The current situation and issues there of related to nursing care at the time of medical examinations for children with developmental disabilities including autism

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ABSTRACT

The objective of this study is to clarify the details regarding nursing care that is currently provided in terms of the situation regarding medical examinations for children with developmental disabilities and to discuss necessary nursing care. I conducted semistructured interviews among 13 parents brining up children with developmental disabilities and analyzed the content of verbatim reports both qualitatively and functionally. Regarding those situations when they feel difficult at the time of undergoing medical examinations at the medical institute, the following four categories were extracted: painful treatment; difficulty in predicting; difficulty in communicating; and trouble in the waiting room. Regarding nursing care felt necessary at the time of undergoing medical examinations, the following six categories were extracted: technique while suppressing pain to a minimum; involvement in providing perspective; adjustment of surrounding environment; provision of opportunities to get acclimatized; provision of warm support; and understanding of patient characteristics. Many difficulties regarding medical examinations were revealed and it was found that they have concerns with regard to health management. It has been suggested that it is important to adjust the surrounding environment during medical examinations.

KEYWORDS

Autism; Developmental Disabilities; Medical Examination

1. INTRODUCTION

It is said that developmental disabilities including autism

are no longer such rare diseases, currently found in 1 out of every 100 children [1]. It is believed that there are many opportunities for nursing personnel to support children with developmental disabilities at medical institutes. There are many difficult situations in which children with developmental disabilities including children with autism "cry", "run around", "become panicked", etc. during medical examinations because their ability to verbally understand is insufficient or they are sensory sensitive [2]. In 2004, the Act on Support for Persons with Development Disabilities went into effect, and in 2007, special needs education was reorganized for the School Education Act, resulting in a prevailing need for support for people with developmental disabilities and as a result, such support has been undergoing rapid progress over the past five years [3]. In the medical field, in May 2001, the Aichi Branch of the Autism Society Japan submitted to the Aichi Medical Association, Nagoya Medical Association, and Aichi Hospital Association a document entitled "Request regarding medical examinations for people with autism", stating the need for individual support while requesting understanding regarding autism and considering medical examinations for people with autism [4]. However, it was found that there are still situations in which difficulties have not yet been overcome, for example, when undergoing medical examinations at a department other than a specialized department such as the Department of Child Psychiatry [5,6]. It is believed that supporting children with developmental disabilities in order to enable them to smoothly visit nearby local medical institutes is a large role expected of nursing personnel.

In Japan, there are currently few studies regarding nursing care for children with developmental disabilities. In the literature regarding studies on nursing care for children with developmental disabilities in Japan, it is stated



that most support is not for the patients themselves but for acceptance of their disability such as with regard to their parents [7]. Furthermore, studies regarding support for children with disabilities are mostly related to support during medical examinations at dentists [8], with nursing care for children with disabilities themselves limited to one case, although there are some reports regarding preparation [9] and informed consent [10]. There are investigations through questionnaires given to parents regarding "good support provided to you by medical personnel" [11], and reports regarding the current situation regarding difficulties experienced by nurses during medical examinations for children with mild developmental disabilities [12], but none of these specifically state how support should be provided and therefore it is believed necessary to clarify the tasks of nurses such as care provided during the course of treatment or assistance during medical examinations.

Referring to overseas references, some literature is available in the US based on several literary reviews clarifying how to become involved with children with developmental disabilities [13]; however, there are differences with regard to cultural background along with the system for medical examinations in Japan and so it predictably diverts from the current situation in Japan with regard to how nurses are intentionally involved. In the UK, a nursing specialty field including nursing care for children with developmental disabilities called learning disability nursing has been established and there are specialized nurses called resisted nurses for learning dishabilles [14]. Moreover, in the US, staff members who are not nurses but are specialized in behavioral management are utilized and may adjust the surrounding environment and advise nurses and doctors in the case of patients with intellectual disabilities and developmental disabilities [15].

Therefore, it is believed necessary to clarify the current situation regarding nursing care in terms of the situation regarding medical examinations for children with developmental disabilities and provide fundamental materials in order to discuss necessary nursing cases. Therefore, we report here on our study to clarify the details regarding nursing care which is currently being conducted in terms of the situation regarding medical examinations for children with developmental disabilities.

