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ORIGINAL ARTICLE

Determinants of maternal satisfaction with diagnosis disclosure of autism



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Received 16 March 2012; received in revised form 30 July 2012; accepted 30 July 2012

KEYWORDS

autism;
disclosure;
informed counseling;
mothers;
satisfaction

Background/Purpose: Diagnosis disclosure is an important clinical issue in developmental disabilities, which may influence parents' ability to cope with their child's conditions. This paper presents the content and patterns of diagnosis-informed counseling for mothers of children with autism and investigates the determinants for maternal satisfaction with this counseling, in order to improve clinical practice.

Methods: Mothers of 151 children, aged 3–12 years, with DSM-IV autistic disorder, confirmed by the Chinese version of the Autism Diagnostic Interview—Revised, were assessed. We collected information about the mothers' experience with diagnosis-informed counseling, their personality characteristics, and the extent to which they were satisfied with the counseling.

Results: Satisfaction with diagnosis-informed counseling was related more to the context of the counseling, including the attitude of the counselors and the timing and duration of counseling, than to its content. Parents' social desirability, educational level, and employment status were negatively associated with their satisfaction with counseling. However, immediate

Conflicts of interest: The authors have no conflicts of interest relevant to this article.

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emotion, neuroticism, and extroversion did not have a significant effect on the satisfaction with counseling. Approximately 60% of the mothers preferred to be informed of having an autistic child after the diagnosis had been confirmed.

Conclusion: Our findings suggest that more efforts are needed to improve the quality of diagnosis-informed counseling in autism, particularly in the context of breaking the news to mothers of children with autism. Future study could further examine the moderating effect of diagnostic subtype of autism spectrum disorders, treatment response, or social support on maternal satisfaction with diagnosis-informed counseling (ClinicalTrials.gov number, NCT00494754).

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Introduction

Parental ability to cope with having a child with disability is greatly influenced by the initial information received.¹ The way in which a child's disability is disclosed affects the parents' adaptation to their child's condition, which may, in turn, affect the early treatment of the child.² Therefore, it is clinically relevant to know the extent of parental satisfaction with the diagnosis-informed counseling, which is defined as how the diagnosis is disclosed to the parents and how the related issues are discussed.

Parental concerns regarding the way in which they were informed of the diagnosis have been studied for decades in case of chromosomal diseases such as Down syndrome,³ congenital malformations such as spina bifida,⁴ or severe mental disability.⁵ Several factors that concern parents include the information addressed, the way counseling is delivered, and the timing of counseling. For example, in case of Down syndrome, several studies have shown that most parents are not satisfied with diagnosis-informed counseling.^{3,6,7} The reasons are counselors' cold attitude and poor communication skill, inadequate information, unanswered questions but too many negative messages, and wrong time for informing about diagnosis. To summarize, most parents wish to know the diagnosis as early and comprehensively as possible, to discuss their own questions, to express their emotions, to have a counselor with a supportive and empathetic attitude, and to feel that they are involved in the management of their child's condition.^{8–11} Besides, the large amount of information should be organized to avoid swamping the parents; regular support is also suggested when communicating an evolutionary diagnosis.¹¹

Three studies using self-administered questionnaires to examine the parental reaction to the disclosure of autism in Japan,¹² Scotland,¹³ and Israel¹⁴ have demonstrated that about one-half to two-thirds of parents were satisfied with the diagnosis disclosure. All highlight the importance of the quality, amount, and type of information conveyed, and the physician's attitude. Besides, full explanation of the disability, instruction about coping strategies and social resources, provision of written information, and opportunity for parents to ask questions are also related to parental satisfaction. Futagi and Yamamoto¹² found that early disclosure was related to early acceptance among parents, and that more acceptance was noted in parents with more understanding of autistic behavior or having better communication with their own child. These studies have

been limited by sample size, except for Brogan and Knussen's study ($n = 126$),¹³ mixed diagnostic groups, and less information on parental characteristics, such as their psychopathology, personality characteristics, and immediate emotion upon diagnosis disclosure, which may influence the parents' reports on their satisfaction. Besides, few studies have addressed whether parental education, occupational status, and socioeconomic status are associated with parental satisfaction.

