行政院國家科學委員會專題研究計畫　成果報告

遺傳諮詢的品質對唐氏症兒的父母之心理適應、家庭功能、婚姻關係和親子關係之影響(III)

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中文摘要

前言: 唐氏症(DS)是智能不足最常見的染色體疾患，有典型的外表特徵。在醫療、經濟、家庭負擔及個人學習表現上，患有唐氏症對其個人、家庭、和社會有巨大的衝擊。

目的: 為了瞭解對唐氏兒父母接受遺傳諮詢的現況，父母對遺傳諮詢經驗的滿意程度，以及影響遺傳諮詢滿意度之相關因素。並探討唐氏症對於家庭的親子關係、養育方式、父母親的心理適應、婚姻關係之影響。

方法: 樣本包括的 45 個唐氏症家庭和 50 位非唐氏症家庭。在唐氏症家庭中，共有 43 位母親及 34 位父親完成所有的測驗評估，只有 32 個家庭父親與母親皆完成測驗。本研究工具包含半結構式會談以獲得遺傳諮詢的內容和懷孕生產史，以及自填問卷評估父母的心理適應和生活品質、親子關係和孩子的氣質和情緒行為。

結果: 研究結果顯示唐氏兒父母的遺傳諮詢 82%由醫生進行，平均諮詢時間為 26 分鐘（標準差= 23.5），只有 20%的父母對遺傳諮詢的經驗感到滿意。諮商者的態度冷漠、敷衍，提供的資訊不夠充足，進行諮詢的地點不適當，進行時間太短等都讓父母感到不滿意。而父母當時的情緒、經濟狀況、外向性格也會影響遺傳諮詢的滿意度。唐氏兒有較多的行為問題，其父母親顯現出較多的心理症狀，而其手足較易受到父母的忽略。

結論： 目前國內對唐氏兒父母的遺傳諮詢，大多是由醫生單方面告知父母有關唐氏症的相關訊息，缺乏雙方的溝通，以及提供心理支持、後續心理輔導、治療的工作。增進遺傳諮詢品質最重要的是改進諮商者的態度，給予父母宣洩情緒的機會和提供足夠的資訊，以協助唐氏兒家庭心理、生活、親子關係等各方面的適應。除了父母的心理健康之外，對唐氏兒之手足的照顧也應該受到重視。

關鍵詞:唐氏症、遺傳諮詢、父母適應、家庭功能、教育方式

Abstract

Context: Down syndrome (DS) is the most common genetic form of mental retardation with a typical physical phenotype. Its impact on individual, family, and society is tremendous in terms of medical treatment, financial cost, family burden, and personal underachievement.

Objective: To examine the content and pattern of genetic counseling and to determine the factors affecting the extent of satisfaction with genetic counseling among parents of children with DS. Also, we examined parental psychopathology, parenting style, and behavioral characteristics among children with DS, their siblings, and controls.

Methods: The sample consisted of one exposed group, including 45 families of children with DS, and one unexposed group, including 50 families of children without DS. Among DS families, only 34 families were assessed completely, including 43 mothers and 34 fathers. Each parent received a semi-structured interview including information about patterns of genetic counseling and their satisfaction with counseling; the questionnaires about parental mental status, family function, dyadic adjustment, parenting style, and child's behavioral problems and temperament.

Results: Physicians had informed 82% of the parents that their child had DS. The mean duration of the counseling session was 26 minutes (standard deviation = 23.5). The majority of parents reported that they did not have a chance to ask question or express their feelings. They also noted that they did not receive enough information regarding the etiology, outcome, and treatment of DS. Predictors of increased satisfaction with genetic counseling included extroverted parents and lower parental economic status, positive counselor's attitude, longer duration of counseling, more information provided, and no negative immediate emotional reaction. Parents of children with DS suffered from more psychopathology, children with DS demonstrated more behavioral problems, and their siblings may not get enough care or parental control than their counterparts.

Conclusion: This study suggests the need for better doctor-patient communication and for greater attention to the scope of genetic counseling sessions for DS in Taiwan. The mental health prevention of parents and siblings of children with DS need to be emphasized not less than that of children with DS.

Keywords: Down syndrome, genetic counseling, parental adjustment, parenting style

目 錄

前言

近二十多年來基因科技的快速進展，不論是在分子遺傳或是遺傳流行病學，都是最熱門的研究方向。隨著基因科技在生物科學上的廣泛應用，有關基因科技的倫理問題逐漸受到重視。許多有關遺傳、染色體異常或基因突變的相關疾病的基因診斷、諮詢及後續處置，是否合乎倫理和人性，以及是否符合社會的規範等議題，不斷的在醫療、法律、家庭和社會的情境中發生。然而到目前為止，並沒有研究深入去探討目前台灣有關遺傳諮詢的現況，以及遺傳諮詢的品質及內容對患者以及其家人的影響程度，或者發展出協助家庭去照顧和教養這些基因異常患者的相關政策。

唐氏症(Trisomy 21)是造成智能不足最常見的染色體疾患，其盛行率是 1-1.5/1000 活產兒，除了智能不足外，唐氏症患者具有典型的一些外表特徵，也常併發心臟、血管、胃腸及血液方面的異常。患有唐氏症對患者本身及他的家庭和社會將會帶來巨大的衝擊，目前國內少有針對遺傳諮詢以及其相關影響的研究資料。本研究的目的希望以唐氏兒為例，探討有關遺傳諮詢的內容和形式，以及遺傳諮詢對唐氏兒及其父母和兄弟姊妹的影響。此外，也希望藉由這個研究的結果可提供國人對目前遺傳諮詢現況的瞭解，並且與國外的情形進一步的比較，以作為改進遺傳諮詢的專業品質的參考資料。

研究目的

1. 在瞭解台灣目前針對唐氏症兒父母的遺傳諮詢的內容和型態。
2. 唐氏兒之父母對於遺傳諮詢經驗的滿意狀況。
3. 以父母的年齡、教育程度、社經地位、人格特質以及遺傳諮詢的經驗探討影響遺傳諮詢滿意度的因素。
4. 探討唐氏兒的父母和非唐氏兒父母在身心狀況、婚姻問題以及家庭關係之差異。
5. 比較唐氏兒、其手足以及非唐氏兒這三組，在行為和情緒問題之差異。
6. 探討唐氏兒、其手足以及非唐氏兒之父母與他們的親子關係之差異。
7. 探討父親與母親對待孩子方式的差異。

文獻探討

基因工程的廣泛研究，不論是在分子遺傳結構上或是基因流行遺傳病學，都是生物學或是藥學一直以來重要而且熱門的研究方向，未來，基因工程也將是研究方向一個重要指標。當科學家們致力於基因遺傳的探討和研究時，其發展對人類生活可能產生之巨大影響，近十年來，有關基因工程倫理問題，也伴隨著基因工程在生物學上的應用而逐漸受到重視。遺傳諮詢，就是在強調倫理的原則之下，著重專業遺傳諮詢師應該要以何種方式以及如何傳遞給個案有關基因遺傳上的發現，並解釋因為此項基因遺傳的變化可能衍生而來的心理社會之功能改變(Murray, 1976)。

遺傳諮詢一向被認為是醫療人員與個案之間複雜的溝通過程，其中包含了與個案以及家族成員討論產前檢查中發現呈現陽性反應之遺傳疾病、新生兒伴隨有醫療上之問題，以及家族史中帶有的遺傳疾病。大部分的遺傳諮詢師認為有效的而且有益處的遺傳諮詢有幾項倫理原則及人性價值應該被尊重而且是重要的：尊重個案自主性以及非指導性語氣、友善的、不具攻擊性的;誠實並且真誠的告知真實情況;豐富性的資料或是資源提供(Yarborough, Scott, & Dixon, 1989)。遺傳諮商師的態度是決定基因諮商成功與否，以及個案日後社會心理是否能適應良好之重要因素(Wertz & Fletcher, 1988)。

本研究提供醫學倫理用於遺傳諮詢之檢驗，所採用之個案為唐氏症兒童，因為唐氏症（trisomy21）是遺傳性疾病中最常見的一種，是造成智能不足最主要已知的染色體疾患，其盛行率是 1-1.5/1000 活產兒(Stoll, Alembik, Dott, & Roth, 1998)。唐氏兒生理以及臉部外觀表現特徵有：新生兒期持續性低血壓、眼球向上且向外歪斜、短且鼻梁平坦的鼻子以及虹膜中間有白色班點。唐氏兒手指短小，小指頭向內彎，有些可能缺少手掌骨，掌紋可能只有單條。頭顱圍通常很小甚至是極小(Cooley & Graham, 1991; Stoll, et al., 1998)。由於以上這些特徵，使得唐氏兒自嬰兒期即開始就與其他非唐氏症兒童顯得十分不同。唐氏兒伴隨有低智商（平均智商低於 50），隨著年齡增加還有下降之趨勢。唐氏兒還常有心血管方面之疾病(Freeman, et al., 1998)、腸胃畸形(Marty, et al., 1995; Torfs, Bateson, & Curry, 1992)、血液異常(Kivivuori, Rajantie, & Siimes, 1996; Zipursky, Brown, Christensen, Sutherland, & Doyle, 1997)以及癲癇症(Dalton & Crapper-McLachlan, 1986)。並且，他們在三十歲左右就漸漸地產生一些衰老的徵兆，例如：稀少的頭髮、乾燥而且縐折的皮膚、神經性的改變等等。這些與其他兒童不同的成長改變以及過程，唐氏兒本身面臨的低學業成就，家庭所需要付出之龐大教育或是醫療費用造成唐氏兒不僅是個人而且是其整個家庭甚至社會巨大而顯著的影響(Stoll, et al., 1998)。

在台灣，母親產檢若發現結果未出生之胎兒患有唐氏症，其遺傳諮詢經常是由婦產科醫師執行。大部分的父母也都會選擇經由人工流產的方式結束胎兒生命(Williamson, Harris, Church, Fiddler, & Rhind, 1996; Yagel & Anteby, 1998)。而對於唐氏兒的父母，遺傳諮詢是由婦產科醫師、小兒科醫師、護理人員或是遺傳諮詢師執行，大都決定於第一次診斷為唐氏症的地點和時間，因此，並不是由專業遺傳諮詢人員執行。研究顯示，父母被告知唐氏症診斷的過程，會對其日後的適應以及他們對待孩子的方式產生影響(Springer & Steele, 1980)，適當和高品質的遺傳諮詢以及

對唐氏兒持續的生理照顧，可以幫助唐氏兒父母親在新生兒時期逐漸適應壓力。國外的研究顯示：多數的父母對於被告知診斷結果的遺傳諮詢經驗感到不滿意。不滿意的原因包括：諮商者的態度冷漠、缺乏溝通技巧；提供與疾病相關之訊息不夠充足，許多疑問仍沒有得到答案；告知的時機不適當，過早或是太晚告知；告知時沒有配偶或孩子在身旁；諮商者所具備之基本知識不足；諮商者傳遞過多負面訊息(Cunningham, Morgan, & McGucken, 1984; Hedov, Wikblad, & Anneren, 2002; Quine & Pahl, 1986; Quine & Rutter, 1994; Spahis & Wilson, 1999)。

遺傳諮詢的進行可以參考下列指導原則：（1）環境的地點與陳設，（2）評估個案家庭之背景資料、教育程度及過去經驗，（3）選擇一個最適宜個案家庭當時所遭遇情境的策略，最後（4）評估個案家庭是否有確實瞭解被提供的資訊(Garwick, Patterson, Bennett, & Blum, 1995)。對父母而言，諮商者的專業知識、諮詢時機、諮詢環境、諮商者的態度為影響遺傳諮詢滿意度之重要指標(Spahis & Wilson, 1999)。在遺傳諮詢時，多數父母希望能夠說出自己的疑問、表達自己的情緒。父母希望可以儘早知道有關孩子的診斷；希望諮商者在諮詢時能表現出支持與同理心；希望能夠得到與孩子的疾病有關的完整訊息(Quine & Pahl, 1986; Quine & Rutter, 1994)。除了第一次的遺傳諮詢之外，接下來的心理支持以及相關建議也是很重要的，除了心理輔導或治療以外，與其他有唐氏兒家庭接觸也可以成為唐氏兒父母安慰與建議的來源(Quine & Pahl, 1987)。

