AUTISM BEFORE DIAGNOSIS

診斷前之自閉症

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Running titles: Autism before Diagnosis

Autism is a pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifested before the age of 3 years [1]. In spite early onset is one of the diagnostic criteria and most caregivers did observe some features of autism in the earlier age, a diagnosis is not often made until the age of 4 or later [2]. The reason for the delay in diagnosing autism at an early age may be related to the nature and development of the condition, the lack of the specialized training, the inadequacy of the services, or the absence of the appropriate standardized assessment procedures [3]. Early interventions to developmental disorders like autism have been considered beneficial and critical to these children and their family [4,5]. However, the delay of the diagnosis forms the obstacle of early interventions. This study retrospectively collected the information about the early features of autistic children from their caregivers, which will provide the basis for the future development of the instrument for early diagnosis of autism [6].

Patients and Methods

Ten caregivers of the preschoolers with autism from the day hospital of National Taiwan University Hospital were voluntarily in-depth interviewed. These children were referred from the special clinics of autism in Children's Mental Health Center of the same hospital Their diagnoses were confirmed by the senior child psychiatrist (Soong) through the comprehensive physical and psychological assessment in the special clinics, and they had regularly participated the training program in day hospital before the interview.

Semi-structured questionnaire was developed to collect information on the early features of autism in general and in several specific aspects, i.e., play, communication, interpersonal relationship, and daily activity. The researcher (Tsai) interviewed these caregivers face to face, which took about 30 minutes. Caregivers were first encouraged to review the early features of their children in detail under general and open questions, then described more specific features. Interviews were tape-recorded, transcribed verbatim, and analyzed word by word. The data analysis followed the collection immediately, and both were performed concurrently. The interviewing was ceased when no more new information emerged from the analysis.

Qualitative data analysis according to Miles and Huberman [7] was used in the analysis. Coding and categorizing were first used to analyze the data. Through the process of data collection and analysis, codes and categories were added or reduced, and their operational definitions got clearer. Cross-case analysis method, including case-oriented and variable-oriented analysis was used to relate, to compare, and to attribute the coded data in order to generate the result [7].

Results

There were 8 boys and 2 girls among 10 cases of autism. The age was between 2-year-0-month and 6-year-8-month (averaged: 4 years and 7.3 months). The age of definite diagnosis was between 1-year-7-month and 3-year-6-month (averaged: 2 years and 5.2 months). Eight caregivers were mothers, one was father and one grandmother.

Three pattern codes were derived from the qualitative analysis: social interaction (Table 1), stereotyped behavior (Table 2), and speech development (Table 3). Categories, features and examples of three pattern codes are presented. The distribution of these features among the children is quite even. All case presented the features of at least 2 pattern codes (Table 4).

Social Interaction

No response was the most common response to others' approach among autistic children. "*Not caring for anybody*" was frequently revealed in the interviews, and even avoiding others' verbal or physical approaches also noted.

Autistic children had little spontaneous speech and behaviors toward people, and "*playing by himself*" was most often reported. Some caregivers even described them acting "*like nobody in the world*".

Expressing the requests with voice or finger pointing like normal children was never noted among the children with autism. The most disabled child "*gave up when he can not get it by himself*." Some children were only able to cry or scream, and waited for caregivers to guess and to fulfill their wishes. The best way for these caregivers' understanding was "*pulling our hands to the place or the thing he wanted*."

Stereotyped Behavior

Stereotyped behaviors in various aspects of activities, including feeding, clothing walking, sleeping, playing and self-stimulating had been developed in autistic children since very early age. Almost every caregiver talked about stereotyped behaviors related to feeding maybe because it took a large part of daily activities in infants and toddlers. Some concerned the food content like refusing anything except liquid, and some the feeding patterns like the fixed posture to drink the milk.

Spinning and arranging were also quite common, including spinning self and objects, and arranging objects in a line. Sometimes stereotyped behaviors were shown interpersonally, such as "*he always stuck on my body while sleeping. When I moved a little, he would wake up immediately and stuck on me again,*" which may be misunderstood by caregivers as a manifestation of normal social development.

Speech Development

Delay and blockade in the speech development are included. About a half of

caregivers considered speech problem as an early feature of autism. Some children totally spoke nothing till 2 to 3 years old, and some had no progress for a long time after first few words developed.

Discussion

This study obtained retrospective reports from caregivers through the use of in-depth interviews and affords a window into early infant behaviors of autism from the caregivers' point of views, which may offer contribution to the basis of community screening questionnaire used in caregivers. Limitations of the design need to be acknowledged, particularly the known liabilities related to distortions and inaccuracies of recall [8], relatively small sample size, and lack of comparison groups. Under these limitations, our results might be less generalizable and less specific for early symptomatology of autism.