Although this topic had been drawing clinical and research attention for decades, recent studies have less examined the determinants for parental satisfaction with informed counseling in autism. Moreover, there is no such information about the Chinese population. Hence, the purpose of this study were as follows: (1) to describe the current practice on diagnosis-informed counseling of autism in Taiwan, (2) to evaluate maternal satisfaction with diagnosis-informed counseling, (3) to identify the factors related to maternal satisfaction, and (4) to present the ideal diagnosis-informed counseling that mothers expect. We hypothesized that maternal satisfaction toward diagnosis-informed counseling could have more than one component and that each factor of satisfaction could be predicted by different determinants. We also assumed that maternal determinants (such as education level, personality, or psychopathology) would influence mothers' perception and play a role in their sense of satisfaction (Fig. 1).

Methods

Participants

We recruited 151 mothers who have one child with autistic disorder (132 boys, 87.4%) from the day hospital unit and outpatient clinic of three medical centers ($n = 115$, 76.2%), one training center for autism at a psychiatric hospital ($n = 24$, 15.9%), and one early intervention center for autism ($n = 12$, 7.9%). The inclusion criteria for autism probands were as follows: children with a diagnosis of DSM-IV autistic disorder, those receiving a treatment program prior to 6 years of age, and those living with both biological parents. Mothers who cannot read or understand Chinese, or patients with Asperger's disorder or other pervasive developmental disorders were excluded from the study. The refusal rate was around 6.2% during study recruitment.

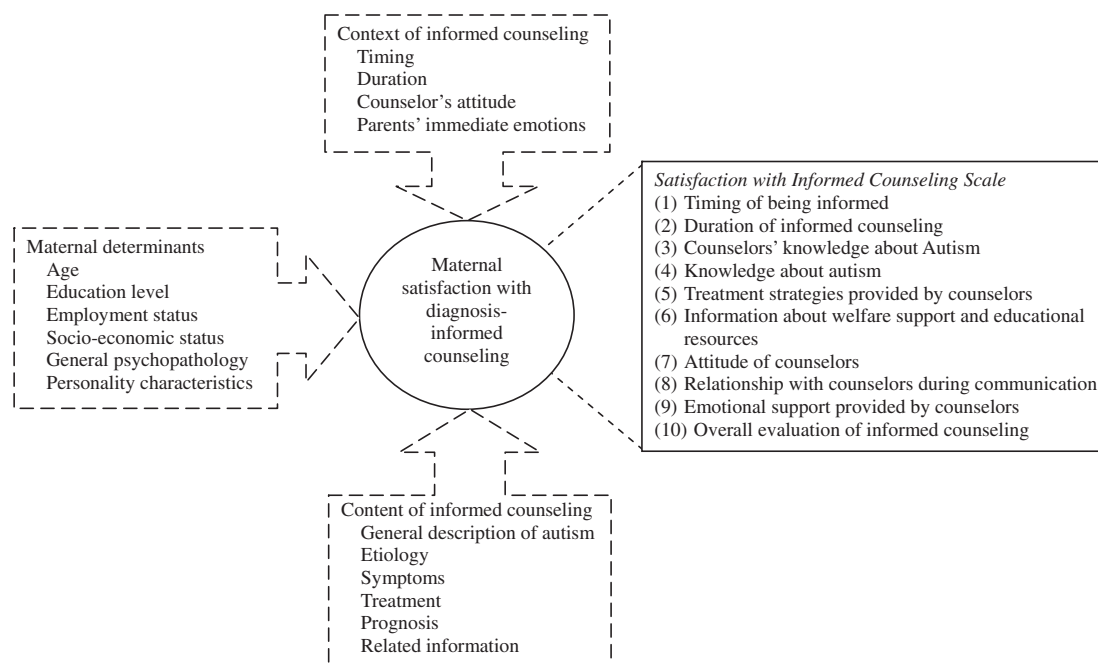


Figure 1 Conceptual framework of determinants for maternal satisfaction with diagnosis-informed counseling.