研究顯示，養育一個有發展障礙的孩子，會給父母親、家庭關係、親子關係帶來負面的影響(Bristol, Gallagher, & Schopler, 1988; Dyson, 1997a)。而部分研究顯示許多家庭在這種情況下仍能夠有效率的去應對、適應(Bennett & DeLuca, 1996b; Ferguson, 2002)。國內相關研究顯示台灣的唐氏兒家庭受到多樣及程度不一的衝擊(黃璉華, 1994)，父母認知真相後會出現不同的調適行為(蔣欣欣 & 喻永生, 1997)。一般而言，母親擔負了起較多照顧孩子的責任(Krauss, 1993)，國外大多數的研究顯示養育唐氏兒對於母親的影響會大於父親(Beckman, 1991a; Goldberg, Morris, Simmons, Fowler, & Levison, 1990a; Pelchat, et al., 1999)，台灣的研究也顯示相同的結果(Cheng & Tang, 1995)。與正常孩子的母親相比，唐氏症兒的母親經歷了較多的焦慮、憂鬱、以及心理壓力(Shek & Cheung, 1990)。除了父母親之外，唐氏兒的手足同樣會面對心理適應的問題(Dyson, 1989)。部分研究認為唐氏兒之手足會出現較多焦慮、行為、情感問題(Lavigne & Ryan, 1979a; Poznanski, 1969a)，而其他研究認為並無影響(Lobato, Barbour, Hall, & Miller, 1987; McHale, Sloan, & Simeonsson, 1986)。目前並無研究探討父母親對唐氏兒及其手足教養方式的差異。

根據以上研究結果，本研究的目的在探討：(1) 台灣目前針對唐氏症兒父母的遺傳諮詢的內容和型態；(2) 唐氏兒之父母對於遺傳諮詢經驗的滿意狀況；(3) 以父母的年齡、教育程度、社經地位、人格特質以及遺傳諮詢的經驗探討影響遺傳諮詢滿意度的因素；(4) 唐氏兒的父母和非唐氏兒父母在身心狀況、婚姻問題以及家庭關係之差異；(5) 唐氏兒、其手足以及非唐氏兒這三組，在行為和情緒問題之差異；(6) 唐氏兒、其手足以及非唐氏兒之父母對他們的教養方式之差異；(7) 父親與母親對待孩子方式的差異。希望依據此研究，探討唐氏症對一個家庭的影響，將唐氏兒家庭接受遺傳諮詢的經驗及想法提供國內作為改進遺傳諮詢方式與品質的參考。

研究方法

研究對象

本研究樣本包括 45 個 1 歲到 10 歲經醫師診斷並領有殘障手冊患有唐氏症的兒童之家庭，以及 50 個非唐氏症兒童之家庭。其中 32 個家庭父母親皆完成此研究，共有 43 位母親及 34 位父親完成所有的評估。

研究步驟

本研究經過台大醫院倫理委員會的同意進行，經由三個途徑收集個案家庭：(1)經由台大醫院的病歷資料確定為唐氏症的病人，寄發研究目的和進行方式的說明信給家長，以徵得其同意進行訪談；(2) 透過中華民國唐氏症關愛協進會先徵詢有唐氏症孩子的父母參加研究的意願；(3) 地毯式地接洽台北縣市所有的特殊教育發展中心和國小的特教班的老師，詢問有無患有唐氏症的學生，若有，且老師同意代轉研究說明書給家長，則再經由老師轉交研究說明書。

最後有 45 個唐氏症家庭參與研究，一位有家庭親職諮詢背景的碩士負責會談母親及父親以獲得有關被告知有唐氏症孩子的遺傳諮詢經驗，以及訪談母親以獲得懷孕生產史。父母親並且完成自填式問卷。父母親同意會談錄音者，給予錄音，以做為控制研究品質，和將來質性研究分析之用。會談的內容經由會談者和第一作者共同討論以決定最符合受訪者的情形之代碼。

研究工具

壹.自填量表部份（Table Ⅰ和 TableⅡ）：

一. 簡式性格量表(MPI)

簡式性格量表（Maudsley Personality Inventory, MPI）乃李明濱等人(M.B. Lee, Hsien, Lin, & Lee, 1990a; M. B. Lee & Lee, 1990)改編自 Eysenck(H.J. Eysenck, 1962)的性格量表，包括 30 題項目，涵蓋神經質、外向及社會期許三個向度。

二. 簡式症狀量表(BSRS)

簡式症狀量表（Brief Symptom Rating Scale, BSRS）是李明濱等人(M. B. Lee & Lee, 1990)根據 Derogatis(Derogatis, Lipman, & Covi, 1973; Derogatis, Rickels, & Rock, 1976)所編著之 SCL-90-R 修訂並翻譯成中文，BSRS 共包含 50 個項目，分為 5 級評分，臨床應用證明此量表的評估有良好的信、效度，能找出 10 個向度的症狀；包括身體化症狀、強迫性症狀、人際間敏感、憂鬱、焦慮、敵意、畏懼、疑心、離群、附加症狀。

三. 兩性適應量表(DAS)

兩性適應量表(Dyadic Adjustment Scale，DAS)編自 Spanier(Spanier, 1976)，為 32 題的自陳式量表，主要為評估婚姻及兩性適應。包括四個向度:意見一致性(dyadic consensus)、滿意度(dyadic satisfaction)、凝聚力(dyadic cohesion)、表達愛的方式(affectionate expression)。

四. 家庭適應量表(FACEIII)

家庭適應凝聚量表（Family Adhesion and Cohehsion Evaluation Scale, FACEIII）編自 Olslon(Olson, 1991)為 30 題的自陳式量表，其著重於評估家庭系統中的凝聚力和適應性(Green, Harris, Forte, & Robinson, 1991a; Olson, 1991)。使用 Circumplex Model Approach，在 FACES III 得到高分代表其為一平衡的家庭類型；低分則代表極端型，而所謂的平衡型，是指其能以一較為有效的方式來運作整個家庭系統。

五. 親子關係量表(PBI)

親子關係量表 (Parental Bonding Inventory, PBI) 乃編自 Parker (Parker, 1979) 的題量表，共 25 題，父母親對待他們的孩子的行為模式和態度，可分別為照顧（care）和保護（protection）兩個量表。在照顧分量表得到高分，反應出富有感情及溫暖；相對的，低分則指出父母親態度為拒絕、冷淡或冷漠。在保護分量表得高分顯示父母有過度保護、控制、命令及鼓勵孩子心理依賴的傾向；低分則表示父母允許或鼓勵兒童獨立及自主。而保護分量表又可進一步分為兩向度，分別為「鼓勵行為自主」和「拒絕心理上的獨立自主」。

六. 兒童行為量表(CBCL)

兒童行為量表包括 112 題，中文版 CBCL 以建立信效度，且廣用於兒童行為研究，衍生出八大行為問題：不專心、焦慮/憂慮、攻擊性、違法、身體抱怨、社交問題、退縮、怪異想法，及二大行為面向；內在性及外在性行為症候群(Achenbach, 1991a)。

貳. 會談量表:

一. 社會人口學資料

包括父母基本資料、居住地、父母的工作、教育程度及婚姻狀態。

二. 遺傳諮商會談量表

包括遺傳諮商的時機、地點、型式、內容、諮商者、對基因諮商的整體評估以及理想中的基因諮商方式。

三. 懷孕史、生產史及發展史

包括母親懷孕前、期間、分娩過程的情形以及孩子出生後的發展情形和滿意度。

四. 養育史

包括養育經驗、養育子女的精神及經濟付出

統計分析

本研究樣本的社會人口學特質以及遺傳諮詢的形式和內容等描述性結果主以百分比來呈現類別變項，以平均值(標準差)來呈現連續變項。將此十個向度的分數加總後作為代表遺傳諮詢滿意度的分數，以一般線性模式分析父母的人格特質、遺傳諮詢經驗與遺傳諮詢滿意度之間的關係，並將所有與遺傳諮詢滿意度有顯著關係的變項（$p < 0.1$）納入為預測變項，進行統計模式選擇，以找出影響遺傳諮詢滿意度的最重要的因素。在比較唐氏兒與非唐氏兒父母的身心適應，婚姻關係與家庭關係上用的是多變量分析。對小孩子的態度以及比較唐氏症兒童、其手足及非唐氏症兒童三組的行為問題上，因為彼此之間並非獨立事件，因此是用混合統計法(Mixed - model)的變異數分析，並以 Duncan's multiple range test 進行事後比較。對於類別變項的比較是用卡方檢定作初步的分析。所有的統計分析以 SAS 8.2 (SAS Institute Inc, Cary, NC)軟體執行。

結 果

一、社會人口學資料

社會人口學資料請見 Table 1。45 位唐氏兒的平均年齡為 7.8 歲（標準差= 3.1），其中有 28 個男生，17 個女生，男女的平均年齡並無差異（F = 0.01, df = 1,43, p = 0.920）。在這 45 個家庭中，只有一個家庭父母親已離婚。接受研究訪談的 34 位父親之平均年齡為 40.3 歲（標準差= 5.7），43 位母親之平均年齡為 37.4 歲（標準差= 5.4）。42%的父親教育程度為高中（職），19%為國中以下，26%為專科，只有 13%教育程度在大學以上。60%的母親教育程度為高中（職），國中以下和專科各佔 15%，教育程度在大學以上的只有 10%。74%的父親從事技術性質的工作，16%為無技術性工作或沒有工作，10%從為專業或半專業人士。60%的母親為全職家庭主婦，其他 40%的職業婦女之中，最多從事非手操技術性工作，佔 23%；其次是無技術性工作，佔 13%；而手操技術性和專業工作各佔 2%。27%的家庭經濟狀況為中下或低收入戶，其餘皆為小康。

二、遺傳諮詢的內容和形式

關於唐氏兒父母接受遺傳諮詢的情形詳見 Table 2。在 77 位父母親之中，有 82%是由醫生告知唐氏症的診斷。與配偶同時得知的只佔 13%，大多是父親或母親其中一方先知道。得知的時間多是產後馬上得知，或在產後一星期以內得知，各佔 38%。告知的地點最多是在病床上，其次是醫院門診、家裡或另約地點，只有少數在醫院會談室進行。當父母知道孩子是唐氏症時，第一時間的情緒反應，大多覺得難過、震驚或是悲傷，部分父母感到絕望、自責以及否認。

遺傳諮詢進行時，除了諮商者（醫生）之外，30%有護士在場，但並沒有任何社工人員或心理師在場。父母親陳述有關諮商者的態度方面，大多是溫和（47%）、正面（33%）、誠懇的（28%），有部分父母感覺諮商者只是敷衍了事（17%）、冷淡的（13%）。整個諮詢的時間短則 2 分鐘長至 2 小時，平均諮詢時間 26 分鐘（標準差= 23.5）。在會談時與諮商者的互動情形方面，65%的父母表示沒有得到情緒上的支持或安慰，78%沒有被鼓勵發問，高達 91%的父母表示沒有獲得表達或宣洩情緒的機會。在遺傳諮詢結束後，47%並沒有任何轉介或後續處理，只有 4%的父母有接受後續的心理輔導或治療。

關於遺傳諮詢的內容請見 Table 3。有 84%的諮商者一開始就提到孩子是唐氏症。有關唐氏症的內容描述方面，大多數提到染色體異常，少部分會提到發生機率或詳細介紹唐氏症徵候群。在唐氏症病因方面，40%的諮商者完全沒有說明病因，少部分會提到母親年齡、遺傳因素、懷孕過程的影響。對可能症狀的描述方面，較多提到的是智能不足、先天性心臟病、肌肉張力不好以及語言障礙。在治療方式方面，大多會告知需要早期療育，部分提到需要語言治療，但有 33%完全沒有告知可能的治療方式。有 47%的諮商者沒有提到對唐氏症的長期預後，只有 30%會提到可能的併發症。接近 40%會提供醫療方面、社會性團體等相關資料，然而有 36%的醫護人員沒有告訴父母任何有關教養、醫療及成長等方面的訊息。

