and Study Project to Support Independence of Persons with Disabilities) Research and study projects to promote the transition of children with disabilities to community life, Report, 111-4, 2010.
- Takemura J, Tomari Y, Kokabu H. Nursing support for children with severe motor and intellectual disabilities in respite hospitalization. The Journal of Kansai University of Social Welfare. 23:51-8. 2020.
- 10) Tokushima S, Fujita Y, Fujiwara C. Expert nurses gaining the trust of families with children with severe motor and intellectual disabilities in respite hospitalization. Journal of Japanese Society of Child Health Nursing. 28:35-41. 2019.

- 11) Takagi S, Okemoto C, Hasegawa T. Needs for the respite service of the primary home caregivers of children or person for severe motor and intellectual disabilities. The Journal of the Nursing Society of University of Toyama. 14(2): 145-58. 2014.
- 12) Ikuta M. Problems faced by visiting nurses when transitioning critically ill children to home. Journal of Child Health. 74(3): 467-73. 2015.
- 13) Matsubasa T, Sawano K, Maruki K. Investigation of meal assistance for children (persons) with severe motor and intellectual disabilities. Journal of Severe Motor and Intellectual Disabilities. 35(1): 119-30. 2010.
- 14) Matsubasa T, Kimura A, Shinohara M, Endo F. Time study of staff members in an institution for severe motor and intellectual disabilities. Pediatrics International. 57 (6): 1154-8. 2015.
- 15) Hosaka T, Yamaoka T, Akimoto T. Survey of the amount of time required for medical care, nursing care, and support for patients at a facility for children (persons) with severe motor and intellectual disabilities. Journal of Severe Motor and Intellectual Disabilities. 37(1): 155-62. 2012.
- 16) Kuwahara Y, Nagata S, Taguchi A, et al. Classification of home visiting nurse clients according to proportion of direct / indirect tasks. Journal of the Japan Society for Healthcare Administration. 37 (227): 37-47. 2012.
- 17) Miyatani M, Komiyama H, Koide F, Irie S, Suzuki E. Survey of length of care time for the school children with home care ventilation. Journal of Japanese Society of Child Health Nursing. 14(1) 36-42. 2005.
- 18) Suzuki Y. Children with severe motor and intellectual disabilities-SMID-MCDG (Medical Care Dependent group) and sub-SMID-MCDG. Japanese Journal of Child Nursing. 24(9): 1090-5. 2001.
- 19) Yamamoto K, Chizoh A, Tanimura M. Reasons why pediatric nursing requires more time and manpower. Pediatric nursing 24-hour time study. Japanese Journal of Child Nursing. 27 (4): 495-508. 2004.
- 20) Asano M. Play, Recreation. New Edition of Pediatric Nursing Series 3: Nursing Care of Developmentally Disabled Children. Supervised by Oikawa I. Tokyo: Medical Friend Co. Ltd. 173-80. 2005.
- 21) Bunnkyo-ku. Home respite project for children with medical care, 2023-1.30, https://www.city.bunkyo.lg.jp/hoken/shogai/zaitaku/resupaito.html
- 22) Setagaya-ku. Home-based respite project for children with severe physical and mental disabilities, 2023-1.30, https:// www.city.setagaya.lg.jp/mokuji/fukushi/002/010/ d00131418.html

- 23) Fukuoka city, Home respite project for children with medical care by Fukuoka city, 2023-1-30, https://www.city.fukuoka.lg.jp/fukushi/syougaisyashien/health/sevice/hukuokasihoumonngatazaitakuresupaitojigyou.html
- 24) Kitakyusyu city, Home-based respite project for children with medical care, 2023-1-30, https://www.city.kitakyushu.lg.jp/ho-huku/17600446.html
- 25) Ikuta.M. Nagata C. Miyazato K. Possibility of Providing Home-based Respite Care for Children with Home Mechanical (HMV) and Their Families - The Actual Condition of the Home-visit Nursing Care for Children and the Issues of Prolonged-Stay-Type Home-visit Nursing Care-. Bulletin of Kumamoto University, School of Health Sciences. 6; 11-22. 2010.