Measures

Content of Informed Counseling Scale

The Informed Counseling Scale (ICS) was originally developed to assess the content and process of informed counseling among parents of children with Down syndrome in Taiwan through structured interviews of the parents.¹⁵ The content of the ICS were decided through a focus group discussion among more than 10 health professionals, including psychiatrists, obstetricians, pediatricians, nurses, psychologists, and experts in genetic studies. It contains the timing, place, means, content, and duration of the counseling session during which parents were informed; attitude of the counselor; and immediate emotional reaction and current emotional status of the parents. The “timing” refers to whether the diagnosis was disclosed prior to or after it was confirmed. The ICS was modified as a self-administered scale in a multiple-choice format to obtain the information about the context and content of current practice. The self-administrated ICS has satisfactory agreement with the interview-based approach (kappa statistics >0.9 for each item).¹⁵

Satisfaction with ICS

This scale includes 10 domains of informed counseling: timing of being informed, duration of informed counseling, counselors’ knowledge of autistic disorder, information about autism and treatment strategies, information about welfare support and educational resources, attitude of counselors, relationship with counselors during communication, emotional support provided by counselors, and overall evaluation. Each item was rated on a five-point Likert scale (0 for very dissatisfied, 1 for not satisfied, 2 for moderately satisfied, 3 for satisfied, and 4 for very satisfied), and the total scale scores ranged from 0 to 40. The same scale had been used in our previous study on Down

syndrome,¹⁵ with good internal validity (Cronbach’s alpha = 0.97) and satisfactory agreement with direct interview (kappa statistics >0.9 for each item).

Maudsley Personality Inventory

The Maudsley Personality Inventory (MPI), a 30-item self-administered scale proposed by Hans Eysenck, was designed to measure three personality traits: neuroticism, extroversion, and social desirability.¹⁶ The Chinese version of the MPI has widely been used in both community and medical settings^{17–20} as a valid and efficient tool to assess personality. In this study, Cronbach’s alpha coefficients were 0.87 for neuroticism, 0.70 for extroversion, and 0.41 for social desirability.

Brief Symptom Rating Scale

The Brief Symptom Rating Scale (BSRS), modified from Derogatis Symptom Check List-90—Revised (SCL-90-R),²¹ is a 50-item self-administered measure used for assessing nine dimensions of psychopathology over the past week, including somatization, obsessive–compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic–anxiety, paranoid ideation, and additional symptoms such as vegetative signs and suicidal ideation. The BSRS is highly correlated with the SCL-90-R²² and has been proved to have excellent reliability as well as a good internal structure in different populations.^{23,24} We used the General Symptom Index, a mean score of all BSRS categories, and MPI to assess maternal personality and psychopathology.

Diagnosis of autism

Diagnosis of autistic disorder was based on DSM-IV criteria for autistic disorder and made by board-certified child psychiatrists across five sites who specialized in the

assessment and treatment of children and adolescents with autism. The diagnosis was confirmed by the Chinese version of the Autism Diagnostic Interview—Revised (ADI-R)²⁵ in a subsample. The ADI-R²⁶ is a standardized, semistructured diagnostic algorithm that focuses on three symptom domains of autism: reciprocal social interaction, communication, and restricted, repetitive, and stereotyped behaviors. Scores of each participant of the subsample reached the cutoff of ADI-R for autism diagnosis and confirmed the clinical diagnosis of autistic disorder.