唐氏症兒父母理想中的遺傳諮詢形式，57%希望是由醫生告知，也有 51%的人希

望由專業的遺傳諮詢人員告知。96%希望是以面對面的告知方式，93%的人希望告知當時配偶能在身邊，而有 14%的人希望社工人員也在場。希望被告知的地點，有 53%希望在醫院的會談室，24%希望在醫院的門診，不到 10%的父母希望是在產房或病房裡。父母很期待被告知唐氏症的病因（64%）、症狀（62%）、長期預後（55%）、治療方式（63%）、復健方式（59%）、教養方式（68%）及相關資源（70%）等內容。

養育一個唐氏症的孩子，55%的父母認為對人生觀是正面的影響，21%認為是負面影響。對夫妻關係的影響，43%認為是正面的，18%認為是負面的，有 33%的人認為沒有影響。59%的父母認為對親子關係是正面的影響。在家庭生活方面，40%認為影響是正面的，21%認為是負面的，33%覺得沒有影響。對於整體生活而言，35%表示是正面的，25%表示是負面的，31%認為沒有影響。約有 10%的父母表示正、負向影響同時存在。唐氏兒的父母在此次接受訪談時的情緒，61%的父母情緒是平靜的，42%表示比以前更珍惜，24%是感恩的，而有 8%的父母仍處於焦慮、自責的情緒。

三、遺傳諮詢的滿意度與影響因素

整體而言，只有將近 20%的父母是感到滿意的。而有超過 40%的父母不滿意諮商者所提供的相關社會、教育資源，以及有關唐氏症的後續處置建議。也有超過 30%的父母對諮商者提供有關唐氏症的知識感到不滿意、會談時間不夠充足，以及在會談時沒有得到適當的情緒支持。

以一般線性模式分析父母的個人特質、遺傳諮詢經驗與遺傳諮詢滿意度之間的關係，結果詳見 Table 4。單因子分析的結果顯示：父母的經濟狀況越好，對遺傳諮詢的滿意度越低。而個性越外向者、諮詢的地點若是在醫院的會談室，而非醫院門診或病房諮詢、進行時間越久、諮商者的態度或父母當時的情緒是正面的，遺傳諮詢滿意度也越高。在遺傳諮詢的內容方面，有關唐氏症之病因、可能症狀、治療或復健方式、長期預後、相關資料等各方面的訊息，諮商者提供越多資訊可以增加父母對遺傳諮詢的滿意度。而父母的年齡、教育程度、職業、遺傳諮詢的時機與遺傳諮詢滿意度之間沒有顯著的關係。

將所有與遺傳諮詢滿意度有顯著關係的項目作為預測變項放入統計模式，以反向選擇決定最後的模式（final model），以找出影響遺傳諮詢滿意度最顯著之因素。最後有顯著的包括外向性格、諮商者的態度、父母當時的情緒以及經濟狀況。父母個性越外向，對遺傳諮詢較容易感到滿意。諮商者的態度若是正面、溫暖、誠懇、耐心的，父母對遺傳諮詢越感到滿意。在接受遺傳諮詢時父母的情緒若是平靜的，較沒有負面的情緒，父母對遺傳諮詢也較會感到滿意。而父母的經濟狀況若越好，可能他們對遺傳諮詢的要求會越高，因此越不易感到滿意。

四、唐氏兒與非唐氏兒父母的人格特質與心理狀態

唐氏兒與非唐氏兒父母的人格特質與心理狀態詳見 Table 5。結果顯示，與非唐氏兒母親相比，唐氏兒母親在各分量表的分數普遍較高，在強迫性症狀、憂鬱、焦慮、離群、一般症狀指數以及陽性症狀總數的差異達到顯著，而在身體化症狀、人際間敏感、畏懼、附加症狀等分量表的差異則是臨界地顯著。唐氏兒父親則是在神經質、身體化症狀上顯著高於非唐氏兒父親，在憂鬱、一般症狀指數的差異達臨界地顯著。

比較父親與母親的差異，唐氏兒的母親顯著比父親焦慮，在人際間敏感性、畏懼的表現上母親臨界地高於父親。在非唐氏兒的雙親方面，母親在敵意的表現、陽性症狀嚴重度上顯著高於父親，而在社會期許的人格特質上父親顯著高於母親。

五、唐氏兒與非唐氏兒父母的婚姻與家庭關係

唐氏兒與非唐氏兒父母的婚姻與家庭關係詳見 Table 6。在婚姻兩性關係方面，唐氏兒與非唐氏兒父母在各項分量表上無顯著的差異。而在對婚姻的滿意度方面，唐氏兒母親臨界地低於唐氏兒父親和非唐氏兒母親。在家庭關係方面，理想中的家庭凝聚力分數，非唐氏兒母親顯著高於唐氏兒母親，臨界地高於非唐氏兒父親。非唐氏兒母親在理想中的家庭凝聚力與現實的差距方面顯著高於父親。

六、唐氏兒、其手足與非唐氏兒三組在行為與情緒問題之差異

唐氏兒、其手足與非唐氏兒的行為與情緒問題比較詳見 Table 7。結果顯示，唐氏兒在注意力、社交、身體化症狀、想法與退避等問題顯著比其手足、非唐氏兒嚴重，但比非唐氏兒顯現出較少的焦慮、憂鬱等症狀。對唐氏兒父母而言，唐氏兒表現出比其手足多不好的、違反規定的行為。唐氏兒之手足與非唐氏症兒在行為和情緒等問題上並無顯著差異。

七、唐氏兒、其手足與非唐氏兒之父母與其親子關係之差異

唐氏兒、其手足與非唐氏兒之父母與其親子關係之差異詳見 Table 8。在母親方面，唐氏兒之手足所得到的情感與照顧顯著比非唐氏兒少，母親給予其的保護也比唐氏兒和非唐氏兒少。另外，唐氏兒之手足的母親對其權威式控制也顯著較非唐氏兒少。在父親方面，唐氏兒之手足得到父親的保護顯著少於唐氏兒及非唐氏兒，以及較唐氏兒少的權威式控制，而父親較會對唐氏兒過度保護，顯著高於其手足與非唐氏兒。

八、父母親在親子關係之差異

父母親在親子關係之差異請見 Table 8。在唐氏兒父母方面，對於唐氏兒母親比父親展現出較多的情感與照顧（p=.026），而父親則展現較多的照顧（p=.027）與過度保護（p=.025）。而在對待唐氏兒手足方面，父親與母親的表現沒有差異。此外，非唐氏兒父母對待孩子的態度也無顯著差異（p=.147~.997）。

結 論

在前兩年的研究當中發現，遺傳諮詢的經驗滿意與否對父母的身心狀態、婚姻關係、親子關係並沒有影響。而在家庭功能和家庭互動上，有負向諮商經驗的父母親會有較多家庭適應或家庭互動上的困難。遺傳諮詢品質的好壞對於父母的影響不是在當場的感覺和情緒的反應，而是後續他們對這個疾病的瞭解、對這個疾病他們是否知道如何協助小孩去獲得足夠的支援，和從知道這個病後他們認知上的接受度、安排自己的生活、教養小孩及重新定位自己、再次出發。不論由醫師或是專業的遺傳諮詢人員給予足夠且品質良好的遺傳諮詢應該是非常重要。雖然目前看到其對親子關係並無太大影響，但是可以想像一個對整個家庭關係滿意度上有問題的父母如何發揮他們的潛能來照顧唐氏症的兒童，這樣的結果更突顯出遺傳諮詢品質的重要性。

一、遺傳諮詢的現況

本研究以有唐氏兒的家庭為研究對象提供國內遺傳諮詢的現況，以及影響遺傳諮詢滿意度的因素。從 77 位唐氏症兒父母的諮詢經驗中發現，目前台灣的醫療體系對於唐氏症這類遺傳、染色體疾患並沒有十分完整健全的處理程序。遺傳諮詢是如何進行的，大多取決於第一次診斷為唐氏症的時間與地點。八成左右的父母是由醫生進行遺傳諮詢，而諮詢地點只有 6%在醫院的會談室。大多數的遺傳諮詢並非坐下來進行的，平均諮詢的時間只有 26 分鐘。遺傳諮詢進行時，大多沒有給父母機會發問或鼓勵他們表達他們的看法，因此，無法解決他們的疑惑或提供足夠的資訊。對於父母剛知道這個訊息時的震驚、不安和焦慮，在諮詢時也沒有給他們表達或宣洩情緒的機會。在遺傳諮詢後，只有 4%的父母有接受後續的心理諮詢與輔導，不到四成的諮商者會提供相關學會或協會的訊息，讓父母可以得到進一步的資訊和協助。從這些結果來看，可以說不能算是完整的遺傳諮詢，僅僅只是醫生單方面告知父母唐氏症的訊息而已，缺少雙方的溝通以及提供心理的支持。

二、影響遺傳諮詢滿意度的因素

本研究發現許多與遺傳諮詢滿意度有關的因素，其中部分與國外的研究結果一致：諮商者的態度冷漠、敷衍，提供的唐氏症相關訊息不夠充足，都是令父母感到不滿意的原因(Cunningham et al., 1984; Hedov et al., 2002; Quine & Pahl, 1986; Quine & Rutter, 1994)。而在許多研究結果中都有提到的告知時機，在本研究中與遺傳諮詢滿意度並沒有顯著的關連，或許是因為國外的研究大都以多種遺傳、染色體疾患做為樣本，與其他遺傳疾病不同的是，患有唐氏症的嬰兒在外表具有典型的特徵，大多在短時間內就會被發現進而診斷，因此較無諮詢時機的問題。本研究獨特的發現是父母的經濟地位、外向性格、遺傳諮詢的地點、進行的時間長短以及父母當時的情緒也會影響遺傳諮詢滿意度。其中影響遺傳諮詢滿意度最重要之因素為：父母之外向性格、諮商者的態度、父母當時的情緒以及經濟狀況。諮商者的態度是決定遺傳諮詢成功與否，以及個案日後社會心理是否能適應良好的重要因素(Wertz & Fletcher, 1988)。由此可知，增進遺傳諮詢品質的方法十分重要的一點是諮商者的態度要正面、溫和、誠懇而且有耐心，雖然父母的個性和經濟狀況等因素無法改變，至少可以透過諮詢或進一步的心理輔導、治療，協助父母表達或宣洩內心的不安與焦慮、給予情緒上的支持與

安慰，緩和他們第一次得到診斷結果時震驚、無助的情緒，使父母能較容易接受及適應孩子為唐氏症的事實，及早準備進行孩子的醫療、發展和教育的療育。

三、理想的遺傳諮詢

國內唐氏兒父母理想的遺傳諮詢形式，與國外的研究結果大多一致(Quine & Pahl, 1986; Quine & Rutter, 1994; Spahis & Wilson, 1999)，都希望諮商者具備足夠的專業知識，能夠得到關於唐氏症種種相關的訊息。進行遺傳諮詢的地點，希望能在一個單獨、不受打擾的空間，例如醫院的會談室，能夠與諮商者面對面坐下來好好的談，而且配偶也能一同在場。或許是因為國內的醫病關係中，醫生是屬於專業權威的一方，病患對醫生的診斷多抱持服從、接受態度，而且國內對於遺傳諮詢的概念尚未普及化，因此多數父母仍希望是由醫生來進行遺傳諮詢，其次才是受過專業訓練的遺傳諮詢人員。然而不論是醫生或專業的諮詢人員，除了對該疾病具備充分的專業知識以外，諮詢會談的技巧和態度是需要專業訓練的。除了讓個案或相關家人能夠充分了解此項疾病之外，還能以具有同理心的態度去了解患者以及他的家人內心的感受，以協助他們心理、生活、家庭等各方面的適應。