Before the formal diagnosis or even any ideas about autism, caregivers had noticed many special behavioral features of their children in daily activities. These early features of autism were categorized in three areas, i. e., social interaction, stereotyped behavior, and speech development. Formal diagnostic requirements are often not met from these features because diagnostic criteria require a certain level of cognitive and language development before particular deficiencies (e. g., peer relationship problems, language abnormalities) become apparent. However, a pattern of distinct social and communicative impairments may be observable within the first 2 years of life [8].

Social Interaction

The information about the features of social interaction is richest（Table 1）. Every caregiver provided much description about this. They observed the children's behaviors and responses toward others, spontaneously or passively, with or without requests, in the context of daily interpersonal activities. Caregivers always felt very hard to interact with these children in these activities, which let them consider the children different or abnormal from others and frequently forced them asking for professional help. This result is consistent with the notion that social deficits are the most prominent DSM-IV characteristics evidenced by very young children with autism and social impairments are central to the disorder [9,10].

The difficulties to request with verbal and non-verbal behaviors were extracted from other features in social interaction for better recognizing and understanding. In their daily lives, most caregivers subjectively felt very frustrated to realize what the children really wanted or were interested in. These children did want something or doing something, but they can not reveal their intentions toward others and certainly

also what they wanted caregivers to know or to do. In the serial studies of Baron-Cohen et al, the protodeclarative pointing (i.e., pointing to indicate interest) had been used as an item of screening checklist and considered as a psychological marker in the detection of autism at 18 months old [11,12].

Stereotyped Behavior

Autistic children developed stereotyped behaviors in various aspects of activities, including feeding, clothing walking, sleeping, playing and self-stimulating since very early age（Table 2）. These abnormal behaviors usually disrupted the daily schedules and upset caregivers very much. By contrast with the presentation of social interaction, these behaviors showed more variability from child to child, and were endorsed with less consistency, which might explains why very little research has ever focused on these behaviors [8]. Adherence to routines or ritual was relatively rarely observed, supporting previous findings that this behavior may emerge later in the developmental course of autism and more apparent in older children than in younger children [9,13,14].

Speech Development

Speech development problems did not take as much attention as others（Table 3）, which may be caused by the collected information emphasizing the features in early stage. Only a half of caregivers considered, if they did observe, speech problem as an early feature of autism. In a study of parental reports and clinical observation in children younger than age 48 months, three language/communication items, i.e. abnormal speech production, abnormal speech content and impaired conversational skills, were seen and reported rarely for young children and are of less utility for screening or diagnostic purposes [15].

The results of this study support several studies based on parental report that the early onset of the autistic symptoms have been identified [16,17] and the clinical diagnosis of autism may be made reliably before the age of 3 years [18,19]. The features observed by caregivers were much more upon social interaction domain, like lack of social reciprocity and non-verbal communication, than other characteristics among the diagnostic criteria like ICD-10 [20] and DSM-IV [10]. Conspicuously the behaviors indicative of disordered peer relationships, abnormal language feature and a need for sameness and routines are likely not yet apparent in such young ages [19,21]. These results most likely reflect the young developmental level of the children, and the usually used diagnostic characteristics thus appeare to be of limited utility for them [9].

References:

1. World Health Organization: *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. Geneva: WHO, 1992.

2. Siegel B, Pliner C, Eschler J, et al: How children with autism are diagnosed: Difficulties in identification of children with multiple developmental delays. *Developmental and Behavioral Pediatrics* 1988; 9:299-304.

3. Vostanis P, Smith B, Chung MC, et al: Early detection of childhood autism: a review of screening instruments and rating scales. *Child: Care, Health and Development* 1994; 20:165-77.

4. Lovaas OI: Behavioral treatment and normal educational and intellectual functioning in young autistic children. *J Consulting and clinical Psychology* 1987; 55:3-9.

5. Howlin P: Prognosis in autism: Do specialist treatments affect long-term outcome? *European Child Adolesc Psychiatry* 1997; 6:55-72.

6. Gillberg C, Nordin V & Ehlers S: Early detection of autism. Diagnostic instruments for clinicians. *European Child Adolesc Psychiatry* 1996; 5:67-74.

