

## Process in which Fathers of Home-Cared Children Acquire Medical Care Nursing Technique

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#### Abstract

The purpose of this study is to clarify the process in which fathers of home-cared children who are in need of medical care acquire technique of care and physical condition management for their children. Subjects of the study were 5 fathers of home-cared children needing medical care of in Prefecture A. Survey period is from May, 2018 to July. The researchers visited home of fathers who agreed with participation in the study and performed semi-structured interview for them. The interview time is average 51 minutes and the revised version of Grounded Theory was used for data analysis. As a result of the analysis, 33 concepts, 13 subcategory and 3 categories were generated. "Challenge the care", "Acquisition of analytical thinking" "Independence of care and judgment" were extracted for the categories. Fathers who just begin to learn about medical care tended to judge conditions of their children with numeric values as a standard, without having expert knowledge. They received instructions from mothers, who mastered care more. After that, the fathers came to see expression and foot colors of their children while observing anaerobic conditions, and minded the mood of the children. Mothers assumed the central role of the care and fathers guessed their symptoms while being unable to predict them. By the time when the children comprehensively and care them Father's support surpassed what nurses could do in observing and caring children.

**Keywords:** Father; Home-cared child; Medical care; Technique; Acquisition

## Introduction

In Medical Section Meeting of Social Security Council of Japanese Ministry of Health, Labour and Welfare held in December, 2013, it was proposed that "It is necessary to build up a system that allows not only elderly but also infants who are treated in NICU for a long period to undergo medical treatment in peace in local community" [1], indicating that establishment of a system for home medical care of infants is important. According to the survey for ultra-severely disabled children younger than 20 years in 8 prefectures in 2007 performed by Ethics Committee of Japan Pediatric Society, 70% of ultra-severely disabled children were in home-care which was mainly performed by their family members [2] and intervention by health care occupations was seen only in few cases in Japan. Since infants who highly depend on medicine easily fall into vital crisis, their parents are in constant tense and are exhausted physically and mentally. Ultra-severely disabled children are often accompanied by respiratory disorders connected directly with eating disorders, dysphagia and vital crisis and therefore appropriate support is indispensable. However, it is predicted to be difficult for parents who do not have expert technique and knowledge to acquire medical and observation techniques such as suction or tube nutrition and take care of their children at home. While 92% of main caregivers of severely disabled children are their mothers, process in which nurturers of children needing medical care accept home care [3] has been clarified and a study that clarified the familial anxiety and needs of family members who raise severely disabled children at home has been reported [4]. Moreover, mothers' role in caring at-home severely disabled children [5] and recognition of role of specialists and parents [6] have been reported. In recent years, a study on how mothers of severely disabled children capture and respond to physical conditions of their children [7] and that on the process in which mothers of home-cared children practice medical care [8] have been reported. The mother noticed ground of the care of their children, then thought about physical states and care of children analytically, and finally became the best specialist of their children. However, the burden on mothers from caring their children at home is huge and support and understanding by fathers living together with them are important. The precedent studies include a research that elucidated fathers' role in their family [9] and research on the process of acquiring nursing behavior by fathers [10]. Fathers assume their role in the families while working. However, the range of acquisition and execution of care technique for home-cared children in need of medical care and acquisition of technique for judging physical conditions have not been clarified. Therefore, this study aimed at obtaining suggestions to family nursing by clarifying the process in which fathers learn medical care techniques.

## Purpose of the Study

The purpose of this study is to clarify the process in which fathers of home-cared children needing medical care obtain technique of caring children and managing their physical conditions.

#### Definition of terms

**Medical care:** Medical actions that fathers and mothers perform daily and temporarily under the instruction of medical doctors to maintain the life of their children.

**Technique:** Methods and steps that include care performed at the time when fathers provide children with medical care

**Care:** Fathers' action of nursing including medical care and observation of their children

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## **Research Methodology**

#### **Subjects**

Subjects were, as shown in Table 1, five fathers of home-cared children in Prefecture A who were utilizing home-visit nursing care service and thought to depend highly on medical care. The age of the fathers ranged from 30s to 60s. The disease of the children included chromosomal aberration and their home care period ranged from 3 months to 18 years. Medical care for the children included respirator, suction, oxygen inhalation therapy, tracheostomy, tube nutrition and so on.