四、唐氏兒父母的心理適應、婚姻關係與家庭關係

由結果可看出唐氏兒的母親卻實有較多的身心症狀，這或許與母親在家庭中必須扮演的角色有關。由於母親必須花較多的時間去照顧患有唐氏症的孩子，包括其生活起居、身體問題、或是特殊教育等問題，結果也間接顯示母親相對於父親感受到更多的壓力(Cheng & Tang, 1995)。而在婚姻關係與家庭關係方面，本研究結果支持部分過去的研究結果，養育唐氏症的孩子並不會對婚姻或家庭帶來負面的影響(Bennett & DeLuca, 1996; Ferguson, 2002; Fishman & Wolf, 1991)，顯示出唐氏兒家庭對於孩子的身體障礙所造成的問題，能夠順利解決與克服，並維持良好的夫妻互動與家庭凝聚力。

五、唐氏兒的行為問題與親子關係

由於唐氏症造成的智能不足與發展障礙，導致唐氏兒與正常發展的孩子相比有較多的注意力、社交、思想、退縮等問題，但是較少焦慮和憂鬱的症狀，或許可以唐氏兒的個性來解釋，相關文獻顯示唐氏兒的個性是比較溫和與友善的(Gibbs & Thorpe, 1983; Gunn & Berry, 1985)。過去的研究較少探討唐氏兒的親子關係，由本研究結果可知，唐氏兒的母親對待他/她的方式與非唐氏兒母親沒有差別，然而唐氏兒父親傾向於對他/她過度保護。

六、唐氏兒之手足的行為問題與親子關係

過去有關唐氏兒對其手足影響的研究尚未有一致的結論，而本研究顯示，唐氏兒之手足並未有較多的情緒和行為問題。在親子關係方面，與唐氏兒相比，其手足從母親那裡獲得的照顧顯著較少，雙親也傾向給於其較多的行為自由。這些唐氏兒之手足所受到教養差異在與非唐氏兒相比時也會發現。這些現象或許是因為母親必須負起照顧唐氏兒生活起居的責任，因此對其發展正常的手足的關注相對減少。父母也可能指派他/她去照顧患唐氏症的手足，因此給予他/她較多的行為自由以及鼓勵他/她獨立。對於唐氏兒與其手足在親子關係方面的研究，過去並未受到重視，然而，根據本研究的結果，家有唐氏兒確實會影響到父母與家中其他孩子的關係，這個議題值得後續進

一步的研究。

七、研究的限制

本研究最困難之處，在於唐氏症的個案少，而且並不在醫療機構長期治療，尤其鮮少在作者所執業的精神科門診，所以收案不易。加上過去醫療和遺傳諮詢的品質對這類病人的照護稍嫌不足，導致收案時遇到不少父母抱怨、發洩對醫療的諸多不滿，最後還是拒絕參加研究。因此研究群經過兩年的努力，只收集 77 位父母的資料。由於母樣本的數目不知，因此，本研究結果應用到其他有唐氏症或染色體異常孩子的家庭的外推性是存疑的。然而本研究應是少數國際上的研究專門探討針對唐氏症遺傳諮詢品質的研究，而收集的個案數不亞於國際上相關的研究。其他的優點包括並用半結構會談和自填問卷收集資料，並採用具有良好信效度的量表。

八、臨床意涵

本研究的結果顯示目前台灣針對先天染色體異常疾病（例如唐氏症）的遺傳諮詢品質仍有改善的空間，以減少如唐氏症患童本身缺陷對他們自己和家庭的衝擊，以增加他們的力量和應對能力去適應和解決面臨的困境。除了增進對唐氏兒醫療照顧、特殊教育之外，唐氏兒父母和手足的心理健康也十分需要重視。希望透過這個研究，能讓國人對現行的遺傳諮詢情形有初步的了解，提供國內的醫療體系作為改進相關疾病諮詢的參考，帶給所有為遺傳、染色體疾病所苦的患者及家庭足夠和適切的協助。除了唐氏症等染色體疾病以外，其他早期發病具有明顯的遺傳傾向的疾病，例如自閉症，也很值得去探討其遺傳諮詢的現況和滿意度。

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附 表

Table 1 Sample characteristics

Variables	DS (N = 45)	Control (N = 50)	Chi-square statistics or *F* statistics
	N (%) or Mean (SD)	N (%) or Mean (SD)	
Mother			
Age	37.33 (5.38)	37.02 (4.41)	$F_{(1, 93)} = 0.10, p = 0.756$
Age of childbirth	30.84 (4.62)	29.26 (4.03)	$F_{(1, 93)} = 3.19, p = 0.078$
Education level			
≦Junior high school	6 (14.29)	1 (2.00)	$\chi^2 = 14.07$, df = 2, $p < 0.001$
Senior high school	26 (61.90)	19 (38.00)	
≧College	10 (23.81)	30 (60.00)	
Employment status			
Employed	14 (34.15)	28 (59.57)	$\chi^2 = 5.68$, df = 1, $p = 0.017$
Unemployed	27 (65.85)	19 (40.43)	
Father			
Age	40.23 (5.81)	40.20 (4.56)	$F_{(1, 92)} = 0.00, p = 0.980$
Education level			
≦Junior high school	7 (16.67)	4 (8.00)	$\chi^2 = 5.61$, df = 2, $p = 0.061$
Senior high school	20 (47.62)	16 (32.00)	
≧College	15 (35.71)	30 (60.00)	
Employment status			
Employed	41 (100.00)	46 (97.87)	$\chi^2 = 0.88$, df = 1, $p = 0.348$
Unemployed	0 (0.00)	1 (2.13)	
Child			
Age	7.82 (3.08)	8.44 (2.80)	$F_{(1, 93)} = 1.05, p = 0.308$
Gender			
Male	28 (62.22)	27 (54.00)	$\chi^2 = 0.81$, df = 1, $p = 0.369$
Female	17 (37.78)	23 (46.00)	
Number of children in family	2.27 (0.81)	2.00 (0.67)	$F_{(1, 93)} = 3.08, p = 0.082$

Note. DS = Down syndrome; SD = standard deviation.

Table 2 Circumstances at the first contact for genetic counseling

		Percentage (%)
Informant	Attending doctor	82
	Spouse	13
	Nurse	3
	Others	3
Who knew first	Mother	47
	Father	38
	Together	13
	Other family	3
Timing	Immediately after birth	38
	Within the first week after birth	38
	One week after birth	25
Place	Ward	31
	Out-patient department	29
	Home or other place	22
	Delivery room	12
	Interview room	6
Parents' emotion	Sad	61
	Shocked	47
	Sorrowful	38
	Self-blamed	25
	Despairing	22
	Denial	17
	Anxious	14
	Peaceful	13
Informant's attitude	Positive	67
	Gentle	47
	Sincere	28
	Patient	17
	Warm	14
	Negative	33
	Perfunctory	17
	Distant	13
Parents' current emotion	Peaceful	61
	Cherished	42
	Grateful	24
	Anxious	8

Table 3 Content of genetic counseling about Down syndrome

		Percentage (%)
Down Syndrome	Mentioned initially and directly	84
	Chromosome abnormality	82
	Incidence	22
	No mention	14
	Syndrome	13
Etiology	No mention	40
	Maternal age	19
	Gene	14
	Pregnancy	12
Symptoms	Mental retardation	70
	Congenital heart disease	61
	Hypotonia	44
	Speech delay	39
	No mention	23
	Visual deficit	16
Treatment	Early intervention	55
	Speech therapy	36
	No mention	32
	Surgery	16
Prognosis	No mention	47
	Complication	30
	Survival rate	25
	Social welfare	22
	Educational resources	13
Related information	Medical treatment	40
	Social organization	38
	No mention	36
	Education	17
	Nurture	16

Table 4 Association between parents' characteristics and their satisfaction with genetic counseling

Variables	**Estimate**	**SE**	**F statistics**
Bivariate Analysis			
Age	-0.06	0.20	$F_{(1,75)} = 0.10, p = .753$
Education level	-2.13	1.29	$F_{(1,75)} = 2.72, p = .103$
Employment status	-1.00	0.63	$F_{(1,75)} = 2.54, p = .115$
Economic status	-4.74	1.75	$F_{(1,75)} = 7.37, p = .008$
Personality characteristics			
Neuroticism	-0.05	0.16	$F_{(1,65)} = 0.08, p = .772$
Extroversion	0.55	0.22	$F_{(1,65)} = 6.00, p = .017$
Social desirability	0.02	0.56	$F_{(1,65)} = 0.00, p = .970$
Genetic counseling			
Timing	1.64	1.27	$F_{(1,75)} = 1.68, p = .200$
Place--Interview room	10.49	4.30	$F_{(1,75)} = 5.94, p = .017$
Duration	0.20	0.04	$F_{(1,75)} = 23.21, p < .001$
Counselor's attitude	10.43	1.95	$F_{(1,75)} = 28.69, p < .001$
Parents' immediate emotion	5.79	3.36	$F_{(1,75)} = 2.97, p = .089$
Down syndrome			
Content	4.47	3.24	$F_{(1,75)}= 1.91, p = .171$
Etiology	5.41	2.15	$F_{(1,75)} = 6.35, p = .014$
Symptoms	8.44	2.41	$F_{(1,75)} = 12.24, p < .001$
Treatment	8.61	2.04	$F_{(1,75)} = 17.71, p < .001$
Prognosis	8.17	1.99	$F_{(1,75)} = 16.85, p < .001$
Related information	7.78	2.09	$F_{(1,75)} = 13.86, p < .001$
Final selected model			
Intercept	14.42	5.31	
Extroversion	0.54	0.19	$F_{(1, 62)} = 7.92, p = .007$
Counselor's attitude	10.18	2.14	$F_{(1, 62)}= 22.71, p < .001$
Parents' immediate emotion	10.00	2.94	$F_{(1, 62)} = 11.58, p = .001$
Economic status	-4.43	1.58	$F_{(1, 62)} = 7.87, p = .007$

Table 5 Psychopathology and personality by Down syndrome and control parents

	Mother		Father		
	1.DS (N = 34)	2.Control (N = 50)	3.DS (N = 33)	4.Control (N = 49)	
Variables	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Statistics ($p < 0.10$)
Personality characteristics					
Neuroticism	8.93 (7.65)	6.72 (6.24)	9.63 (7.77)	6.04 (5.82)	3 vs. 4 $F_{(1,81)} = 5.76, p = 0.019$
Extroversion	16.31 (4.99)	17.48 (4.82)	15.03 (5.53)	15.80 (5.00)	2 vs. 4 $F_{(1,98)} = 2.94, p = 0.090$
Social desirability	4.55 (1.90)	3.99 (2.20)	4.79 (2.50)	4.92 (2.11)	2 vs. 4 $F_{(1,98)} = 4.69, p = 0.033$
Psychopathology					
Somatization	0.97 (0.79)	0.66 (0.66)	0.73 (0.68)	0.47 (0.42)	1 vs. 2 $F_{(1,82)} = 3.94, p = 0.051$
					3 vs. 4 $F_{(1,80)} = 4.57, p = 0.036$
Obsession	1.05 (0.89)	0.71 (0.58)	0.76 (0.57)	0.63 (0.48)	1 vs. 2 $F_{(1,82)} = 4.68, p = 0.033$
Interpersonal sensitivity	0.82 (0.79)	0.55 (0.54)	0.55 (0.46)	0.41 (0.41)	1 vs. 2 $F_{(1,82)} = 3.68, p = 0.059$
					1 vs. 3 $F_{(1,65)} = 3.06, p = 0.085$
Depression	0.72 (0.77)	0.43 (0.42)	0.54 (0.45)	0.35 (0.40)	1 vs. 2 $F_{(1,82)} = 4.99, p = 0.028$
					3 vs. 4 $F_{(1,80)} = 3.93, p = 0.051$
Anxiety	0.65 (0.71)	0.29 (0.37)	0.35 (0.40)	0.31 (0.44)	1 vs. 2 $F_{(1,82)} = 9.21, p = 0.003$
					1 vs. 3 $F_{(1,65)} = 4.62, p = 0.035$
Hostility	0.88 (0.77)	0.77 (0.71)	0.70 (0.48)	0.48 (0.39)	3 vs. 4 $F_{(1,80)} = 5.26, p = 0.025$
					2 vs. 4 $F_{(1,97)} = 6.31, p = 0.014$
Phobia	0.51 (0.58)	0.28 (0.49)	0.26 (0.43)	0.21 (0.29)	1 vs. 2 $F_{(1,82)} = 3.84, p = 0.053$
					1 vs. 3 $F_{(1,65)} = 3.85, p = 0.054$
Paranoid	0.57 (0.64)	0.39 (0.42)	0.48 (0.58)	0.35 (0.37)	
Psychoticism	0.49 (0.54)	0.27 (0.42)	0.43 (0.56)	0.29 (0.37)	1 vs. 2 $F_{(1,82)} = 4.33, p = 0.041$
Addition symptoms	0.58 (0.57)	0.35 (0.51)	0.50 (0.67)	0.39 (0.41)	1 vs. 2 $F_{(1,82)} = 3.78, p = 0.055$
General symptom severity index (GSI)	0.73 (0.65)	0.46 (0.41)	0.53 (0.42)	0.39 (0.32)	1 vs. 2 $F_{(1,82)} = 5.52, p = 0.021$
					3 vs. 4 $F_{(1,80)} = 2.78, p < 0.10$
Positive symptom total number (PST)	23.29 (15.61)	16.48 (11.37)	19.67 (13.78)	16.20 (12.04)	1 vs. 2 $F_{(1,82)} = 5.36, p = 0.023$
Positive symptom distress index (PSDI)	1.41 (0.43)	1.29 (0.35)	1.23 (0.56)	1.07 (0.40)	2 vs. 4 $F_{(1,80)} = 8.55, p = 0.004$

Note. DS = Down syndrome; SD = standard deviation.