2. METHOD OF STUDY

2.1. Study Subjects

The study subjects were parents raising children with developmental disabilities. In this study, in order to extract nursing situations that take into account the characteristics of disabilities, the type of disability, severity and age were not limited. We mailed a request for an investigation to the representatives of parent groups of children with developmental disabilities (autism) along with the representatives of medical institutions. We requested them to reply in writing regarding whether or not we could distribute an explanatory document to obtain their cooperation with the study. If they agreed to cooperate with the study, we asked them to distribute the explanatory document of the study to applicable parents. We asked the parents agreeing to cooperate with the study to directly mail back the researcher their written consent and schedule arrangement form.

2.2. Maintaining the Integrity of the Specifications

After individually arranging the interview schedule, we secured a location to conduct interviews that would allow the privacy of the subject to be protected. For cases in which we were able to obtain the consent of the subject, we recorded the content of the interview on an IC recorder and created a verbatim report.

2.3. Investigation Method

After individually arranging the interview schedule, we secured a location to conduct interviews that would allow the privacy of the subject to be protected. For cases in which we were able to obtain the consent of the subject, we recorded the content of the interview on an IC recorder and created a verbatim report.

2.4. Analysis Method

We investigated situations they feel are difficult to handle when undergoing medical examinations at medical institutes (excluding the Department of Child Psychiatry) along with the support provided by medical personnel that they think is necessary in such situations according to the interview guidelines based on the following items.

- 1) Basic attributes consisting of questions including age, gender, name of disability in children with disabilities, with or without a physical disability certificate and severity, and the relationship of the subjects under study with their children with disabilities.
- 2) Situations in which they feel difficulty at the time of undergoing medical examinations at a medical institute.
- 3) Nursing care which they feel necessary at the time of undergoing medical examinations.
- 4) Other than the above, we asked them to state freely how they think nursing care should be provided when they visit medical institutes, etc.

2.5. Ethical Considerations

Upon arrival of the research participants, we recorded the content of the interview on an IC recorder. We created

recorded data to make a verbal report, qualitatively and inductively analyzed the contents according to the following procedures, extracted nursing care which is currently being conducted and nursing care that they think is necessary, and classified by similarity of content according to the following procedures.

- 1) We repeatedly read the recorded verbal report of the interview and extracted chunks of expressions.
- 2) We also referred to the memorandum that the researchers created during the interview and summarized it so as to be clear without changing the meaning of the sentence.
- 3) We divided the summarized sentences into groups with similar meaning and content and extracted sub-categories which represent common meanings.
- 4) We further divided the sub-categories into groups based on the meanings and extracted categories that represent common meanings.

During the course of analysis, we reviewed the analysis results repeatedly in an attempt to maintain validity.

2.6. Ethical Considerations

Upon request for investigation and implementation, we explained in writing with regard to privacy protection and ethical considerations to the parent groups and medical institutes, in addition to providing both written oral explanations to the subjects under study. We explained that we will ensure anonymity, keep the collected data confidential, not use the data and contact information for anything other than the intended purpose, that they can cancel even after giving approval, that they will not incur any disadvantage even should they remove their approval, etc., and we orally obtained final confirmation at the beginning of the investigation. All the prothe Ethics Committee of Chubu University (Approval No.

cedures were conducted upon receiving approval from 240014).

3. RESULTS

We welcomed 13 participants from one parents group and two medical institutes and obtained each of their approval to record the interview. The interview time was 28 to 49 minutes. The opinions we obtained regarding subject attributes, situations in which they feel difficulty at the time of medical examinations, nursing care that they think necessary at the time of medical examination for children with disabilities, and support that they think important at the time of medical examinations at medical institutes are shown below aggregated into categories with [], sub-categories thereof with {}, and collected individual content with "".

3.1. Subject Attributes

Table 1 shows the backgrounds of the subjects. The subjects were all female and their relationships with the children or people with disabilities were all as mothers. Children with developmental disabilities included 9 males and 2 females ranging from 4 to 34 years old, with an average of 13.3 ± 9.10 years old.

3.2. Situations in Which They Feel Difficulty at the Time of Undergoing Medical Examinations at the Medical Institute

Table 2 shows the situations in which they feel difficulty at the time of undergoing medical examinations classified into 17 items and 4 categories along with the number of subjects mentioning the situation. Each category is described below.