#### Data acquisition period and method

The survey period was from May to July, 2018. The researchers visited home of the fathers who agreed with the visit and performed one semi-structured interview for one subject according to the interview guide. The subject is five father of home cared children in need of medical care. The average interview time was 51 minutes. The interview contents was recorded in an IC recorder according to the agreement by the fathers. Contents of the interviews included physical states of the children and medical care, contents of medical care for which the fathers received instruction, method to acquire care, method to judge children's conditions and so on. The modified grounded theory approach (hereinafter called M-GTA), which is based on the qualitative inductive method, was employed for the data analysis method in this study [11]. In M-GTA, data are interpreted from analysis theme and analysis focal subjects. The analysis focal subjects were "Fathers of children needing medical care to live at home", and the analysis theme was "The process in which fathers of children needing medical care obtain care technique". The researchers made transcriptions of the subjects' narration data and created concepts along the process of the father's medical care practice. An analysis worksheet (Table 2) was used for the conceptualization. Theoretical memos were filled in from concrete examples and concepts' names and definitions were considered. The authors aimed at clarifying how the fathers learned to grasp observation point of children and judge symptoms and if they practiced medical care in interaction with their mothers. Therefore, we created concepts of the process along the context focusing on fathers' methods to observe their children and judge symptoms and to practice medical care. We examined relevance, analogy and polarity between the concepts while pushing forward data collection and analysis in parallel, and divided and integrated the concepts. Figure 1 was modified and revised during the analysis. The analysis was supervised by researchers of children nursing and those engaged in research guidance for M-GTA to raise reliance and validity of the analysis.

#### **Ethical considerations**

This study was approved by Research Ethics Committee of University A. Subjects were explained both orally and in writing explained that their privacy was going to be protected, the study could be withdrawn at any stage and research results were not going to be used for the purposes except the study and written consents were obtained from them. There is no conflict of interests regarding the publication of this study.

#### Results

Categories of sentences are described with ``, subcategories are with < >, concepts are with " ", and specific examples of mothers' narrations are described with "italic type". As a result of analysis, 30 concepts, 14 subcategories and 3 categories were generated. 'Challenge the care ', 'Acquisition of analytical thinking' and 'Independence of care and judgment' were extracted as categories.

#### Results of figure and story line

Perspective of the result is shown by Figure 1 and story lines. Fathers went to NICU when their children were born. Mother received instruction for suction or tube nutrition earlier though fathers also received instruction and 'challenged the care'. Fathers cared "being timid first" and they were <afraid> to join the care. Sputum "could not be removed even by suction" in some cases though they "felt learning something by devising as a trail". <Judgmental standard was oxygen level> and they did "not have special knowledge". Moreover, in the case that the fathers cared in wrong ways, they were "scolded by mothers". Fathers "confirmed saturation at the time when cramps occurred" in their care activity, and "observed the child by checking their expression and foot color" to <confirm their anaerobic conditions>. Moreover, they <cared about the child's mood> for the concept "understand why the child is in bad mood". After that, the fathers came to <judge> themselves more often such as "judgment for tube nutrition remained in stomach", "put hands to judge temperature", "judge from edema and complexion", "judge effect of suction by sound", "judgment of medication at the time of cramps" and so on while <care was

Subject (Father)	Father's age	Child's age	Child's disease	Years of home care	Medical care performed for the child till before the survey started
1	60s	18 years	Chromosomal aberration	18 years and 0 months	Suction, aspiration, tracheostomy, tube nutrition
2	30s	1 year and 4 months	Brain neurological disease	10 months	Suction, tube nutrition, at-home oxygen inhalation therapy
3	30s	11 months	Chromosomal aberration	8 months	Tube nutrition, at-home oxygen inhalation therapy
4	30s	2 years and 6 months	Chromosomal aberration	1 year and 6 months	Respirator, suction, tube nutrition
5	30s	9 months	Barter syndrome	3 months	Intestinal fistula, tube nutrition, vesicle fistula, at-home oxygen inhalation therapy

Table 1: Attribution of subject.