Procedures

The Research Ethics Committee approved the protocol prior to study implementation. Written informed consent was obtained from the mothers of children with autism after explanation of the purpose and procedure of the study. Mothers completed the questionnaire at the clinics. A research assistant provided nondirective explanation of the questionnaires to the mothers. Demographic data, including age and sex of children and parents, maternal age at childbirth, number of children in the family, birth order of the proband child, and parents' employment status, educational level, marital status, and socioeconomic status, were collected by interview. Socioeconomic status was self-rated into four classes: "low income", "middle income", "above average", and "rich"; the latter two classes were coded as "higher-income family".

Data analysis

SAS 9.1 (SAS Institute Inc., Cary, NC, USA) was used for statistical analysis. Descriptive results were displayed as frequency and percentage of categorical variables, and mean and standard deviation of continuous variables. A principal-axis factor analysis was performed using the FACTOR procedure to ascertain the factor structure of the nine items of the satisfaction with ICS (the item "overall evaluation" was excluded). A scree plot of ordered eigenvalues of a correlation matrix was used to determine the appropriate number of factors. Internal consistency of each factor was evaluated by Cronbach's alpha coefficients. A linear regression model with stepwise selection was used to identify the significant predictors of maternal satisfaction with informed counseling. To identify the most important factors for satisfaction, variables with $p < 0.1$ were chosen as predictive variables for model fitting. Considering multiple comparison issue, we chose a more conservative significant level of $p < 0.015$ for univariate regression analysis.

Results

Sample description

Table 1 summarizes the characteristics of the children and their parents who participated in the study. The mean age of the children was 7.8 ± 2.9 years. More than half of the children with autism (68.8%) were raised full time by at least one parent. The mean maternal age at childbirth was 30.2 ± 3.8 years (Table 1).

Table 1 Sample description (N = 151).

Variables	N or mean	% or SD
Child		
Age	7.8	2.9
Sex		
Male	132	87.4
Female	19	12.6
Number of children in family	2.3	0.6
Rearing experience		
Fully by mother/father	99	68.8
Daytime by others, nighttime by parents	38	26.4
By parents only on weekends	2	1.4
Visited by parents sometimes	5	3.5
Familial socioeconomic status		
Low- and middle-income family	32	21.2
Higher-income family	119	78.8
Mother		
Age	37.1	4.5
Age at childbirth	30.2	3.8
Education level		
≤Junior high (≤9 y)	13	8.7
Senior high (10–12 y)	69	46.3
≥College (≥12 y)	67	45.0
Employment status		
Employed	45	30.2
Not currently employed	104	69.8
Father		
Age	40.3	5.0
Education level		
≤Junior high	11	7.6
Senior high	42	29.0
≥College	92	63.5
Employment status		
Employed	136	97.8
Not currently employed	3	2.2

Current practice of diagnosis-informed counseling in autism

Diagnosis of autism was disclosed to mothers mostly by physicians (81.7%), followed by counselors (4.7%), spouse (2.0%), other family members (4.7%), nursing staffs (0.68%), and social workers (0.68%). Settings used for diagnosis-informed counseling were outpatient clinics (79.1%), interview rooms (8.8%), or others (12.2%). Counseling session began after informing the parents about the possible diagnosis of autism. It involved the process of communication with parents on diagnosis and management of their child, and parental adjustment. The mean duration of the counseling session was 46.6 ± 58.1 minutes. Diagnosis of autism was confirmed at a mean age of 3.3 ± 1.5 years.

Diagnosis of autism was initially mentioned in 61.5% of counseling. More than 30% of the 151 mothers reported that they had not been told about the etiology (49.3%), nature (41.2%), prognosis (34.5%), or clinical manifestations (21.0%) of autism during counseling.

Concerning the maternal perception about counseling, more mothers reported that the counselor's attitude was positive and warm (71%), but 19% reported it to be negative and pessimistic. More than one-third of mothers (42.3%) reported to receive emotional support and be encouraged to enquire further. The initial emotional reactions upon being informed were sadness (64.2%), followed by shock (36.5%), anxiety (35.8%), sorrow (32.4%), self-blame (26.4%), denial (11.5%), and despair (11.5%).