1) Painful treatment

Table 1. Subject Attributes.

			No
		6 or younger	3
		7 - 10	2
	A	Early teens	4
	Age	Late teens	2
		Early 20s	1
		Late 30s	1
		Male	11
	Gender	Female	2
Children with disabilities		Autism	8
	Name of disability	High-functioning autism	3
		Diffuse development disability	2
		Intellectually severe	7
		Intellectually moderate	2
	With or without a physical disability certificate	Intellectually mild	1
		Psychologically moderate	1
		None	2
Subject Relationship		Mother	13

Table 2. Situations in which they feel difficulty at the time of undergoing medical examinations at the medical institution.

Category	Situations pointed out	No. subjects pointing out
Painful treatment	We must hold him/her down when receiving painful treatment such as drawing blood or receiving injections or he/she will go into a rage.	9
	He/she cannot maintain the same posture while measuring brain waves, taking X-rays, etc.	6
	He/she refuses treatment in places that he/she cannot see such as the ears or nose.	1
	He/she dislikes the sound of machines for grinding teeth at the dentist and gets nervous in the waiting room.	1
	He/she refuses to allow a stethoscope to be applied.	1
Difficulty in predicting	He/she dislikes changes in sequence during medical examination.	2
	He/she cannot perform some procedures because they cannot understand complicated procedures such as inhalation.	4
	He/she repeatedly asks questions if questions regarding when and how healing will occur are clarified.	1
Difficulty in communicating	During the vision test, he/she was able to say "left or right and up or down" in words, but was unable to do so using their fingers.	1
	During the hearing test, when he/she was requested to answer whether they could hear sound from earphones, they answered "I can hear" because they heard the voice asking "Can you hear?"	1
	He/she cannot complain about their symptoms and therefore we have difficulty understanding how they feel sick.	6
Trouble in the waiting room	He/she talks to themselves and therefore people nearby give him/her odd looks in the waiting room.	4
	He/she dislikes children's crying and becomes aggressive to children crying in the waiting room.	1
	He/she commits other injurious behavior in the waiting room.	2
	He/she cannot sit while waiting and walks around.	4
	He/she behaves in a way that bothers others such as jumping or running around in the waiting room.	5
	He/she dislikes places where there are many people and cannot enter the waiting room.	1

This category included 5 situations: "We must hold him/her down when receiving painful treatment such as drawing blood or receiving injections or he/she will go into a rage", "He/she cannot maintain the same posture while measuring brain waves, taking X-rays, etc.", "He/she refuses treatment in places that he/she cannot see such as the ears or nose", "He/she dislikes the sound of drills at the dentist and gets nervous in the waiting room", and "He/she refuses to allow a stethoscope to be applied". In this category, most subjects pointed out "We must hold him/her down when receiving painful treatment such as drawing blood or receiving injections, or he/she will go into a rage".

2) Difficulty in predicting

This category included 3 situations: "He/she dislikes changes in sequence during medical examinations", "He/she cannot perform some procedures because they cannot understand complicated procedures such as inhalation", and "He/she repeatedly asks questions if questions regarding when and how healing will occur are clarified". In this category, most subjects pointed out "He/she cannot perform some procedures because they cannot understand complicated procedures such as inhalation".

3) Difficulty in communicating

This category included 3 situations: "During the vision test, he/she was able to say "left or right and up or down" in words, but was unable to do so with their fingers", "During the hearing test, when he/she was requested to answer whether they could hear sound from earphones, they answered 'I can hear' because they heard the voice asking 'Can you hear?"", and "He/she cannot complain

about their symptoms and therefore we have difficulty understanding how they feel sick". In this category, most subjects pointed out "He/she cannot complain about their symptoms and therefore we have difficulty understanding how they feel sick".

4) Trouble in the waiting room

This category included 6 situations: "He/she talks to themselves and therefore people nearby give him/her odd looks in the waiting room", "He/she dislikes children's crying and becomes aggressive to children crying in the waiting room", "He/she commits other-injurious behavior in the waiting room", "He/she cannot sit while waiting and walks around", "He/she behaves in a way that bothers others such as jumping or running around in the waiting room", and "He/she dislikes places where there are many people and cannot enter the waiting room".