Table 6 Dyadic adjustment and Family function by Down syndrome and control parents

	Mother		Father		Statistics ($p < 0.1$)	
	1.DS (N = 35)	2.Control (N = 50)	3.DS (N = 33)	4.Control (N = 49)		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
Dyadic adjustment						
Dyadic consensus	45.58 (10.42)	46.50 (9.77)	44.17 (8.54)	46.90 (7.60)		
Dyadic cohesion	11.51 (5.88)	12.88 (4.72)	11.75 (4.81)	13.22 (5.21)		
Dyadic satisfaction	28.18 (5.08)	30.19 (4.77)	30.25 (3.85)	31.18 (4.51)	1 vs. 2	$F_{(1,83)} = 3.48, p = 0.066$
					1 vs. 3	$F_{(1,66)} = 3.54, p = 0.064$
Affection expression	8.20 (2.58)	8.97 (1.86)	8.85 (2.31)	8.92 (2.07)		
Dyadic adjustment	93.43 (20.62)	98.60 (17.93)	95.41 (14.81)	100.25 (15.53)		
Family function						
Adaptation						
Current	34.06 (7.39)	33.78 (5.35)	33.02 (6.33)	33.84 (4.90)		
Ideal	37.55 (6.42)	38.08 (4.44)	36.05 (6.24)	36.94 (5.29)		
Difference	3.49 (4.78)	4.30 (3.69)	3.03 (3.85)	3.09 (3.77)		
Cohesion						
Current	38.76 (6.76)	39.81 (5.42)	37.97 (7.22)	40.10 (5.29)		
Ideal	41.95 (5.89)	44.27 (4.23)	41.12 (7.22)	42.70 (4.44)	1 vs. 2	$F_{(1,82)} = 4.41, p = 0.039$
					2 vs. 4	$F_{(1,98)} = 3.27, p = 0.074$
Difference	3.18 (4.55)	4.46 (5.00)	3.15 (3.91)	2.60 (3.43)	2 vs. 4	$F_{(1,98)} = 4.69, p = 0.033$
Dissatisfaction	6.17 (5.23)	6.65 (5.72)	5.21 (4.68)	5.05 (4.08)		

Note. DS = Down syndrome; SD = standard deviation.

Table 7 Emotional and behavior problems by children with Down syndrome, siblings and controls

	1. DS (N = 33)	2. Siblings (N = 31)	3. Controls (N = 50)	Statistics with Duncan	
T score	Mean (SD)	Mean (SD)	Mean (SD)	F value	Comparisons ($p < 0.05$)
Aggressive behavior	50.03 (8.42)	48.84 (10.60)	50.69 (10.71)	$F_{(2,111)} = 0.32$, $p = 0.724$	
Anxious/Depressed	47.21 (5.96)	49.69 (10.60)	52.07 (11.34)	$F_{(2,111)} = 2.42$, $p = 0.093$	1 vs. 3
Attention problems	58.63 (9.82)	45.87 (7.87)	46.87 (7.66)	$F_{(2,111)} = 24.66$, $p < .001$	1 vs. 2, 1 vs. 3
Delinquent behavior	52.53 (11.63)	47.23 (7.42)	50.06 (10.03)	$F_{(2,111)} = 2.29$, $p = 0.107$	1 vs. 2
Social problems	60.14 (9.33)	45.03 (6.67)	46.39 (6.99)	$F_{(2,111)} = 41.02$, $p < .001$	1 vs. 2, 1 vs. 3
Somatic complaints	54.81 (13.11)	47.91 (7.87)	48.12 (7.61)	$F_{(2,111)} = 5.82$, $p = 0.004$	1 vs. 2, 1 vs. 3
Thought problems	54.55 (12.88)	47.23 (6.10)	48.75 (8.81)	$F_{(2,111)} = 5.43$, $p = 0.006$	1 vs. 2, 1 vs. 3
Withdrawn	55.00 (11.97)	48.82 (8.38)	47.48 (8.29)	$F_{(2,111)} = 6.55$, $p = 0.002$	1 vs. 2, 1 vs. 3

Note. DS = Down syndrome; SD = standard deviation.

Table 8 Parental attitude toward children with Down syndrome, siblings and controls

	1.DS	2.Siblings	3.Controls	Statistics with Duncan	
	Mean (SD)	Mean (SD)	Mean (SD)	*F* value	Comparisons ($p < 0.05$)
Mother	(N = 40)	(N = 32)	(N = 50)		
Affection	27.53 (4.31)	26.85 (4.78)	29.10 (4.27)	$F_{(2,119)} = 2.85$, $p = 0.062$	2 vs. 3
Protection	14.74 (5.16)	12.26 (4.97)	14.94 (4.64)	$F_{(2,119)} = 3.32$, $p = 0.040$	1 vs. 2, 2 vs. 3
Overprotection	8.03 (3.33)	6.50 (4.13)	7.84 (3.25)	$F_{(2,119)} = 1.95$, $p = 0.147$	
Authoritative controlling	6.71 (2.98)	5.76 (2.80)	7.10 (2.27)	$F_{(2,119)} = 2.50$, $p = 0.086$	2 vs. 3
Father	(N = 37)	(N = 25)	(N = 50)		
Affection	25.27 (4.40)	25.07 (4.26)	26.01 (5.19)	$F_{(2,106)} = 0.42$, $p = 0.661$	
Protection	17.08 (3.79)	12.56 (4.97)	14.48 (4.44)	$F_{(2,106)} =8.42$, $p < .001$	1 vs. 2, 1 vs. 3
Overprotection	9.65 (2.83)	6.80 (3.19)	7.89 (3.20)	$F_{(2,106)} =6.90$, $p = 0.002$	1 vs. 2, 1 vs. 3
Authoritative controlling	7.43 (2.81)	5.76 (2.68)	6.58 (2.71)	$F_{(2,106)} = 2.84$, $p = 0.063$	1 vs. 2

Note. DS = Down syndrome; SD = standard deviation

附錄一

遺傳諮詢的內容及影響諮詢滿意度的相關因子—以唐氏症為例

（將刊登於台灣精神醫學第 19 卷，第 3 期，2005）

摘　要

目的：為了瞭解唐氏兒父母接受遺傳諮詢的現況，父母對遺傳諮詢經驗的滿意程度，以及影響遺傳諮詢滿意度之相關因素。

方法：本研究訪談了 77 位唐氏兒的父母有關遺傳諮詢的內容及滿意度評估，父母並完成簡式性格量表（Maudsley Personality Inventory, MPI）等自填式問卷。

結果：研究結果顯示唐氏兒父母的遺傳諮詢 82%由醫生進行，平均諮詢時間為 26 分鐘 (標準差= 23.5)，只有 20%的父母對遺傳諮詢的經驗感到滿意。諮商者的態度冷漠、敷衍，提供的資訊不夠充足，進行諮詢的地點不適當，進行時間太短等都讓父母感到不滿意。而父母當時的情緒、經濟狀況、外向性格也會影響遺傳諮詢的滿意度。

結論：目前國內對唐氏兒父母的遺傳諮詢，大多是由醫生單方面告知父母有關唐氏症的相關訊息，缺乏雙方的溝通，以及提供心理支持、後續心理輔導、治療的工作。增進遺傳諮詢品質最重要的是改進諮商者的態度，給予父母宣洩情緒的機會和提供足夠的資訊，以協助唐氏兒家庭心理、生活、親子關係等各方面的適應。

關鍵詞：唐氏症，遺傳諮詢，遺傳諮詢滿意度

前　言

隨著近二十多年基因科技的快速發展以及在生物學上的廣泛應用，有關基因科技的倫理問題逐漸受到重視。許多有關遺傳、染色體異常或基因突變等相關疾病的遺傳診斷、諮詢及後續處置，是否合乎倫理與人性，以及是否符合社會的規範等議題，不斷地在醫療、法律、家庭和社會等情境中發生。遺傳諮詢，就是在強調倫理的原則之下，著重於專業遺傳諮詢師應該要以何種方式，如何傳遞給個案有關基因遺傳上的發現，並解釋因此項基因遺傳的變化可能衍生而來的心理社會之功能改變[1]。

遺傳諮詢一向被認為是醫療人員與個案之間複雜的溝通過程，其中包含與個案及其家族成員討論檢查所發現之遺傳疾病、新生兒所伴隨之醫療問題，以及家族遺傳史。遺傳諮詢包含有教育性[2]以及社會心理性[3]的內容。有效而且有益的遺傳諮詢，包含幾項重要的倫理原則：尊重人性價值和個案自主性；以友善、不具攻擊性、非指導性的語氣，誠實並且真誠地告知真實情況；提供適當和足夠的訊息或是相關資源的資料[4]。遺傳諮詢師的態度是決定遺傳諮詢成功與否，以及個案日後是否有良好的社會心理適應之重要因素[5]。一直以來，有關於遺傳諮詢的研究報告成果數量不多，在少量僅有的文獻之中，著墨的也多是西方國家。目前在台灣醫學院學生的養成教育中，雖然有許多致力於醫學倫理與醫病關係的理念與課程，但是醫學倫理在實際臨床醫學中應用的實例與指導仍顯不足。

本研究提供醫學倫理用於遺傳諮詢之檢驗，所採用之個案為唐氏症兒童。因為唐氏症（trisomy 21）是遺傳性疾病中最常見的一種，是造成智能不足最主要已知的染色體疾患，其盛行率是 1-1.5/1000 活產兒[6]。唐氏兒具有典型的生理以及臉部外觀特徵，使他們自嬰兒期即開始與其他非唐氏症兒童顯得十分不同[7]。唐氏兒伴隨有低智商（平均智商低於 50），隨著年齡有下降之趨勢，在身體方面，唐氏兒常有心血管方面之疾病[8]、腸胃畸形[9,10]、血液異常[11,12]以及癲癇症[13]。並且，他們在三十歲左右就漸漸地產生一些衰老的徵兆，例如：稀少的頭髮、乾燥而且縐折的皮膚、神經性的改變等等。

唐氏兒具有與其他兒童不同的生理及認知心理發展的過程、本身面臨的低學業成就、家庭所需要付出龐大的教育訓練以及醫療費用，對其個人、家庭甚至社會造成的影響甚鉅[6]。研究顯示，父母被告知唐氏症診斷的過程，會對其日後的適應以及他們對待孩子的方式產生影響[14]，適當和高品質的遺傳諮詢以及對唐氏兒持續的生理照顧，可以幫助唐氏兒父母親在新生兒時期逐漸適應壓力。國外的研究顯示：多數的父母對於被告知診斷結果的遺傳諮詢經驗感到不滿意。不滿意的原因包括：諮商者的態度冷漠、缺乏溝通技巧；提供與疾病相關之訊息不夠充足，許多疑問仍沒有得到答案；告知的時機不適當，過早或是太晚告知；告知時沒有配偶或孩子在身旁；諮商者所具備之基本知識不足；諮商者傳遞過多負面訊息[15,16,17,18,19]。