Overall maternal satisfaction with diagnosis-informed counseling

More than half of the mothers were satisfied or very satisfied with their counselor's attitude (68.3%), their relationship with counselors during communication (55.9%), and counselors' knowledge about autism (55.5%). However, the majority of the mothers were unsatisfied with the timing of being informed (77.9%), short duration of counseling (71.7%), and inadequate information about welfare systems (i.e., government subsidies and medical allowance) and educational resources (71.7%). Overall, 43.2% of mothers were reported to be satisfied or very satisfied with the counseling (Table 2).

Factors related to the degree of maternal satisfaction with diagnosis-informed counseling

The exploratory factor analysis for the ICS revealed two factors: the information subscale with an eigenvalue of 5.34 and the context subscale with an eigenvalue of 1.03 (Table 2). Both subscales had high internal consistency (Cronbach's alpha, 0.90 and 0.86, respectively; 0.91 for the full scale).

The univariate regression analysis showed that mother's educational level (college degree or higher) and being employed were associated with lower satisfaction with diagnosis-informed counseling, as revealed in the full scale

and information subscale (Table 3). Considering the context of informed counseling, the timing, duration of counseling, and attitude of the counselors were associated with satisfaction in the full scale and two subscales. Moreover, mothers' immediate emotional reaction, personality traits measured by MPI, and psychopathology measured by BSRS were not related to satisfaction. Regarding the content of diagnosis-informed counseling, information about treatment strategies was the only item to be associated with satisfaction in information subscale (Table 3).

In the final fitted model for maternal satisfaction (Table 4), parental college degree, timing, duration, and counselor's attitude predicted satisfaction in the full scale and context subscale. For information subscale, college degree of mothers, counselor's attitude, and treatment strategies provided predicted satisfaction. The results were similar if age of probands or treatment programs they received were further controlled in the model (data not shown).

Maternal expectation of ideal diagnosis-informed counseling

The ideal mode of information delivery was face-to-face communication between physicians and parents (74.3%), at the clinic (53.4%) or interview room (45.2%), with the parent being accompanied by the spouse (88.2%). Mothers preferred to be informed about the diagnosis of autistic disorder only after the diagnosis had been confirmed (60.8%), rather than when it was under suspicion. Regarding the content of counseling, most of the mothers expected more information on treatment options (78.8%), education and parenting (68.5%), educational and welfare resources (63.0%), and rehabilitation (58.2%).

Discussion

This is the first study in Chinese population to examine the content and patterns of diagnosis-informed counseling and

Table 2 Factor loadings and item–total correlations of satisfaction with diagnosis-informed counseling ($N = 151$).

	Satisfactory and very satisfactory, n (%)	Full scale			Subscale	
		Factor 1 loading	Factor 2 loading	Item–total correlations	α	Item–total correlations
Information level						
					0.90	
Counselors' knowledge about autism	84 (55.5)	0.65	0.28	0.78		0.74
Information about autism provided by counselors	68 (45.2)	0.85	0.03	0.75		0.80
Treatment strategies provided by counselors	59 (39.0)	0.93	−0.05	0.75		0.81
Information about welfare support and educational resources	43 (28.3)	0.94	−0.13	0.68		0.74
Counseling context level						
					0.86	
Timing of being informed	33 (22.1)	−0.22	0.86	0.46		0.49
Duration of informed counseling	43 (28.3)	0.00	0.79	0.59		0.62
Attitude of counselors	103 (68.3)	0.31	0.65	0.76		0.78
Relationship with counselors during communication	84 (55.9)	0.37	0.58	0.76		0.77
Emotional support provided by counselors	67 (44.5)	0.36	0.56	0.77		0.73

Eigenvalue: factor 1 = 5.34, factor 2 = 1.03; Cronbach's α for internal consistency: 0.91.

Table 3 Association between maternal determinants, context and content of diagnosis-informed counseling, and maternal satisfaction with diagnosis-informed counseling by univariate linear regression analysis ($n = 151$).