3.3. Nursing Care Felt Necessary at the Time of Undergoing Medical Examinations

Table 3 shows nursing care felt necessary at the time of undergoing medical examinations classified into 6 categories. Each category is described below.

1) Technique while suppressing pain to a minimum This category comprises the categories [Suppress pain] including "When he/she experiences pain due to unskilled technique, he/she might hesitate to undergo treatment next time. It is necessary for a skilled nurse to perform treatment", and "Conduct medical examinations only as necessary", and [Technique to secure the body] including "Ineffective techniques in securing the body will take a

Table 3. Nursing care felt necessary at the time of undergoing medical examinations.

Category	Sub-category	Desired care
Technique while suppressing pain to a minimum	Suppress pain	When he/she experiences pain due to unskilled technique, he/she might hesitate to undergo treatment next time. It is necessary for a skilled nurse to perform treatment.
		Conduct medical examinations only as necessary.
	Technique to secure the body	Ineffective techniques in securing the body will take a longer time and cause pain. We wish to secure him/her tightly.
		Have him/her see other people undergoing the same treatment in order to image what he/she will be undergoing.
	Vieual cunnort	Show the procedures using pictures cards, etc.
	Visual support	Show with letters.
Involvement in providing perspective		Show the tools to be used during the actual medical examination or let him/her handle them in order to understand the upcoming procedure.
		Explain using short and simple words.
	Verbal explanation	During painful treatments such as injections, tell the truth using explanations such as "it will be painful but please be patient" rather than "it will not be painful".
	Provide perspective	Provide perspective regarding when and how things will proceed.
	Waiting room environment	Can wait in a private room.
		Can wait in the car and be called when our turn comes.
Explanation regarding surrounding environment		Can wait outside and be called on the cellphone when our turn comes to take the medical examination.
	Personal environment	There are many nurses and support at the time of treatment so the number of family members attending the hospital should be limited.
		Nursing staff will skillfully handle any trouble among children.
	Avoid painful care	If his/her condition is not so severe, avoid forcibly holding him/her down or giving painful treatment from the beginning.
D		Acclimatize him/her step-by-step.
Provision of opportunities to get acclimatized		Even for minor injuries, he/she can undergo medical examinations in the form of regular medical checkups.
		Praise with clapping for what he/she is able to handle even for small things and increase what he/she is able to do.
Provision of warm support	Support for family	Even for situations in which carrying out the medical examination is difficult, avoid looking frustrated and provide encouragement that everything is okay.
		Avoid demanding reasons regarding why he/she cries or is confused, performing medical examinations and providing treatment in a straightforward manner.
	Support for patients	Whether or not he/she is able to understand an explanation, provide the explanation directly to the patient themselves.
Understanding of patient characteristics	Attitude in trying to understand patient characteristics	Trying to understand what kind of characteristics he/she has.
		Being asked at the reception counter "What kind of support do you need?"
		Make a support book available.

longer time and cause pain. We wish to secure him/her tightly".

2) Involvement in providing perspective

This category comprises the categories [Visional support] including "Have him/her see other people undergoing the same treatment in order to image what he/she will be undergoing" by showing situations actually experienced by their parent such as sampling blood, "Show the procedures using pictures cards, etc.", "Show with letters", and "Show the tools to be used during the actual medical examination or let him/her handle them in order to understand the upcoming procedure", [Verbal explanation] including "Explain using short and simple words",

"During painful treatments such as injections, tell the truth using explanations such as 'it will be painful but please be patient' rather than 'it will not be painful'", and [Provide perspective] how things will proceed".

3) Adjustment of surrounding environment

This category comprises the categories [Waiting room environment] including "Can wait in a private room", "Can wait in the car and be called when our turn comes", and "Can wait outside and be called on the cellphone when our turn comes to take the medical examination", and [Personal environment] including "There are many nurses and support at the time of treatment so the number of family members attending the hospital should be lim-

ited", and "Nursing staff will skillfully handle any trouble among children".

4) Provision opportunities to get acclimatized This category comprises the category [Provision of opportunities to get acclimatized] including "If his/her condition is not so severe, avoid forcibly holding him/her down or giving painful treatment from the beginning", "Acclimatize him/her step-by-step" "Even for minor injus-

down or giving painful treatment from the beginning", "Acclimatize him/her step-by-step", "Even for minor injuries, he/she can undergo medical examinations in the form of regular medical checkups", and "Praise with clapping for what he/she is able to do even for small things and increase what he/she is able to do".

