A Study of Tending Methods in the Parents of Autistic Children

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Abstract:
The main purposes of this research were to investigate tending methods in the parents of autistic children who lived in Chiang Mai province. The sample selected for the study was 10 families, with good development of their autistic children, in order to ascertain tending methods that these parents used in their daily lives.

The study was a qualitative research. The principal participants were parents of autistic children who were selected by purposive sampling from those who came to service at rehabilitation center, Muang, Chiang Mai. Data were collected by in depth interview using the concept of Health Belief Model as guideline of questions, which covering the areas of perceived susceptibility, seriousness, benefits and barriers of treatment programs. The study also used Human Occupation Model as leading conversation to explore volition, or a determination toward success, which relevant to several factors including personal causation, values and interest of good raising strategies and tending methods of parents with good development autistic children.

The main results of the study were as follows. There were a variety of physical and mental health conditions of the mothers of the autistic children that affected them during pregnancy and differences were also found in the delivery methods. Prior to the diagnosis of autism, all parents bringing up their children as normal persons. However, after the diagnosis of autism, these parents sought for a variety of methods to stimulate the development of their children, comprising of acceptance of their children as autistic persons, perceived susceptibility, seriousness, benefits and barriers of treatment programs and increased attention to their child’s development. In addition, they had strong determination to devote themselves as good caretakers. They also valued their performance and were interested in the progression of their children’s development. They were not only seeking helpful information but also brought their children to regularly receive developmental stimulation services from health professionals including psychiatrists, occupational therapists, speech pathologists, and special educators. The practice programs were held both in hospital and at home.

Regarding the education of their children, they also communicated with the teachers and director of the schools to exchange information about the children’s performance. Other techniques that these parents used, rather than what was suggested by the health professionals, were the selection of treatment activities that suited the interest of these children, use activities of daily living as treatment media, playing with siblings and providing practice equipments at home.

Keyword: Autistic, Tending Method, Health Belief Model, Human Occupation Model, Development

Introduction:

1 A research submitted for the degree of Doctor of Philosophy, Behavioral Science Research Institute, Srinakharinwirot University, Thailand
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to the age of autistic children. (Oratay Tongpetch. 2002) There are only some government authorities within the circle of specialist physician and special educator who seriously concern this kind of children. The shortage of specialist professional and dissemination of concern affect the parents on lack of knowledge information for tending the children. Therefore, the development in various aspects of children may not be fully performed as to the potential capability. The treatment and support of autistic children are quite complicated and require patience, knowledge, understanding, experiences, and continuous duration. The parents then have to perceive the sickness and symptom (Prapapan Suwan. 1984) as well as the limitations of the children thoroughly in order to form the earnestly cooperation with the therapists. (Umamorn Trongkasombat. 2002) Presently, many parents only suspect or formally realize that their children are autistic. Those parents have not yet known the therapy method or developmental stimulation for their children to escape from delayed development. The parents mostly perceive the therapy method when the children are too old to stimulate the development effectively. Hence, the researcher is interested in studying the tending behavior of the parents who created the good development to their autistic children. The study will be the guideline for the other forthcoming parents who have autistic children in order to facilitate the appropriate tending behavior, which will be an important basis for the better development.

Objective:

To study the tending method in the parents of autistic children who obtain the good development.

Material and Method:

The study was a qualitative research using in depth interview to the parents who had autistic children with good development. Those children received the developmental stimulation at Department of Occupational Therapy in Faculty of Associated Medical Sciences of Chiang Mai University, Clinical Services Center in Faculty of Associated Medical Sciences of Chiang Mai University, and Special Child Center (Northern) of Chiang Mai Ram 1 Hospital in Chiang Mai Province. The Childhood Autism Rating Scale (C.A.R.S) was implemented as a standard questionnaire to assess the symptom seriousness of each child by interviewing the parents. The researcher also collected the data by observation and recording. The parents were observed while being interviewed by the researcher. In addition, the observation was conducted while the parents were bringing children to receive the developmental stimulation, waiting for receiving the developmental stimulation, or leaving after the completion of stimulation. The researcher would obtain the information of tending guideline according to the real situation. Methodological triangulation, data triangulation, and field note were conducted after each interview. After that, the researcher transcribed the conversation word for word from the recorder without any translation in order to maintain the original language and meanings. The dialogues then were taken for content validity check with the information provider again prior to editing. The entire mentioned procedures were able to produce internal validity (Pattraporn Toengpankarn, Kanuengnit Chailangkarn. 2003; refer to Sandeloski. 1986) to this research. Finally, those data were gathered and analyzed using inductive analysis method (Supang Chantawanich. 2002).
The information providers for this research were totally 11 persons including 2 males (Father) and 9 females (Mother) from 10 families (Both father and mother from 1 family were interviewed). The range of age was 25-48 years old (39.21 years old average). 10 interviewers and 1 interviewer obtained university education and primary education respectively. Their occupation comprised 5 government officers and hiresings, 3 working at home, and 3 housewives. The data indicated that the average household income over 30,000 Baht per month, 10,000-20,000 Baht per month, and 20,000-30,000 Baht per month from 6, 3, and 1 families, respectively. The pattern of families was composed of 8 single families and 2 extended families. The total numbers of autistic children being brought up by the parents participating in this research were 10 persons including 7 males and 3 females. The range of age was 3-6 years old with 4.64 years old average. The symptom seriousness of these children was in moderate level. The information were collected not only from the parents but also the cousins of the children such as aunts or nannies who were in place of the parents to take the children to receive the stimulation occasionally as well as the involved medical personnel such as physicians and occupational therapists. Moreover, the researcher interviewed the personnel in the families such as nanny, aunt, grandfather, and grandmother for 4 persons. The result of the research can be concluded as follows:

1 Child tending prior to the diagnosis of autism includes 2 periods i.e.

1.1 During pregnancy - The study indicated that the mothers of autistic children had normal physical and mental health conditions. They provided good tending to the child during the pregnancy. There were a variety of pregnancy conditions from this research.