對父母而言，諮商者的專業知識、諮詢時機、諮詢環境、諮商者的態度為影響遺傳諮詢滿意度之重要指標[19]。在遺傳諮詢時，多數父母希望能夠說出自己的疑問、表達自己的情緒。父母希望可以儘早知道有關孩子的診斷；希望諮商者在諮詢時能表現出支持與同理心；希望能夠得到與孩子的疾病有關的完整訊息[17,18]。除

了第一次的遺傳諮詢之外，接下來的心理支持以及相關建議也是很重要的，除了心理輔導或治療以外，與其他有唐氏兒家庭接觸也可以成為唐氏兒父母安慰與建議的來源[20]。

在台灣，遺傳諮詢是由婦產科醫師、小兒科醫師、護理人員或是遺傳諮詢師執行，大都決定於第一次診斷為唐氏症的地點與時間，並不是完全由專業遺傳諮詢人員執行。國內相關研究顯示台灣的唐氏兒家庭受到多樣及程度不一的衝擊[21]，父母認知真相後會出現不同的調適行為[22]。這些研究明白顯示出唐氏兒的父母親初次知道小孩為唐氏兒時，情緒反應為悲痛、驚訝、否認、無助以及失望。唐氏兒父母確實對於關於唐氏症資訊及相關事實感到需要，也需要更豐富的教育資源以及社會資源的資訊提供。本研究之目的在瞭解台灣目前針對唐氏症兒父母的遺傳諮詢的內容和型態、父母親對遺傳諮詢經驗的滿意狀況、以及影響遺傳諮詢滿意度的因素。並希望根據這些唐氏兒父母的遺傳諮詢經驗，提供國內改進遺傳諮詢方式與品質的參考。

材料與方法

研究對象

本研究樣本包括 45 個 1 歲到 10 歲經醫師診斷並領有殘障手冊患有唐氏症的兒童之家庭，其中 32 個家庭父母親皆完成此研究，共有 43 位母親及 34 位父親完成所有的評估。這 45 個唐氏症兒童的樣本有 24 個（53%）來自臺大醫院，5 個（11%）經由中華民國唐氏症關愛協進會轉介，5 個（11%）經由台北縣市的學前特教中心轉介，11 個（24%）經由台北縣市國小特教班轉介。

研究工具

本研究的工具包括半結構式會談以獲得遺傳諮詢的內容和懷孕生產史，以及自填問卷評估父母的身心狀況、親子關係和孩子的發展特徵、氣質及情緒行為。以下僅描述本文所用到的研究工具：

一、以半結構式會談完成「遺傳諮詢會談量表」：此量表是事先訪談了十位從事基因遺傳的婦產科、小兒科醫師和相關專業人員，了解遺傳諮詢的內容與過程，綜合相關專業的意見後編製而成的。量表內容包括第一次被告知孩子有唐氏症的遺傳諮詢的時機、地點、型式、諮詢的內容、諮商者的態度、諮詢所花的時間、當時及現在的情緒狀態，對 10 項遺傳諮詢滿意度的評估，最後讓父母表達其理想中的遺傳諮詢方式與內容。

諮詢滿意度是以五點量表對遺傳諮詢的經驗進行滿意度的評估，「0」為非常不滿意，「1」為不滿意，「2」為還好，「3」為滿意，「4」為非常滿意。此量表包括遺傳諮詢滿意度的十個項目：告知時機、會談時間、諮商者對唐氏症的瞭解程度、提供有關唐氏症的知識、唐氏症後續處置之建議、相關社會及教育資源、諮商者的態度、與諮商者的溝通關係、所得到的情緒支持以及整體評估。

二、自填問卷分為兩部分：

(1).社會人口學資料：包括父母親的基本資料、居住地、教育程度、職業、經濟狀況及婚姻狀態。

(2).簡式性格量表：簡式性格量表（Maudsley Personality Inventory, MPI）乃李明濱等人[23,24]改編自 Eysenck[25]的性格量表，涵蓋神經質（13 題）、外向（13 題）及社會期許（4 題）三個向度，共 30 題。以北部 2919 名成人樣本求得本量表各向度的內在一致性（Cronbach α）良好：神經質（$\alpha = 0.79$）、外向（$\alpha = 0.76$）、社會期許（$\alpha = 0.32$）。以本研究所得的內在一致性（α）為：神經質（0.87）、外向（0.70）、社會期許（0.41）。

研究步驟

本研究經過台大醫院倫理委員會的同意進行，經由三個途徑收集個案家庭：(1) 經由台大醫院的病歷資料確定為唐氏症的病人，寄發研究目的和進行方式的說明信給家長，以徵得其同意進行訪談；(2) 透過中華民國唐氏症關愛協進會先徵詢有唐氏症孩子的父母參加研究的意願；(3) 地毯式地接洽台北縣市所有的特殊教育發展中心和國小的特教班的老師，詢問有無患有唐氏症的學生，若有，且老師同意代轉研究說明書給家長，則再經由老師轉交研究說明書。

最後有 45 個唐氏症家庭參與研究。一位有家庭親職諮詢背景的碩士負責會談母親及父親以獲得有關被告知有唐氏症孩子的遺傳諮詢經驗，以及訪談母親以獲得懷孕生產史。父母親並且完成自填式問卷。父母親同意會談錄音者，給予錄音，以做為控制研究品質，和將來質性研究分析之用。會談的內容經由會談者和第一作者共同討論以決定最符合受訪者的情形之代碼。

統計分析

本研究樣本的社會人口學特質以及遺傳諮詢的形式和內容等描述性結果主以百分比來呈現類別變項，以平均值(標準差)來呈現連續變項。遺傳諮詢滿意度量表的因素結構是以主要成分因素分析法分析。將依 Scree plot 及 Eigenvalues 決定因素的數目。並以 Cronbach’s alpha 係數進行因素內在各項目一致性分析。將此十個向度的分數加總後作為代表遺傳諮詢滿意度的分數，以一般線性模式分析父母的人格特質、遺傳諮詢經驗與遺傳諮詢滿意度之間的關係，並將所有與遺傳諮詢滿意度有顯著關係的變項（$p < 0.1$）納入為預測變項，進行統計模式選擇，以找出影響遺傳諮詢滿意度的最重要的因素。另外，父母的簡式性格量表得分依常模計算 T-分數，T-分數為 Z-分數乘以 10 再加上 50。因此，T-分數的平均值是 50，標準差是 10。所有的統計分析以 SAS 8.2 (SAS Institute Inc, Cary, NC)軟體執行。

結　　果

社會人口學資料與性格特質

45 位唐氏兒的平均年齡為 7.8 歲（標準差= 3.1），其中有 28 個男生，17 個女生，男女的平均年齡並無差異（$F = 0.01$, df = 1,43, $p = 0.920$）。在這 45 個家庭中，只有一個家庭父母親已離婚。接受研究訪談的 34 位父親之平均年齡為 40.3 歲（標準差= 5.7），43 位母親之平均年齡為 37.4 歲（標準差= 5.4）。42%的父親教育程度為高中（職），19%為國中以下，26%為專科，只有 13%教育程度在大學以上。60%的母親教育程度為高中（職），國中以下和專科各佔 15%，教育程度在大學以上的只有 10%。74%的父親從事技術性質的工作，16%為無技術性工作或沒有工作，10%從為專業或半專業人士。60%的母親為全職家庭主婦，其他 40%的職業婦女之中，最多從事非手操技術性工作，佔 23%；其次是無技術性工作，佔 13%；而手操技術性和專業工作各佔 2%。27%的家庭經濟狀況為中下或低收入戶，其餘皆為小康。在 77 位父母當中，共有 67 位完成簡式性格量表，以 2919 位成人為常模，計算在各性格向度之 T 分數，結果神經質的 T 分數為 47.93，外向的 T 分數為 50.73，社會期許的 T 分數為 54.86。

遺傳諮詢的內容和形式

關於唐氏兒父母接受遺傳諮詢的情形詳見表一。在 77 位父母親之中，有 82%是由醫生告知唐氏症的診斷。與配偶同時得知的只佔 13%，大多是父親或母親其中一方先知道。得知的時間多是產後馬上得知，或在產後一星期以內得知，各佔 38%。告知的地點最多是在病床上，其次是醫院門診、家裡或另約地點，只有少數在醫院會談室進行。當父母知道孩子是唐氏症時，第一時間的情緒反應，大多覺得難過、震驚或是悲傷，部分父母感到絕望、自責以及否認。

遺傳諮詢進行時，除了諮商者（醫生）之外，30%有護士在場，但並沒有任何社工人員或心理師在場。被告知時的姿勢和位置的安排方面，50%的父母是坐著，另外50%則是站著或躺著被告知；55%諮商者、34%其他在場的人是坐著的，其餘是採站姿，所以絕大多數僅僅只是站著進行諮詢。父母親陳述有關諮商者的態度方面，大多是溫和（47%）、正面（33%）、誠懇的（28%），或是有耐心（17%）、溫暖熱心的（14%），有部分父母感覺諮商者只是敷衍了事（17%）、冷淡的（13%）。整個諮詢的時間短則 2 分鐘長至 2 小時，平均諮詢時間 26 分鐘（標準差= 23.5）。在會談時與諮商者的互動情形方面，65%的父母表示沒有得到情緒上的支持或安慰，78%沒有被鼓勵發問，高達 91%的父母表示沒有獲得表達或宣洩情緒的機會。在遺傳諮詢結束後，47%並沒有任何轉介或後續處理，只有 4%的父母有接受後續的心理輔導或治療。

關於遺傳諮詢的內容請見表二。有 84%的諮商者一開始就提到孩子是唐氏症。有關唐氏症的內容描述方面，大多數提到染色體異常，少部分會提到發生機率或詳細介紹唐氏症徵候群。在唐氏症病因方面，40%的諮商者完全沒有說明病因，少部分會提到母親年齡、遺傳因素、懷孕過程的影響。對可能症狀的描述方面，較多提到的是智能不足、先天性心臟病、肌肉張力不好以及語言障礙。在治療方式方面，大多會告知需要早期療育，部分提到需要語言治療，但有 33%完全沒有告知可能的治療方式。有 47%的諮商者沒有提到對唐氏症的長期預後，只有 30%會提到可能的併發症。接近 40%會提供醫療方面、社會性團體等相關資料，然而有 36%的醫護人員沒有告訴父母任何有關教養、醫療及成長等方面的訊息。

唐氏症兒父母理想中的遺傳諮詢形式，57%希望是由醫生告知，也有 51%的人希望由專業的遺傳諮詢人員告知。96%希望是以面對面的告知方式，93%的人希望告知當時配偶能在身邊，而有 14%的人希望社工人員也在場。希望被告知的地點，有 53%希望在醫院的會談室，24%希望在醫院的門診，不到 10%的父母希望是在產房或病房裡。父母很期待被告知唐氏症的病因（64%）、症狀（62%）、長期預後（55%）、治療方式（63%）、復健方式（59%）、教養方式（68%）及相關資源（70%）等內容。

養育一個唐氏症的孩子，55%的父母認為對人生觀是正面的影響，21%認為是負面影響。對夫妻關係的影響，43%認為是正面的，18%認為是負面的，有 33%的人認為沒有影響。59%的父母認為對親子關係是正面的影響。在家庭生活方面，40%認為影響是正面的，21%認為是負面的，33%覺得沒有影響。對於整體生活而言，35%表示是正面的，25%表示是負面的，31%認為沒有影響。約有 10%的父母表示正、負向影響同時存在。唐氏兒的父母在此次接受訪談時的情緒，61%的父母情緒是平靜的，42%表示比以前更珍惜，24%是感恩的，而有 8%的父母仍處於焦慮、自責的情緒。