5) Provision of warm support

This category comprises the categories [Support for family] including "Even for situations in which carrying out the medical examination is difficult, avoid looking frustrated and provide encouragement that everything is okay", and "Avoid demanding reasons regarding why he/she cries or is confused, performing medical examinations and providing treatment in a straightforward manner", and {Support for patients} including "Whether or not he/she is able to understand an explanation, provide the explanation directly to the patient themselves".

6) Understanding of patient characteristic

This category comprises the category [Understanding of patient characteristic] including "Trying to understand what kind of characteristics he/she has", "Being asked at the reception counter 'What kind of support do you need?", and "Make a support book available".

3.4. Opinion, etc. Regarding Nursing Care when They Undergo Medical Examinations at the Medical Institutes

Table 4 shows the opinions, etc. regarding nursing care when they undergo medical examinations at medical institutes. Here, the categories [Concerns about the future] including "It is difficult to undergo examination such as complete medical checkups unless sick. We wish it were possible to undergo complete medical checkups at hospitals for those with disabilities", "We cannot receive treatment even when dialysis or treatment for diabetes is necessary", and "We hear that following surgery he/she may touch the injury or remove the sutures even when restrained. We do not believe we can handle such surgical situations", [Difficulty getting to the hospital] including "If possible, we wish to treat him/her with commercial drugs and avoid going to the hospital", "Even if he/she undergoes a medical examination, drugs cannot be used, so we do not go to the hospital unless the symptoms are severe", "It is most annoying when we have to bring our autistic child with us in order to take his/her brother or sister to the hospital", and "We believe there are few medical personnel who accurately understand disabilities", [Parents also strive to make the medical examinations go smoothly] including (We try to show picture books or picture cards to have him/her image what will take place in advance), (We bring something with which he/she can pass the time), and [Selec-

Table 4. Opinions, etc. regarding nursing care when they undergo medical examinations at the medical institutes.

Category	Items pointed out		
	It is difficult to undergo examination such as complete medical checkups unless sick. We wish it were possible to undergo complete medical checkups at hospitals for those with disabilities.		
Concerns about the future	We cannot receive treatment even when dialysis or treatment for diabetes is necessary.		
	We hear that following surgery he/she may touch the injury or remove the sutures even when restrained. We do not believe we can handle such surgical situations.		
Difficulty getting to the hospital	If possible, we wish to treat him/her with commercial drugs and avoid going to the hospital.		
	Even if he/she undergoes a medical examination, drugs cannot be used, so we do not go to the hospital unless the symptoms are severe.		
	It is most annoying when we have to bring our autistic child with us in order to take his/her brother or sister to the hospital.		
	We believe there are few medical personnel who accurately understand disabilities.		
Parents also strive to make the medical examinations go smoothly	We try to show picture books or picture cards to have him/her image what will take place in advance.		
	^y We bring something with which he/she can pass the time.		
Selection of hospitals	We try to select hospitals that may possibly understand children with development disabilities through information exchange among parents.		
	We try to select hospitals that are able to understand what kind of treatment is required, such as a family doctor which we have regularly visited from a younger age.		
	We will not select a hospital crowded with patients.		

tion of hospitals] including "We try to select hospitals that may possibly understand children with development disabilities through information exchange among parents", "We try to select hospitals that are able to understand what kind of treatment is required, such as a family doctor which we have regularly visited from a younger age", and "We will not select a hospital crowded with patients" are included.