During the observation of abnormal development prior to the diagnosis of autism - The study indicated that, prior to the diagnosis of autism, all parents brought up their children as normal as the general children. Those parents increased the tending in different dimensions just after the children were older and behaved abnormally comparing to the general children or cousins' children. They conducted development observation of children by comparing the abnormal behaviors and development between their children and general children. The observation was conducted both by themselves and relevant people such as cousins, intimate friends, or teachers as well as the pediatricians. All of them found various types of delayed development in term of communication such as no response to calling, being unable to express their needs, restless behavior, too naughtiness, fierce emotion, no interrelationship with people, delayed development of speaking skill, etc. Consequently, all parents arose the interests to search the relevant information from television, books, or magazines. Most of parents commented that there was not sufficient media to educate them about the symptom observation and tending method. Some parents attempted to solve the delayed development by themselves at first such as making a superstitious sacrifice. They would bring the children to the physician after they had spent time to seek the preliminary information and prove that the developments of their children were abnormal. Besides the previous mentioned seeking, most of parents took children to various hospitals in order to receive the exact diagnostic. There was just only 1 parent who immediately took the child to receive the developmental stimulation according to the recommendation from a health professional. The continuous tending was an important factor to stimulate the
development of the children fastest. The immediate treatment after the abnormality found would reduce the disability potential and rehabilitate the potential capability of children (Siegel.1996 : 56) especially before 5 years old which is the age of overall growth and development (Penkhae Limsila.1995 : 358).

2. Child tending method after the autism diagnostic

2.1 The acceptance of child as an autistic person - Family had to understand and accepted the development problems of child as fast as possible. The supports from the family members would increase hope to the parents. As a result, they would concentrate on children development instead of being depressed by the autism. (Hornby, 1992: 18 referred in Wongduean Decharint. 2003)

2.2 The parents seek the knowledge concerning the autism and relevant treatments - The parents will perceive susceptibility, seriousness, and benefits and barriers of treatment programs, which conformed to the Health Belief Model. The susceptibility and seriousness perception were composed of symptoms, causes, treatment programs, and tending method. After the diagnosis by the physician until the parents were able to accept the abnormal development of their children, they started to aware of various aspects especially the symptoms of autism from the media. That information could be acquired from doctors, therapists, and other media such as books, televisions, or Internet. Every parent observed the abnormal behaviors of their children and compared with the obtained information. All families did not know the exact causes of autism but they attempted to gather the related information from media. For the treatment aspect, the parents had commenced the treatment since they had suspected the development of their children. After the exact diagnosis, they started to increase searching information. The parents perceived the benefits and barriers of treatment programs preliminarily from physicians, health professionals, medias or other parents who also had autistic children. Once they implemented those programs, the good development was indicated. The barriers were mainly composed of insufficient practicing place, high expense to receive developmental stimulation, availability of caretaker to be with children in the school, and lack of recommendations from physician during the initial stage.

2.3 The parents increase attention to their children - As a result of the perception of susceptibility, seriousness, and benefits and barriers of treatment programs, the parents increase attention to their children.

2.4 The parents bring their children to receive the stimulation of development regularly with specialist and utilize the various methods to them at home – The parents had strong determination to stimulate the good development toward success. They also valued their performance and were interested in the progression of children’s development. The progression resulted from regularly receive practice program both in hospital and at home as per the recommendations with the additional attention as well as the cooperation with teachers in children’s tending. One parent who believed in superstitious and religious belief conduct the medical treatment together with her own method as believe. After receiving the developmental stimulation services, applying all recommendations at home, and distinguishing the progression, all parents agreed upon the value of this method and increased attention to their children. Therefore, it encouraged the parents to implement the method from health professionals effectively. They might expect their
children to live in the society on their own in the future. The tending method, which the parents were conducting, conformed to the Human Occupation Model.

2.5 The parents have to coordinate closely with the school personnel concerning the tending of their children – The discussion with school management and class teachers concerning the development and behavior of the child was necessary in order to look after continuously. A health professional was required to attach with the child who had behavior problems such as being unable to sit for a long period, very short attention in any matters, and being unable to communicate with people. He would aid and improve the behavior, education, and socialization among the same aged children.

2.6 Developmental stimulation in various aspects by specific health professionals which included consulting psychiatrists, stimulation the development by occupational therapists and apply behavior therapy, encouraging the communication by speech pathologists, and encouraging the education by special educators.

2.7 Technique of tending being used by parents – Besides the suggestions from health professionals, each parent had each own technique which was the arrangement of stimulation in every opportunity during daily life such as taking a shower, cooking, etc. In order to stimulate the development, parents had to train the children by the created activities at the same time of daily activities before adding the other training. The necessary training tools should be provided to increase the stimulation. Brothers or sisters of autistic child might be able to practice the social skills by playing together.

Conclusion

1. There were 2 stages of tending before the realization of autism from children. Autistic children were brought up as normal children during pregnancy stage. Regarding the stage during the observation of abnormal indication prior to the diagnosis of autism, the parents just observed the development comparing to other normal children and sought the information of abnormality.

2. The method of tending after the diagnosis of autism

Families had to understand and accept the abnormal development of child as fast as possible. Furthermore, the support among the family members, seeking the knowledge of autism and treatment, devoting more attention to the child, bringing the child receive development stimulation regularly, and apply the methods from the hospital at home. During the age of education, parents had to coordinate with the school personnel and health professional closely concerning the tending and development stimulation in various aspects. Finally, the child also had to receive the facilitation of development at home.
Reference