Variables	Full scale		Information subscale		Context subscale	
	Estimate (SE)	<i>F</i> statistics, <i>p</i>	Estimate (SE)	<i>F</i> statistics, <i>p</i>	Estimate (SE)	<i>F</i> statistics, <i>p</i>
Maternal determinants						
Age	0.00 (0.10)	$F = 0.00, p = 0.963$	0.00 (0.06)	$F = 0.00, p = 0.954$	0.01 (0.07)	$F = 0.02, p = 0.901$
Education level	-1.34 (0.52)	$F = 6.63, p = 0.011$	-0.81 (0.28)	$F = 8.17, p = 0.005$	-0.68 (0.35)	$F = 3.78, p = 0.054$
Employment status	-2.53 (0.98)	$F = 6.76, p = 0.010$	-1.31 (0.53)	$F = 6.03, p = 0.015$	-1.57 (0.65)	$F = 5.83, p = 0.017$
Socioeconomic status	-1.08 (1.10)	$F = 0.97, p = 0.326$	-0.39 (0.60)	$F = 0.43, p = 0.515$	-1.01 (0.73)	$F = 1.91, p = 0.170$
General Symptom Index	0.05 (0.93)	$F = 0.00, p = 0.958$	-0.10 (0.51)	$F = 0.04, p = 0.848$	0.23 (0.62)	$F = 0.14, p = 0.712$
Personality characteristics						
Neuroticism	-0.00 (0.06)	$F = 0.00, p = 0.969$	-0.01 (0.04)	$F = 0.07, p = 0.798$	0.00 (0.04)	$F = 0.00, p = 0.952$
Extroversion	0.00 (0.08)	$F = 0.00, p = 0.976$	-0.01 (0.05)	$F = 0.10, p = 0.747$	0.02 (0.06)	$F = 0.12, p = 0.732$
Social desirability	-0.40 (0.21)	$F = 3.82, p = 0.053$	-0.19 (0.11)	$F = 2.69, p = 0.103$	-0.28 (0.14)	$F = 4.06, p = 0.046$
Context of informed counseling						
Timing	0.94 (0.30)	$F = 9.88, p = 0.002$	0.45 (0.17)	$F = 7.46, p = 0.007$	0.63 (0.20)	$F = 9.86, p = 0.002$
Duration	0.02 (0.01)	$F = 5.57, p = 0.020$	0.01 (0.00)	$F = 2.39, p = 0.125$	0.02 (0.01)	$F = 8.70, p = 0.004$
Counselor's attitude	4.67 (1.54)	$F = 9.26, p = 0.003$	2.09 (0.85)	$F = 6.07, p = 0.015$	3.35 (1.02)	$F = 10.85, p = 0.001$
Parents' immediate emotion	-1.60 (1.37)	$F = 1.36, p = 0.245$	-0.86 (0.75)	$F = 1.33, p = 0.250$	-0.93 (0.91)	$F = 1.04, p = 0.309$
Content of informed counseling						
General description of autism	0.80 (0.92)	$F = 0.75, p = 0.388$	0.45 (0.50)	$F = 0.80, p = 0.373$	0.43 (0.61)	$F = 0.49, p = 0.486$
Etiology	0.38 (0.91)	$F = 0.18, p = 0.674$	-0.02 (0.50)	$F = 0.00, p = 0.961$	0.62 (0.60)	$F = 1.06, p = 0.305$
Symptoms	-1.01 (1.13)	$F = 0.79, p = 0.375$	-0.22 (0.62)	$F = 0.13, p = 0.722$	-0.91 (0.75)	$F = 1.46, p = 0.229$
Treatment	5.16 (2.74)	$F = 3.55, p = 0.062$	3.20 (1.49)	$F = 4.59, p = 0.034$	2.42 (1.84)	$F = 1.74, p = 0.189$
Prognosis	0.80 (0.96)	$F = 0.70, p = 0.404$	0.31 (0.52)	$F = 0.35, p = 0.553$	0.65 (0.64)	$F = 1.05, p = 0.307$
Other information	1.11 (1.34)	$F = 0.69, p = 0.408$	0.72 (0.73)	$F = 0.96, p = 0.328$	0.56 (0.90)	$F = 0.39, p = 0.531$

SE = standard error.