4. DISCUSSION

4.1. Regarding the Situations in Which They Feel Difficulty at the Time of Undergoing Medical Examinations at the Medical Institute

There were situations that many subjects described as being difficult as well as situations that a portion of the subjects described as difficult. "Not good at painful treatment" and "unable to complain regarding symptoms", etc. were stated by many subjects as difficult; however, although there were difficult situations believed to be derived from the characteristics of developmental disabilities, not all the subjects described having the same difficulty and each individual characteristic is different even within the same disability of autism. Based on this, it is necessary for nursing personnel to understand situations in which many children with disabilities feel difficult as a characteristic of their disability and take action to try to understand each individual characteristic. In addition, many subjects pointed out situations derived not only from painful treatments such as injections, but also unpredictability or difficulty in communication with medical personnel as being difficult. Although, as measurements for these there are brochures showing support methods such as visual support including showing procedures with pictures, it is believed necessary for these kind of measures to be widely spread among medical personnel and the families of children with disabilities. For difficult situations, besides direct medical examinations, many problems with regard to hospital environments such as speaking out in the waiting room and trouble with other patients were pointed out. Based on this, adjustment of the surrounding environment such as by allowing patients to wait in a private room, if the physical situation permits, is believed to be a good idea not only for children with disabilities and their families but also other patients, thus suggesting that it is necessary to take this into consideration as much as possible.

4.2. Regarding Nursing Care They Felt Necessary at the Time of Undergoing Medical Examinations Authors and Affiliations

In terms of nursing care that parents think necessary,

having them prospect with letters or pictures, etc. depending on disability characteristic was pointed out. As far as we can tell after overviewing several textbooks included in basic nursing education courses, this individual support is not included [16,17], leading us to believe that nurse students may not have been properly trained by the time they graduate. It is suggested that it is necessary for nurses to be provided with an opportunity to take training after graduation. Furthermore, one situation was pointed out in which, when suppression is necessarv at the time of treatment for children with disabilities, etc., a plurality of family members have to attend the medical examination for the children with disabilities. so it is desirable that many nurses who can assist or hospital nursery staff members who can handle trouble among children be made available. It is believed that even in local clinics, in which manpower such as nurses is usually not so large, a large staff will allow families to easily undergo medical examinations. It is suggested that although the number of staff members such as nurses is believed to be limited, it is necessary in case of manpower shortages for staff members other than nurses to become involved in medical examinations in addition to creating a situation in which a plurality of family members do not have to addend medical examinations.

In this study, it is stated that over the course of several opportunities to undergo medical examination, children with disabilities become acclimatized to and are able to undergo medical examinations. It is believed that this is not only because children with disabilities grow up and come to have a good understanding, but also because they can become acclimatized to and learn behaviors during medical examinations. It is believed that this is because the children with disabilities in this study also included adults and they experienced becoming able to behave well at medical examination as they grew up. In several studies on parents of children with autism, they stated their experience regarding having been turned down for medical examinations, so it is believed that it is necessary to support providing opportunities to visit clinics with the goal of becoming acclimatized to medical examinations while the symptoms are mild, rather than turning down medical examinations or creating an atmosphere that makes it difficult to visit again because of difficulties involved with taking medical examinations. Furthermore, it is believed that for parents who feel burdened due to the difficulties involved with taking medical examinations, medical personnel need to inform them that there are instances for children to become acclimatized and make taking medical examination easier so that parents may stay hopeful and possibly reduce their feeling burdened. It is suggested that it is necessary for nurses to intentionally discuss this.

4.3. Opinions, etc. Regarding Nursing Care When They Undergo Medical Examinations at Medical Institutes

Other items stated included serious concern for the future such as difficulty in the event of surgery or continuous treatment due to chronic disease. Regarding the prevention of adult disease or complete medical checkups for patients with autism pointed out in this study, there is a study on the approach of a support system for medical examinations by means of IT [18] and a preceding thesis indicating the effectiveness of this approach based on a review of results implemented in a hospital [19]. However, neither of these are even tentative and according to our research, we cannot find such a system even in specialized hospitals for children with disabilities; thus, it has been found that it is actually difficult for children with disabilities to undergo examinations in order to maintain their health such as via complete medical checkups. As indicated from statements for various difficult situations that families try to handle with commercial drugs so as to avoid visiting hospital as much as possible or select hospitals that are easy to visit based on information exchange among parents, it is desirable that opportunities to undergo medical examination be increased by adjusting the surrounding environments for medical examination.

5. LIMITATIONS OF STUDY

In this study, the subjects under study were not limited by severity or age. Although we were able to extract a lot of individual supports, it has not led us to clarify the characteristics of the necessary support derived from these patient attributes. In the future, it is believed necessary to increase the number of subjects, clarify the difficulties that many children with disabilities encounter, and create guidelines that people can reference regarding nursing care depending on individual disabilities.

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