7. Miles MB, Huberman AM: *Qualitative Data Analysis.* 2nd ed. Thousand Oaks: SAGE Publications, 1994.

8. Stone WL: Autism in infancy and early childhood. In: Cohen DJ, Volkmar FR, eds. *Handbook of Autism and Pervasive Developmental Disorders.* 2nd ed. New York: Wiley, 1997: 266-82.

9. Stone WL, Lee EE, Ashford L, et al: Can autism be diagnosed accurately in children under 3 years? *J Child Psychol Psychiatry* 1999; 40:219-26.

10. American Psychiatry Association: *Diagnostic and Statistical Manual of Mental Disorders,* 4th ed (DSM-IV). Washington, DC: APA, 1994.

11. Baron-Cohen S, Allen J & Gillberg C: Can autism be detected at 18 months? the needle, the haystack and the CHAT. *Bri J Psychiatry* 1992 161:839-43.

12. Baron-Cohen S, Cox A, Baird G, et al: Psychological markers in the detection of autism in infancy in a large population. *Bri J Psychiatry* 1996; 168:158-63.

13. Dahlgren SO & Gillberg C: Symptoms in the first two years of life. *European Archives of Psychiatry and Neurological Science* 1989; 238:169-74.

14. Lord C: Follow-up of two-year-olds referred for possible autism. *J Child Psychol Psychiatry* 1995; 36:1365-82.

15. Stone WL, Hoffman EL, Lewis SE, et al: Early recognition of autism. Parental report vs. clinical observation. *Arch Pediatr Adolesc Med* 1994; 148:174-9.

16. Spitzer RL & Siegel B: The DSM-III-R field trial of pervasive developmental disorders. *J Am Acad Child Adolesc Psychiatry* 1990; 29:855-62.

17. Volkmar FR, Cohen DJ, Hoshino Y, et al: Phenomenology and classification of

childhood psychoses. *Psychol Med* 1988; 18:191-201.

18. Gillberg C, Ehlers S, Schaumann H, et al: Autism under age 3 year: A clinical study of 28 cases referred for autistic symptoms in infancy. *J Child Psychol Psychiatry* 1990; 31:921-34.

19. Lord C: Follow-ups of two-year-olds referred for possible autism. In: *the meeting of the society for Research in Child Development, 1991, Seattle, WA.*

20. World Health Organization: *The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research.* Geneva: WHO, 1994.

21. Stone WL & Hogan KL: A structured parent interview for identifying young children with autism. *J autism Develop Disorders* 1993; 23:639-52.

Table 1. Categories, features and examples of social interaction in early autism

Category and features	Examples
Responses to others' approach	
no response	*she showed no responses at all while we talked to her*
avoiding	*he went away when we wanted to hug him*
Spontaneous behaviors toward others	
no spontaneous approach	*he played in the corner himself without any interest to others*
non-interacting behavior	*he talked and laughed by himself, enjoying only himself*
Requesting	
pulling others' hand	*he pulled your hand to the pot when he wanted to drink water*
non-directive behavior	*he only cried, and I had never known what he wanted*
no requesting	*he gave up when he can not get what he wanted*

Table 2. Categories, features and examples of stereotyped behavior in early autism

Category and features	Examples
Feeding related stereotyped behavior	
fixed content of food	*he was very stubborn about the food, he only ate certain things and refused others*
fixed pattern of feeding	*he must watch commercial on TV when he drank milk*
Spinning	
spinning self	*he liked others holding him and turning circles, and he kept asking for that*
spinning objects	*he span everything, such as dolls, pens, paper...etc*
Arranging objects in a line	*he liked to arrange everything of larger amount in a very straight line*
Other stereotyped behavior	*he was obsessed in TV commercial very much*
	he followed the exactly same route to the park

Table 3. Categories, features and examples of speech development in early autism

Category and features	Examples
Delay in speech development	*he cannot call 'papa', 'mama' until one and a half years old*
Blockade in speech development	*his speech development had no progress for 7 months after the first word at one year old*

Table 4. The distribution of early features in 10 cases of autism

Categories & Features \ Case No.	1	2	3	4	5	6	7	8	9	10
Social Interaction										
Response to others' approach	X	X		X		X	X	X	X	X
Spontaneous behaviors toward others	X	X	X	X	X	X	X	X	X	X
Requesting	X	X	X	X	X	X	X	X	X	X
Stereotyped Behavior										
Feeding related stereotyped behavior	X		X	X		X	X		X	X
Spinning	X		X	X				X	X	X
Arranging objects in a line	X	X	X							
Other stereotyped behavior	X		X	X	X		X	X	X	X
Speech Development										
Delay in speech development	X						X	X		X
Blockade in speech development			X							