

[EP-110.624] National survey results of care burden: focusing on 567 families whose children require advanced and complex medical care in domiciliary settings in Japan Hirotoshi Maeda, M.D. 1), Izumi likura 2), Masahiro Ikari 3), Ikuko Tomomatsu, Ph.D. 4) 1), 2), 3) Medical Incorporated Foundation Harutaka Kai Results 4) TOMO Lab LLC

Background

1) Neonatal mortality is sharply declining in Japan



(C-NAMC) in Japan

[Reference : Health and Labor Sciences Research Grants : 201918009A]



Extinction between medical care and welfare It is supposed that C-NAMCs are in a hospital, not in a There are no schemes to connect between medical professionals, welfare and care professionals, and educational professionals, nevertheless it is the key to support C-NAMCs Lack of social resources and human resources. Difficulties among C-NAMCs and their families Excessive burden of mothers Difficulties to go to school Lack of day-care service Without respite care, mothers cannot rest. Once the mother got sick, no one can treat the child Less cares for brothers and sisters

No criteria in place for the assessment of care burden for the C-NAMC and determine the amount of support needed.

Figure#4

Objectives

- To assess quantitatively the medical care provided at home for non-bedridden C-NAMC.
- To determine the amount of expenses for supporting these children.
- This is the first basic research required to create a public support system for such children in Japan.

Physicians and nurses have empirically known the amount of care burden for the 'not-bedridden C-NAMC'. However, as the methodological framework to measure the care burden for the 'not-bedridden C-NAMC' has not been established, there was no quantitative data to create a public support systems.

Methods

1) Video Analysis

- Participants: 15 C-NAMC and their families
- (informed consents were obtained beforehand)
- Data collection period:
- November, 2018 February, 2019
- ② February, 2020 June 2020.

Movements of children and their families were recorded in various duration from 5h and 10 min to 24h.



· Up to 8 cameras were set and simultaneous recordings were performed from different angles. The camera used in this study is Sopak-C made by Kobayashi Manufacture Co.Ltd. This was specially developed for process analysis.

• Primary caregivers (mostly mothers) filled out time-study sheet in which 24hr was divided into 5min (288 frames x 5 min). Each 5 mins frame was marked either "care conducted" or "no care conducted" • Video data and the time-study sheet for each children are compared.

2) Time study by caregivers and risk assessment by physicians

- 1.162 paediatric home-based patients from 18 medical institutions in Japan (including childhood onset transition cases).
- Data collection period : from September 2019 to February 2020
- Survey contents:

Major caregivers of the patient

- \checkmark basic data including profile of the patients and their major caregivers (mainly family caregivers)
- \checkmark a time study about medical care at home (max. 24 hours)
- \checkmark time needed to each type of medical care
- \checkmark subjective sense of care burden for above medical care

<u>Physicians</u>

✓ a risk assessment from a clinical perspective

[Procedure for measuring time]

- i. The time (duration) needed for each medical care was measured using a stopwatch. The measurement was performed by the caregivers for every medical care event conducted at home.
- ii. The duration was multiplied by the frequency of each care to calculate the total hours of medical care provided per day.

[Procedure for measuring the subjective sense of care burden]

- i. Participants provided responses regarding their subjective sense of care burden (SSCB) for each medical care event on a 5-point scale ii. The number of times of each medical care (NTMC) was implemented was calculated for each participant.
- iii.Calculate SSCB x NTMC for each patient. (e.g., e.g., SSCB of tube feeding=1, NTMC involving tube feeding was implemented 5 times a day=5; ESTIMATE of care burden of tube feeding is: $1 \times 5 = 5$).

[Procedure for measuring the risk level]

- . The physician in charge fills out a survey form regarding the medical devices and medical care used by the patient.
- ii. The physician estimates the level of risk on a 4-point scale in terms of medical equipment and medical procedures.
- iii. For certain medical devices and medical cares, risks become higher depending on child's condition, then the physician adds evaluated risk factors.

< Evaluation criteria of the sense of care burden >		< Evaluation criteria of the risk level >			
score	Evaluation criteria	score	Evaluation criteria		
0	l don't feel any burden at all.				
1	I feel a little burdened.	0	Not life-threatening		
2	I feel a little burden.	1	Can become serious		
3	l feel a great burden.	2	Can become serious in a short time		
4	I feel extremely heavy burden	3	Directly life-threatening on the spot		
	Table#1			Table#2	
	Data collection results				

 $\mathbf{\nabla}$ **D**ata collection results Caregivers' response rate in the survey: 567/1162 (48.8%) Number of responses of the self-reported 24-h Time-Study Samples: 552 -Number of valid Time-Study Samples: 497/552 (total) - Valid estimations of risk level by physicians: 986/1162 (total) (84.9%)

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Results

1) Video analysis

This study revealed the impact of medical care on the daily rhythms of caregivers.

The video recordings were analyzed separately during daytime (all 15 participants) and during nighttime (7 participants). Time without medical care during daytime ranged from 25 min (minimum) to 2 h and 45 min (maximum) and that during nighttime ranged from 2 h (minimum) to 5 h and 55 min (maximum)

The result shows that it is difficult for caregivers to take adequate rest and sleep.