Table 4 Final selected model for maternal satisfaction with diagnosis-informed counseling ($n = 151$).

Variables	Full scale		Information subscale		Context subscale	
	Estimate (SE)	F statistics, <i>p</i>	Estimate (SE)	F statistics, <i>p</i>	Estimate (SE)	F statistics, <i>p</i>
Intercept	16.86 (2.33)		5.40 (1.77)		9.07 (1.12)	
Education level	-1.08 (0.54)	$F = 4.03, p = 0.047$	-0.78 (0.28)	$F = 8.01, p = 0.005$	—	—
Timing of being informed	0.70 (0.31)	$F = 5.30, p = 0.023$	—	—	0.54 (0.20)	$F = 7.24, p = 0.008$
Duration of counseling	0.02 (0.01)	$F = 4.20, p = 0.043$	—	—	0.01 (0.01)	$F = 6.85, p = 0.010$
Counselor's attitude	4.61 (1.67)	$F = 7.57, p = 0.007$	1.93 (0.83)	$F = 5.40, p = 0.022$	3.39 (1.09)	$F = 9.62, p = 0.002$
Treatment of autism			3.30 (1.44)	$F = 5.22, p = 0.024$	—	—

A linear regression model with backward selection was used to identify the significant predictors of the degree of maternal satisfaction with informed counseling. Variables with $p < 0.1$ were chosen as predictive variables for model fitting, including maternal education level, maternal employment status, timing, duration, and content regarding treatment of autism.

maternal satisfaction when a diagnosis of autism was disclosed. The results revealed several important findings. Overall, maternal satisfaction with informed counseling was moderate (43%). The degree of satisfaction was dependent on both contextual and information levels, but more on the former. Besides, mothers' educational level was found to correlate with the degree of satisfaction.

Although the overall maternal satisfaction rate (43.2%) was higher than that we found in case of Down syndrome (20%),¹⁵ it was lower than that in children with other disabilities, such as developmental delay (82.6%),¹⁰ cerebral palsy (46–70%)^{27,28} and severe learning difficulties (60%),⁸ and in other studies of Down syndrome (36–58%).^{3,29} The lower rate of maternal satisfaction with diagnosis-informed counseling can be explained partially by the culture difference across countries. In the context of Chinese culture, families in Taiwan are greatly influenced by the Confucian tradition, which emphasizes children's academic achievement and prioritizes the family over the individual.³⁰ The bad news of having an "abnormal" child was so troublesome for the family that the parents would rather believe that it was the doctor who made a wrong diagnosis. Although the stigma is eased nowadays in Taiwan, mothers tend to take more responsibility for caretaking,²⁵ which may put them under further stress and result in lower satisfaction with the medical service provided such as diagnosis-informed counseling, compared to that in non-Confucian culture. On the other aspect, different diagnoses may also contribute to different levels of satisfaction toward diagnosis disclosure, in terms of the unique nature and development of autism. More specifically, autism differs markedly from other chromosomal disorders or congenital abnormalities in several ways. Unlike chromosomal disorders that demonstrate characteristic dysmorphism at birth,^{7,10} most children with autism do not show obvious dysmorphic features. Besides, their motor or other developmental milestones, which are easier to be observed by caregivers prior to the confirmation of diagnosis, is usually not far behind that of typically developing children.^{31,32} Thereafter, when a mother is informed that her child is autistic, the reaction is often shock and denial.^{33,34} Additionally, typical symptoms of autism (impairments in social reciprocity, communication, and repetitive behaviors) and lack of effective treatment both impact child-rearing by the parents, particularly the mothers.^{35,36} Occasionally, autistic or obsessive traits in one or both parents may make the condition even more difficult because the parents may have limited ability to cope with diagnosis disclosure.³⁷ These factors further explain our findings of the lower maternal satisfaction with diagnosis disclosure in autism.