遺傳諮詢的滿意度

十個滿意度題目經因素分析發現只有一個共同的因素結構（請見表三），其 Eigenvalue 為 7.85，因素負荷介於 0.58（告知的時機）到 0.95（對遺傳諮詢的整體評估）之間。內部一致性（Cronbach α）達 0.97，各題與扣除該題後總分之相關介於 0.52（告知的時機）至 0.93（對遺傳諮詢的整體評估）之間。遺傳諮詢的滿意度總分介於 0-39 分之間，平均分數為 18.19（標準差= 9.60）。整體而言，只有將近 20%的父母是感到滿意的。而有超過 40%的父母不滿意諮商者所提供的相關社會、教育資源，以及

有關唐氏症的後續處置建議。也有超過 30%的父母對諮商者提供有關唐氏症的知識感到不滿意、會談時間不夠充足，以及在會談時沒有得到適當的情緒支持。

影響遺傳諮詢滿意度的因素

以一般線性模式分析父母的個人特質、遺傳諮詢經驗與遺傳諮詢滿意度之間的關係，結果詳見表四。單因子分析的結果顯示：父母的經濟狀況越好，對遺傳諮詢的滿意度越低。而個性越外向者、諮詢的地點若是在醫院的會談室，而非醫院門診或病房諮詢、進行時間越久、諮商者的態度或父母當時的情緒是正面的，遺傳諮詢滿意度也越高。在遺傳諮詢的內容方面，有關唐氏症之病因、可能症狀、治療或復健方式、長期預後、相關資料等各方面的訊息，諮商者提供越多資訊可以增加父母對遺傳諮詢的滿意度。而父母的年齡、教育程度、職業、遺傳諮詢的時機與遺傳諮詢滿意度之間沒有顯著的關係。

將所有與遺傳諮詢滿意度有顯著關係的項目作為預測變項放入統計模式，以反向選擇決定最後的模式（final model），以找出影響遺傳諮詢滿意度最顯著之因素。最後有顯著的包括外向性格、諮商者的態度、父母當時的情緒以及經濟狀況。父母個性越外向，對遺傳諮詢較容易感到滿意。諮商者的態度若是正面、溫暖、誠懇、耐心的，父母對遺傳諮詢越感到滿意。在接受遺傳諮詢時父母的情緒若是平靜的，較沒有負面的情緒，父母對遺傳諮詢也較會感到滿意。而父母的經濟狀況若越好，可能他們對遺傳諮詢的要求會越高，因此越不易感到滿意。

討　論

遺傳諮詢的現況

本研究以有唐氏兒的家庭為研究對象提供國內遺傳諮詢的現況，以及影響遺傳諮詢滿意度的因素。從 77 位唐氏症兒父母的諮詢經驗中發現，目前台灣的醫療體系對於唐氏症這類遺傳、染色體疾患並沒有十分完整健全的處理程序。遺傳諮詢是如何進行的，大多取決於第一次診斷為唐氏症的時間與地點。八成左右的父母是由醫生進行遺傳諮詢，而諮詢地點只有 6%在醫院的會談室。大多數的遺傳諮詢並非坐下來進行的，平均諮詢的時間只有 26 分鐘。遺傳諮詢進行時，大多沒有給父母機會發問或鼓勵他們表達他們的看法，因此，無法解決他們的疑惑或提供足夠的資訊。對於父母剛知道這個訊息時的震驚、不安和焦慮，在諮詢時也沒有給他們表達或宣洩情緒的機會。在遺傳諮詢後，只有 4%的父母有接受後續的心理諮詢與輔導，不到四成的諮商者會提供相關學會或協會的訊息，讓父母可以得到進一步的資訊和協助。從這些結果來看，可以說不能算是完整的遺傳諮詢，僅僅只是醫生單方面告知父母唐氏症的訊息而已，缺少雙方的溝通以及提供心理的支持。

影響遺傳諮詢滿意度的因素

本研究發現許多與遺傳諮詢滿意度有關的因素，其中部分與國外的研究結果一致：諮商者的態度冷漠、敷衍，提供的唐氏症相關訊息不夠充足，都是令父母感到不滿意的原因[16,17,18,19]。而在許多研究結果中都有提到的告知時機，在本研究中與遺傳諮詢滿意度並沒有顯著的關連，或許是因為國外的研究大都以多種遺傳、染色體疾

患做為樣本，與其他遺傳疾病不同的是，患有唐氏症的嬰兒在外表具有典型的特徵，大多在短時間內就會被發現進而診斷，因此較無諮詢時機的問題。本研究獨特的發現是父母的經濟地位、外向性格、遺傳諮詢的地點、進行的時間長短以及父母當時的情緒也會影響遺傳諮詢滿意度。其中影響遺傳諮詢滿意度最重要之因素為：父母之外向性格、諮商者的態度、父母當時的情緒以及經濟狀況。諮商者的態度是決定遺傳諮詢成功與否，以及個案日後社會心理是否能適應良好的重要因素[5]。由此可知，增進遺傳諮詢品質的方法十分重要的一點是諮商者的態度要正面、溫和、誠懇而且有耐心，雖然父母的個性和經濟狀況等因素無法改變，至少可以透過諮詢或進一步的心理輔導、治療，協助父母表達或宣洩內心的不安與焦慮、給予情緒上的支持與安慰，緩和他們第一次得到診斷結果時震驚、無助的情緒，使父母能較容易接受及適應孩子為唐氏症的事實，及早準備進行孩子的醫療、發展和教育的療育。

理想的遺傳諮詢

國內唐氏兒父母理想的遺傳諮詢形式，與國外的研究結果大多一致[17,18,19]，都希望諮商者具備足夠的專業知識，能夠得到關於唐氏症種種相關的訊息。進行遺傳諮詢的地點，希望能在一個單獨、不受打擾的空間，例如醫院的會談室，能夠與諮商者面對面坐下來好好的談，而且配偶也能一同在場。或許是因為國內的醫病關係中，醫生是屬於專業權威的一方，病患對醫生的診斷多抱持服從、接受態度，而且國內對於遺傳諮詢的概念尚未普及化，因此多數父母仍希望是由醫生來進行遺傳諮詢，其次才是受過專業訓練的遺傳諮詢人員。然而不論是醫生或專業的諮詢人員，除了對該疾病具備充分的專業知識以外，諮詢會談的技巧和態度是需要專業訓練的。除了讓個案或相關家人能夠充分了解此項疾病之外，還能以具有同理心的態度去了解患者以及他的家人內心的感受，以協助他們心理、生活、家庭等各方面的適應。

研究的限制

本研究最困難之處，在於唐氏症的個案少，而且並不在醫療機構長期治療，尤其鮮少在作者所執業的精神科門診，所以收案不易。加上過去醫療和遺傳諮詢的品質對這類病人的照護稍嫌不足，導致收案時遇到不少父母抱怨、發洩對醫療的諸多不滿，最後還是拒絕參加研究。因此研究群經過兩年的努力，只收集 77 位父母的資料。由於母樣本的數目不知，因此，本研究結果應用到其他有唐氏症或染色體異常孩子的家庭的外推性是存疑的。

然而本研究應是少數國際上的研究專門探討針對唐氏症遺傳諮詢品質的研究，而收集的個案數不亞於國際上相關的研究。其他的優點包括並用半結構會談和自填問卷收集資料，人格特質的評估採用具有良好信效度的量表。

臨床意涵

本研究的結果顯示目前台灣針對先天染色體異常疾病（例如唐氏症）的遺傳諮詢品質仍有改善的空間，以減少如唐氏症患童本身缺陷對他們自己和家庭的衝擊，以增加他們的力量和應對能力去適應和解決面臨的困境。希望透過這個研究，能讓國人對現行的遺傳諮詢情形有初步的了解，提供國內的醫療體系作為改進相關疾病諮詢的參考，帶給所有為遺傳、染色體疾病所苦的患者及家庭足夠和適切的協助。除了唐氏症等染色體疾病以外，其他早期發病具有明顯的遺傳傾向的疾病，例如自閉症，也很值

得去探討其遺傳諮詢的現況和滿意度。

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Table 1. Circumstances at the first contact for genetic counseling

		Percentage (%)
Informant	Attending doctor	82
	Spouse	13
	Nurse	3
	Others	3
Who knew first	Mother	47
	Father	38
	Together	13
	Other family	3
Timing	Immediately after birth	38
	Within the first week after birth	38
	One week after birth	25
Place	Ward	31
	Out-patient department	29
	Home or other place	22
	Delivery room	12
	Interview room	6
Parents' emotion	Sad	61
	Shocked	47
	Sorrowful	38
	Self-blamed	25
	Despairing	22
	Denial	17
	Anxious	14
	Peaceful	13
Informant's attitude	Positive	67
	Gentle	47
	Sincere	28
	Patient	17
	Warm	14
	Negative	33
	Perfunctory	17
	Distant	13
Parents' current emotion	Peaceful	61
	To cherish	42
	Grateful	24
	Anxious	8

Table 2. Content of genetic counseling about Down syndrome

		Percentage (%)
Down Syndrome	Mentioned initially and directly	84
	Chromosome abnormality	82
	Incidence	22
	No mention	14
	Syndrome	13
Etiology	No mention	40
	Maternal age	19
	Gene	14
	Pregnancy	12
Symptoms	Mental retardation	70
	Congenital heart disease	61
	Hypotonia	44
	Speech delay	39
	No mention	23
	Visual deficit	16
Treatment	Early intervention	55
	Speech therapy	36
	No mention	32
	Surgery	16
Prognosis	No mention	47
	Complication	30
	Survival rate	25
	Social welfare	22
	Educational resources	13
Related information	Medical treatment	40
	Social organization	38
	No mention	36
	Education	17
	Nurture	16

Table3. Factor loadings and item-total correlations of satisfaction with genetic counseling

Item	Factor loading	Item-total correlations
1. Timing	0.58	0.52
2. Duration of genetic counseling	0.89	0.87
3. Counselors' knowledge about Down syndrome	0.91	0.88
4. Information about Down syndrome provided by counselors	0.93	0.91
5. Treatment strategies provided by counselors	0.91	0.88
6. Informatioin about welfare support and educational resources	0.89	0.86
7. Attitude of counselors	0.91	0.88
8. Communication relationships with counselors	0.92	0.90
9. Emotional supports provided by counselors	0.91	0.89
10. Overall evaluations of genetic counseling	0.95	0.93

Eigenvalue:7.85; Cronbach alpha for internal consistency:0.97

Table4. Association between parents' characteristics and their satisfaction with genetic counseling

Variables	**Estimate**	**SE**	**F statistics**
Bivariate Analysis			
Age	-0.06	0.20	$F_{(1,75)} = 0.10$, $p = .753$
Education level	-2.13	1.29	$F_{(1,75)} = 2.72$, $p = .103$
Employment status	-1.00	0.63	$F_{(1,75)} = 2.54$, $p = .115$
Economic status	-4.74	1.75	$F_{(1,75)} = 7.37$, $p = .008$
Personality characteristics			
Neuroticism	-0.05	0.16	$F_{(1,65)} = 0.08$, $p = .772$
Extroversion	0.55	0.22	$F_{(1,65)} = 6.00$, $p = .017$
Social desirability	0.02	0.56	$F_{(1,65)} = 0.00$, $p = .970$
Genetic counseling			
Timing	1.64	1.27	$F_{(1,75)} = 1.68$, $p = .200$
Place--Interview room	10.49	4.30	$F_{(1,75)} = 5.94$, $p = .017$
Duration	0.20	0.04	$F_{(1,75)} = 23.21$, $p < .001$
Counselor's attitude	10.43	1.95	$F_{(1,75)} = 28.69$, $p < .001$
Parents' immediate emotion	5.79	3.36	$F_{(1,75)} = 2.97$, $p = .089$
Down syndrome			
Content	4.47	3.24	$F_{(1,75)}= 1.91$, $p = .171$
Etiology	5.41	2.15	$F_{(1,75)} = 6.35$, $p = .014$
Symptoms	8.44	2.41	$F_{(1,75)} = 12.24$, $p < .001$
Treatment	8.61	2.04	$F_{(1,75)} = 17.71$, $p < .001$
Prognosis	8.17	1.99	$F_{(1,75)} = 16.85$, $p < .001$
Related information	7.78	2.09	$F_{(1,75)} = 13.86$, $p < .001$
Final selected model			
Intercept	14.42	5.31	
Extroversion	0.54	0.19	$F_{(1, 62)} = 7.92$, $p = .007$
Counselor's attitude	10.18	2.14	$F_{(1, 62)}= 22.71$, $p < .001$
Parents' immediate emotion	10.00	2.94	$F_{(1, 62)} = 11.58$, $p = .001$
Economic status	-4.43	1.58	$F_{(1, 62)} = 7.87$, $p = .007$

Patterns of Genetic Counseling and Factors Affecting Satisfaction for Parents of Children with Down Syndrome in Taiwan

Objective: To examine the content and pattern of genetic counseling and to determine the factors affecting the extent of satisfaction with genetic counseling among parents of children with Down syndrome.