Age	Physical	Medical devices	Time duration of Video recordings	Total hours	Maximum time without medical care during daytime		Maximum time without medical care during nighttime		
	ability				5-mins frame	total hours	5-mins frame	total hours	Time duration
6	bedridden / able to move legs and arms	tracheostomy + ventilator + tube feeding	16:00~16:00 (next day)	24 hours	9	45 mins	24	2 hours	3:30~5:30
2	bedridden / able to move legs and arms	tracheostomy + ventilator + tube feeding	16:00~16:00 (next day)	24 hours	12	1 hour	24	2 hours	3:30~5:30
3	bedridden / unable to move legs and arms	tracheostomy + ventilator + tube feeding	16:00~16:00 (next day)	24 hours	10	50 mins	71	5 h 55 mins	1:05~7:00
2	bedridden / able to move neck	peritoneal dialysis + tracheostomy + ventilator + ED tube + nasogastric tube	16:00~12:00 (next day)	20 hours	12	1 hour	34	2h 50 mins	3:00~5:50
2	bedridden / able to move legs and arms	bipap [°] + nasogastric tube	20:00~8:05 (next day)	12 h 5 mins	5	25 mins	42	3 h 30 mins	1:30~5:00
8	bedridden / able to move legs and arms	tube feeding	16:00~16:00 (next day)	24 hours	15	1 h15 mins	63	5 h 15 mins	1:45~7:00
4	bedridden / able to move arms	tracheostomy + nasogastric tube	16:00~16:00 (next day)	24 hours	25	2 h 5 mins	70	5 h 50 mins	1:10~7:00
3	able to stand up	Oxysian + tube feeding	8:30~17:30	9 hours	9	45 mins	_	_	_
1	able to stand up	tracheostomy + ventilator + nasogastric tube feeding	11:10~18:45	7 h 35 mins	18	1 h 30 mins	_	_	_
4	able to stand up	tracheostomy + ventilator + nasogastric tube feeding	15:30~20:35	5 h 5 mins	14	1 h 10 mins	_	_	_
6	able to stand up	tracheostomy + ventilator + tube feeding	9:30~17:05	7 h 35 mins	26	2 h 10 mins	_	_	_
3	able to stand up	tracheostomy + ventilator + tube feeding	17:20~22:35	5 h 15 mins	33	2 h 45 mins	_	_	_
11	able to stand up	tracheostomy + ventilator + tube feeding	9:00~19:05	10 h 5 mins	12	1 hour	_	_	_
2	able to crawl	tracheostomy + ventilator + tube feeding	10:30~14:30 16:00~17:30	5 h 30 mins	12	1 hour	_	_	_
2	ablle to stand up	tracheostomy + ventilator + tube feeding + IVH	8:30~17:30	9 hours	15	1 h 15 mns	_	_	_

2) Time study by caregivers

This study NOT prove an increase in care burden with improvement of child's physical ability, which physicians and nurses are empirically feelina

Motor function was classified into the following three levels: 1) bedridden, 2) not bedridden but unable to stay in sitting position, and 3) not bedridden and able to stay in sitting position).

 \bullet There were no correlation between the time required for medical care and the level of motor function of patients (* r = -0.08, p=0.1).

There was a weak negative correlation between the level of care-burden and the level of physical function of patients (r= -0.2, p=0.19) The care burden tended to reduce as the level of motor function increased





Table#3

In the case of medical care via tube feeding, the time for care became longer and the burden became greater with the increase in the child's bodily function.

In terms of the care burden by medical care, tube feeding ranked second. In terms of the time required, tube feeding ranked third after peritoneal dialysis and central venous feeding.

We performed cross-correlation analysis between care burden and motor function of children, and between time (duration) needed for medical care and motor function of children in terms of categories of medical care. The result showed both care burden and time (duration) needed for medical care of tube feeding increased as the child's motor function increased.



For each category of medical care, the correlation coefficient was calculated between the level of burden and the level of motor function, and between the time required for medical care and the level of motor function.

The result showed that only for the category of tube feeding, both care burden and time required for medical care increased as the child's motor function increased.

1) bedridden, 2) not bedridden but unable to stay in sitting position, 3) not bedridden and able to stay in sitting position





3) Risk evaluation by physicians

The average risk score of 2 (could become serious in a short time) or higher was for tracheostomy (2.5) and peritoneal dialysis (2.3). The average risk score of 1 (could become serious) or higher was for ventilator (1.8), Intravenous hyperalimentation IVH (catheterization: 1.2), oxygen (1.2), and drains (1.4). (1.2), oxygen (1.2), and drains (1.4).

Discussion

- The actual status of medical care for C-NAMC provided at home was quantified.
- 2. In Japan, most medical care for C-NAMC is provided by families, in particular mothers. Under the situation, the time to complete medical care was significantly longer than our assumption, and subjective sense of the care burden and risk control of medical care were significantly greater than our assumption.
- Based on the knowledge shared among the physicians and nurses and the analysis of video data collected in the first period, we hypothesized that the duration of the medical care and subjective sense of care burden increase along with the increase of child's motor function.
- However, there were no correlations of the time to complete the care and subjective sense of the care burden with a child's level of bodily function.
- . The degree of medical care risk assessed by physicians depends on the type of medical care provided. The risk of suction and ventilators was significantly higher than that associated with other types of medical care.
- With the medical care required for tube feeding, both the amount of time required for medical care and subjective sense of the care burden increased with the improvement motor function.
- The time-based study using the video data and self-reported questionnaire were not sufficient enough to demonstrate the increasing care burden with the improved child's motor function.
- The development of new methods is necessary in order to demonstrate the correlation between the time for the medical care and subjective sense of the care burden and child's motor function.
- The new approach is presented [2905-HP-QA.174] Development of a methodology to assess the care burden for the children with high motor function who require advanced medical care

Conclusion

The burden of medical care included "the burden of the amount of care required to be implemented" and "the burden of increased risk with improved bodily function in children."

In the case of medical care via tube feeding, the time for care became longer and the burden became greater with the increase in the child's bodily function.

The time-based using the video data and self-reported questionnaire solely could not prove SSCB increased as the child's motor function increased which physicians and nurses are empirically feeling.

Key References

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"Questionnaire survey on Pediatric Home Mechanical Ventilation Abroad"