Compatible with previous studies on other physical or mental disabilities,^{9,38} we also found that the attitude of the counselor, in addition to the timing and duration of counseling, is significantly associated with maternal satisfaction. Interestingly, the duration, rather than the content, of counseling is predictive of maternal satisfaction in the context subscale. Previous studies have found that duration of counseling is not proportional to the amount of information obtained^{9,10}; our finding also suggests that parents may be more concerned about whether they have enough time to digest the message delivered by a counselor.

The majority of the mothers in our sample reported that they would rather be informed only after the diagnosis had been confirmed. Prior studies on other diseases and abnormalities demonstrated mixed results on the timing of being informed^{8,38,39}; most of them concluded that a delayed or uncertain diagnosis was likely to cause additional distress for the parents and have a lasting effect on their relationship with doctors. Notably, more than three-fourths of probands were recruited from medical centers who may have visited several physicians and have difficulties in confirming or accepting the diagnosis. Nonetheless, one-third of the mothers prefer to be informed as early as possible rather than to wait for a definitive diagnosis. The communication on diagnosis should be taken care in a personalized way.

Surprisingly, mothers who had college degree were less likely to be satisfied with the counseling they received. Our explanation is that mothers with higher education may have better access to information, have higher expectations to their children, and be more anxious about the diagnosis, treatment, and outcomes of autism. As a result, they may hold higher expectations from the health professionals and the services provided. On the other hand, this study did not support a relationship between maternal satisfaction and personality trait, immediate emotional reaction, or psychopathology at assessment. It is possible that other factors may also moderate or mediate the perceived satisfaction, such as the nature of the disability, treatment response, therapeutic alliance, and social support.^{11,13} Nevertheless, when the potential confounding factors, such as age of probands or treatment programs they received, were controlled, the results were similar. Other determinants for parental satisfaction are worth studying further.

The strengths of this study are its relatively large sample size and inclusion of several factors related to satisfaction with diagnosis-informed counseling. Yet, we need to interpret our findings with caution considering the methodological limitations. First, because we did not collect information at the time when diagnoses were informed, this study is subject to potential recall bias. However, our findings do reflect what mothers think and feel about the counseling. Second, although the diagnosis of autism was made by board-certified child psychiatrists experienced in treating this population, a standard instrument (e.g., ADI-R) was not applied for the whole sample. Nevertheless, all the participants of the subsample receiving ADI-R confirmed the diagnosis. Third, restriction of the probands to typical autism and to those who undertook treatment program prior to the age of 6 years minimized the heterogeneity of this group, and limited us to examine the effect of diagnostic subtype of autism spectrum disorders on maternal satisfaction. Finally, we did not compare the demographics and satisfaction between refusal cases and participants, although the refusal rate was low (less than 10 patients) compared to the whole sample ($n = 151$).

In conclusion, our findings suggest that mothers of children with autism in Taiwan are concerned about the duration of diagnosis-informed counseling and wish to receive more information about treatment, parenting, and resources. Besides, the timing of information delivery and the counselor's attitude during counseling are significant determinants of parental satisfaction. Lower rates of maternal

satisfaction in our sample suggest that more efforts should be made to improve the quality of diagnosis-informed counseling in order to facilitate the treatment process and enhance parental compliance with treatment for autism.

Funding/Support

This work was supported by grants from the National Science Council (gs1) (NSC96-3112-B-002-033; NSC96-3112-B-002-033; NSC97-3112-B-002-009; NSC98-3112-B-002-004), Taiwan.

Acknowledgments

The authors would like to express their thanks to Ming-Fong Chen, MS, for her assistance in manuscript preparation and to the mothers of participants in this study.

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