Concept name	Wives mostly manage		
Definition	Wives mostly manage the procedure and care for their children		
Variation (specific example)	What my wife can do is more that what I can do(5) I feel I probably can but I did it alone just once in the hospital(4)		
Theoretical memo	Wives manage most of the management and procedure of the medical care for their children, and they comprehend the whole. Therefore father cannot see the entire picture of the care.		

Table 2: Analysis worksheet example.

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mainly performed by mothers> and therefore they followed mothers' instructions. Moreover, they became able to <understand> medical stuff such as "principle of care" and "effects of medicine". Fathers became able to "guess why the alarm rings" and "guess possibility of constipation" from the child's condition. They "calculated in and out of moisture" to guess the physical condition of their children and 'acquired analytical thinking'. The fathers became able to understand "characteristics of anatomical physiology" of their children and "perform medical without problem". Moreover, they became able to "understand their children's conditions comprehensively by symptoms" and to "care while seeing their conditions". "The fathers were more experienced than nurses" and "able to perform well without mothers" and therefore they were 'able to care and judge independently'. However, "mothers judged condition of their children" and "mothers mostly managed".

# Result of analysis on the process in which fathers of home cared child acquire medical care technique

This study has revealed that the process in which fathers of home cared child acquire medical care technique progresses in a step-by-step manner.

**Stage of "challenge the care":** After their children were born, the fathers went to NICU during work while the mothers "went NICU everyday". The fathers received instruction for medical care from nurses at NICU and performed suction and tube nutrition though they were afraid of performing the technique "being timid first". as seen in the comment <<I was afraid thinking what should I do if the kid suddenly moved....(Subject 4).>> Moreover, the father tried to perform suction

though "sputum and mucus were not sucked" because they were not used to the technique as seen in the comment <<No matter how I tried sputum and mucus were not sucked... so I was wondered why...(Subject 2).>> However, they "felt learning something by devising as a trail" as seen in the comment <<I learned how I should treat it by twisting the tip of the suction tube or changing the interval of taking out and sticking in.....(Subject 2).>> <Judgmental standard was oxygen level> as seen in the comment <<You know, oxygen level does not rise in many cases... when it get below 77, the alarm keeps beeping (Subject 3)>>, indicating that they did "not have special knowledge" regarding medical stuff for children. Moreover, the father took care of children by their own method though they 'challenged the care' being "scolded by mothers" who had already learned the technique as seen in the comment <<I'm often scolded by my wife, like you should not pull it that strong....(Subject 5).>>

Acquisition of analytical thinking: While the fathers continued caring, they "confirmed saturation at the time when cramps occurred" as seen in the comment <<I checked apnea for few seconds first... just thinking to recover the saturation, oxygen anyway...(Subject 3).>> They <observed their anaerobic conditions> by "checking the expression and foot color" receiving instructions as seen in the comment <<I was told by the nurse and my wife that I've got to see the face to see the conditions. Like.. I should do this or that when the color of this changed...(Subject 5).>> They <cared about the child's mood> for the concept "understand why the child is in bad mood" as seen in the comment <<The kid was in bad mood because stool didn't come out, I tried to stimulate....(Subject 4).>> After that, the fathers came to

<judge> themselves and made "judgment for remains of tube nutrition in stomach" as seen in the comment <<At first I see how much of milk is left and delay the time for milk according to it.... (Subject 4).>> Moreover, they "put hands to judge temperature" as seen in the comment <<I feel the kid has got fever touching the neck and back in some cases and then I take body temperature (Subject 2).>> Moreover, they "judged from edema and complexion" as seen in the comment <<I judge if something is happening by seeing complexion or edema.... our kid doesn't have one of the kidneys (Subject 5).>> The fathers "judged suction by sound" as seen in the comment << I don't know if I'm right but I heard they judge removal of sputum hearing the sound so...(Subject 3).>> However, <care was mainly performed by mothers> and therefore the fathers followed mothers' instructions as seen in the comment <<In most cases we look at the kid and decide we gonna do this and that in the morning.... she says like... take good care of the kid, or give me a call if something happened (Subject 1).>> Moreover, they became able to <understand> medical stuff such as "principle of care" and "effects of medicine" as seen in the comment << .... Vesical fistula is... you know... there is a hole opened on the stomach and raw diet (saline) is injected from it, and a balloon is blown up there so that it does not come out from the stomach....(Subject 5).>> and << Thyradin is for thyroid gland and atenolol is for pulse, right? (Subject 4).>> The fathers became able to "guess why the alarm rings" as seen in the comment <<The alarm sometimes rings. That's probably because saturation is not captured properly, I guess <<Sunject 5).>> and to "guess possibility of constipation" from the child's condition as seen in the comment << The heart rate does not rise to the level that cramps may occur but I wonder why he's trying to strain.... that reminds me like... when did he poo last? (Subject 2).>> They "calculated in and out of moisture" to guess the physical condition of their children and 'acquired analytical thinking' as seen in the comment <<I need to see water content of the milk injected and ratio of excretion amount contained in pee and poo to decide if I should give medicine for central diabetes insipidus (Subject 2).>>

Independence of care and judgment: The fathers became able to understand "characteristics of anatomical physiology" of their children as seen in the comment <<His right nose may be small. I learned that a suction catheter is inserted more smoothly from the left. I guess the right one is difficult (Subject 4).>> and "came to understand medical care and improved the technique" as seen in the comment <<I've become able to perform without problem (Subject 5).>>, <<I've got used to it. Well, I don't know if I'm doing it well (Subject 3).>> and <<Sometimes, you know... maybe I can see if he is holding his breath or not.....(Subject 4).>>, indicating that they became able to see "breath holding". The fathers "judged comprehensively by seeing symptoms and states" as seen in the comment <<if he has fever, sweat appears on his nose or head. So anyway, I look at everything I can and observe the conditions while removing possibilities one by one (Subject 2).>> They became able to "care while seeing their conditions" as seen in the comment <<Well, I have become able to care while seeing their conditions now (Subject 4).>> "The fathers are more experienced than nurses" as seen in the comment <<Nurses change each time and same one never comes so.....(Subject 1)).>>. Moreover, the fathers were "able to perform well without mothers" and therefore they were 'able to care and judge independently' as seen in the comment <<Recently, my wife is sometimes out of home for a half a day then I care the kid all day (Subject 2).>> However, "mothers judged condition of their children" as seen in the comment << Perhaps my wife is able to notice more detail things (Subject 4).>> and therefore "mothers mostly managed" as seen in the comment <<My wife always accompanies the kid and does all things so....(Subject 5).>>

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## Discussion

This study has clarified that the process to learn medical care advances progressively through the description of the process in which fathers of children needing medical care obtain care technique. The Dreyfus model for five stages of skill acquisition [12] and Study on skill acquisition of nurse have been reported as precedent studies. In a precedent study [8], mothers acquired medical care techniques through a process similar to those. The fathers in this study also followed the process similar to them.

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#### Stage of "Challenge the care"

Fathers who just started to learn medical care were afraid of performing the medical care technique. Mothers judged their children's conditions based on oxygen saturation values taught by medical persons [8]. Moreover, fathers also judged their children's conditions based on oxygen saturation values taught by their wives and medical persons. A nurse at a beginner level attempts to figure out the conditions based on intake and excretion, temperature, blood pressure, pulse and so on, which are objective and measurable and indicate the patient's conditions [13]. Fathers also judge conditions of their children with numerical values as standard while they did not understand observation points on their children's body with no expert knowledge. Therefore, the fathers cared their children while receiving instruction from their wives who already mastered the care. According to the precedent study, mothers grasped the tendency of their children by taking memos of the time of symptoms and attacks. Moreover, they understood the conditions of their children by asking medical persons and looking up themselves. Having doubts or failure experience when care was not performed well motivated them to know the reason [8]. Mothers presented exploratory behaviors such as taking memos about symptoms, searching the Internet, which were not seen in fathers. Fathers have jobs and busy every day and therefore are unable to collect information, meaning that their information source is their wives.

### Stage of "Acquisition of analytical thinking"

Father understood observation points of their children. Experienced fathers may be able to make decisions and predict outcomes if they can see mutual relations of elements that constitute the state [12]. The fathers grasped conditions of their children by seeing complexion and foot colors to observe their anaerobic conditions. In the precedent study, mothers judged conditions of sputum from pharyngeal sound and observed raising condition of chest as an anaerobic symptom [8]. They minded the mood of children, and groped for reasons for the bad mood as seen in the comment <<When I found him crying, I check his body to see if he's got swell or pain.>> [7]. Likewise, fathers also minded the mood and observed conditions of their children. Fathers come to often judge conditions of their children, and calculated injection rate and time from the amount of tube nutrition remained in stomach as they were taught by their wives. They put their hands on the body, and judged temperature. Moreover, they judged conditions of their children from degrees of edema and by seeing how blue the skin was. Moreover, they judged effects of suction from the sound similar to their wives. Mother systematically judged symptoms developed on children while fathers made fragmentary judgement that they could for remains in stomach, fever and edema and so on. Mothers, whose time of spending with their children is predominantly longer than the fathers, assumed the main role in care and the fathers followed their instructions. In this period, they grope for life stability and adjust, and begin to acquire ability to make judgement while utilizing surrounding people [14]. In other words, the fathers guessed causes by themselves not depending on oxygen values as a standard. Father judged conditions

of their children by observing them. However, the mothers assumed the main role in care.

Mothers were able to assess and judge symptoms systematically at this stage while fathers guessed symptoms being unable to predict them. The fathers made judgement by partly helping their wives care. The mothers observed and judged the overall conditions of children.

#### Stage of 'Independence of care and judgment'

Father became able to collectively judge physical conditions of the children based on their fever, sweat and saturation level and care them 1 to 2 years after the children were discharged from NICU. Moreover, they knew well about the anatomical features such as shape of nasal cavity or trachea junction of the children well, and executed medical care that matched it. Further, the fathers became able to notice the condition that the children were not breathing. In the precedent study, mothers judged dealt with conditions that symptoms of the children turned worse relating by observing complexion, lip color, oxygen saturation values, edema and sweating [8]. Professional nurses choose the best method for arranging what they should do intuitively, comparing elements that are thought to be important based on the experience and dealing by combining them in accordance with rules [12]. Mothers felt that they had improved in executing medical care and observing their children, believing that the they were the best expert for them [8]. Therefore, the intuition that enabled the mothers to catch and judge subtle change in the children was working. The fathers did not reach that level. The mothers managed daily care of children and the fathers assumed supporting roles. However, the authors presume that the fathers' support was better in observing and caring children. Specialists need to learn new techniques from parents and exchange information with the parents for judgement in medical care before giving advice [6].

#### Conclusions

1) The process in which fathers of children needing medical care acquire techniques consists of three stages;

- 'Challenge the care'
- 'Acquisition of analytic thinking' and
- 'Independence of care and judgment'

2) At the stage of "Challenge the care", fathers were afraid of caring their children though they acquired techniques through trials and became able to judge based on concrete numerical values such as oxygen.

3) In 'Acquisition of analytic thinking', fathers became able to observe and make judgement for care and symptoms of their children. However, mothers assume major roles in caring their children and fathers followed the mothers' instructions. Father became able to guess symptoms yet they did not reach the level at which they were able to predict them. 4) In 'Independence of care and judgment', fathers judged condition of children comprehensively and independently care them and made judgment and therefore they understood conditions of their children better than nurses. However, mothers assumed the overall management.

#### Limitation of the Study

This study targeted fathers who were cooperative with the care of their children needing medical care and agreed with interview and therefore do not cover all cases as a limitation. Moreover, since there were limitations to collect subjects, we analyzed interview results from 5 subjects.

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