Methods: The participants were 77 parents of children with Down syndrome who were from 1 to 11 at the time of parental enrollment. Each parent received a semi-structured interview including information about patterns of genetic counseling and their satisfaction with counseling. A 10-item scale with 4-point Likert scale from 0 to 4 was employed. A self-administrated questionnaire, the Maudsley Personality Inventory, was also given to assess the personality of each participant.

Results: Physicians had informed 82% of the parents that their child had Down syndrome. The mean duration of the counseling session was 26 minutes (SD = 23.5). The majority of parents reported that they did not have a chance to ask question or express their feelings. They also noted that they did not receive enough information regarding the etiology, outcome, and treatment of Down syndrome. Factor analysis only identified one factor associated with counseling satisfaction, with an eigenvalue of 7.85. Predictors of increased satisfaction with genetic counseling included extroverted parents and lower parental economic status, positive counselor's attitude, longer duration of counseling, more information provided, and no negative immediate emotional reaction.

Conclusions: This study suggests the need for better doctor-patient communication and for greater attention to the scope of genetic counseling sessions for Down syndrome in Taiwan. (Full text in Chinese)

Key words: Down syndrome, genetic counseling, satisfaction with counseling

附錄二

Parenting, Parental Characteristics, and Behavioral Problems among Children with Down Syndrome, Their Siblings and Controls

（American Journal on Mental Retardation 已接受，審核中）

Abstract

Using 45 families of children with Down syndrome (DS) and 50 control families, this paper examined parental psychopathology, parenting style, and behavioral characteristics among children with DS, their siblings, and controls. Both parents reported on the Chinese version of the Brief Symptom Rating Scale, Family Adaptation and Cohesion Scale, Parental Bonding Instrument, Dyadic Adjustment Scale, and Child Behavioral Checklists. Our findings showed that parents of children with DS suffered from more psychopathology, children with DS demonstrated more behavioral problems, and their siblings may not get enough care or parental control than their counterparts. The mental health prevention of parents and siblings of children with DS need to be emphasized not less than that of children with DS.

Parenting, Parental Characteristics, and Behavioral Problems among Children with Down Syndrome, Their Siblings and Controls

Parents of children with disabilities face more challenges to raise their children, and have more family and parenting dysfunction (Bristol, et al., 1988; Dyson, 1997b; Hauser-Cram, et al., 2001; Pelchat, et al., 1999) than parents of typically developing children. The long-term care, additional medical expenses, and the characteristics and behavior problems of the disabled children are some of the sources of stress (Dyson, 1991; Sloper, Knussen, Turner, & Cunningham, 1991). However, some studies did not reveal the same negative influences of raising a disabled child on the families (Dyson, 1991; Fisman & Wolf, 1991), and found that many families can effectively cope with, and adapt well to their children's disabilities (Bennett & DeLuca, 1996a; Ferguson, 2002). The factors which have been identified to increase the levels of stress in the family included parents with younger age (Flynt & Wood, 1989), lower socioeconomic status (SES) (Flynt & Wood, 1989; Rabkin & Struening, 1976), less social support (Beckman, 1991b), and particular types of disabilities in children (Goldberg, Morris, Simmons, Fowler, & Levison, 1990b; Pelchat, et al., 1999).

Down syndrome (DS), 1 to 1.5 in every 1,000 live birth, is the most common chromosomal disorder associated with mental retardation (Stoll, et al., 1998) with typical physical features and varied degree of a wide range of health problems (Cooley & Graham, 1991; Marino, et al., 1996). Comparing to mothers of normal children, mothers of children with DS display higher level of depression, stress, anxiety, and emotional distress (Cummings, Bayley, & Rie, 1966; Miller, Gordon, Daniele, & Diller, 1992; Pelchat, et al., 1999). Similar coping and psychological distress to Westerners are found in the Chinese parents of children with DS (Cheng & Tang, 1995), but Chinese parents may show some particular coping strategies, such as praying to ancestors or appealing to supernatural power (Shek & Cheung, 1990).

Despite prominent physical and mental abnormalities, several studies have shown that compared to parents of children with autism (Abbeduto, et al., 2004; Kasari & Sigman, 1997; Piven & Palmer, 1999), psychosis (Ryde-Brandt, 1991), and other developmental delay (Hauser-Cram, et al., 2001), parents of children with DS have perception of less difficult temperament in these children (Kasari & Sigman, 1997), lower level of pessimism about their children's future (Abbeduto, et al., 2004; Kasari & Sigman, 1997), more extensive networks of support (Hauser-Cram, et al., 2001), fewer family problems (Fidler, Hodapp, & Dykens, 2000), better well-being (Abbeduto, et al., 2004), less anxiety (Ryde-Brandt, 1991), and lower rates of major depression and social phobia (Kasari & Sigman, 1997; Piven & Palmer, 1999). In contrast, other researchers did not find higher levels of well-being in parents of children with DS compared to other types of disabilities (Cahill & Glidden, 1996; Gath & Gumley, 1986; Rodrigue, Morgan, & Geffken, 1992). Combining these findings, although parental adjustment between DS and other types of disabilities varied according to comparisons with different disabled groups, mothers of children with DS showed obvious maladjustment than mothers of normally developing children.

In general, mothers tend to have primary responsibility for child care, and subject to most difficulties of their children's disabilities (Bristol, et al., 1988; Krauss, 1993), particularly in Chinese families, in which mothers play the major role of child-rearing

(Chao, 1994; Lin & Fu, 1990). Most studies have demonstrated that mothers receive greater impact of children's disabilities than fathers (Beckman, 1991b; Goldberg, et al., 1990b; Pelchat, et al., 1999). However, this difference between fathers and mothers was not supported by other studies in terms of parental stress and well-being, social support, or family function (Dyson, 1997b; Krauss, 1993). Fathers and mothers in the same family may show distinct adaptation and coping strategies to their children's disabilities (Damrosch & Perry, 1989; Sloper, et al., 1991). This difference is supported by a study in Chinese population, which shows that mothers report higher levels of distress and lower level of optimism than fathers (Cheng & Tang, 1995). Sloper et al. (1991) reported that paternal stress and satisfaction with life are associated with marital relationship and extra-family factors, while maternal stress is associated with children's characteristics and behavior problems, family relationship, and SES. In terms of moderating effect from personality factors on parental reactions to stress, Damrosch and Perry (1989) found that fathers predominantly depict their adjustment to children's disabilities in terms of a steady, gradual recovery, and most mothers report a peaks-and-valleys, periodic crises pattern.

The personality characteristics of children with DS are placid, good-tempered, affectionate, cheerful, and easy to manage (Gibbs & Thorpe, 1983; Gunn & Berry, 1985). But they display more behavior problems, especially attention deficits, thought disorder, social withdraw, and compulsive-like behaviors, than their siblings (Cuskelly & Dadds, 1992) and non-disabled peers (Stores, Stores, Fellows, & Buckley, 1998). The siblings of children with DS and non-disabled children display similar behavior patterns (Stores, et al., 1998).

In addition to the impact on parental adjustment, having a child with disability may shape the behaviors and development of the other non-disabled children (Dyson, 1989). Siblings of disabled children are at risk for anxiety, negative self-esteem, behavior problems, emotional problems, and somatic complaints (Lavigne & Ryan, 1979b; Poznanski, 1969b). However, these findings were not supported by other studies (Lobato, et al., 1987; McHale, et al., 1986). Despite an important research question, there has been no study examining the parenting style or behavioral problems among siblings of children with DS as compared to children with DS and normal children.

This study is the pilot study to examine the impact of having a child with disability on the Chinese family. We targeted families of children with DS to answer the following four research questions: (1) Do parents of children with DS have more psychopathology, marital problems, and family dysfunction than parents of normal children? (2) Do children with DS display more behavioral and emotional problems as compared to their siblings and controls? (3) Do parents of children with DS treat their children with and without DS similarly? And (4) do mothers and fathers treat their children with or without DS differently? Among the four research questions, the behavioral problems and parenting styles among siblings of children with DS has not yet been explored before. We anticipate that given the impact of taking care of a child with DS, the child rearing for the other child or children without DS in the same family would be influenced.

Method

Participants

The sample consists of 45 case families, in which one child suffered from DS, and

50 control families. The 45 index cases were recruited from a medical center in Taipei (*n* = 24, 53.3%), the Chinese Down Syndrome Foundation (*n* = 5, 11.1%), preschool intervention centers (*n* = 5, 11.1%), and primary schools (*n* = 11, 24.5%) in northern Taiwan. The controls were recruited from the similar neighborhood of the cases according to the gender and age structure of the cases. Forty-three mothers and 34 fathers of the case families and 50 mothers and 50 fathers of the control families completed the self-administered measures.

Instruments

Maudsley Personality Inventory (MPI). The MPI, a 30-item self-administered scale, is designed to measure three personality traits-- neuroticism (13 items), extroversion (13 items), and social desirability (4 items). Each item was rated as 0 if no, 1 if yes. The MPI was originally developed to measure the personality construct proposed by Hans Eysenck (S.G.B. Eysenck, 1965). The Chinese version of the MPI has been proved to be a reliable and valid instrument and widely used in both community and medical settings in Taiwan (Chen, Lee, Lee, & Tseng, 1998; M. B. Lee, Hsien, Lin, & Lee, 1990b). Prior to this study, the reliability of the MPI using 2919 adults in 2002 revealed that the Chronbach's alpha for internal consistency were 0.79 for neuroticism, 0.76 for extroversion, and 0.32 for social desirability. In this study, the alpha coefficients were 0.87 for neuroticism, 0.70 for extroversion, and 0.41 for social desirability.

Brief Symptom Rating Scale (BSRS). The BSRS is a self-administered measure with 50 items rated from 0 to 4 on the basis of the degree of distress caused over the past week. Each item was scored 0, not at all; 1, a little bit; 2, moderately; 3, quite a bit; or 4, extremely. The BSRS was modified from the widely used Derogatis Symptom Check List-90-Revised (SCL-90-R) (Derogatis, et al., 1973). Like SCL-90-R, the BSRS covers nine dimensions of psychopathology: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic-anxiety, paranoid ideation, and additional symptoms including vegetative signs and suicidal ideation. The General Symptom Index is essentially a mean score of all BSRS categories. The BSRS has been proved to be a reliable and valid psychiatric self-rating scale for use in clinical and community settings (M. B. Lee & Lee, 1990; M. B. Lee, et al., 2003). In this study, the Chronbach's alpha for internal consistency of the 10 BSRS subscales ranged from 0.73 to 0.87.

Child Behavior Checklist (CBCL). The CBCL, is a parental report concerning their children aged 4-18. Eight narrow-band syndromes were derived from the 118 emotional and behavioral items including attention problems, anxious/depressed syndrome, aggressive behaviors, delinquent behaviors, social problems, somatic complaints, thought problems, and withdrawn (Achenbach, 1991b). Each item was scored as 0 if not true, 1 if somewhat true or sometimes true, and 2 if very true or often true. The Chinese version of CBCL, a reliable and valid instrument, has been prepared by Huang et al. (1994) and widely used to measure children's behavioral syndromes in Taiwanese child populations (Yang, Chen, & Soong, 2001). Prior to this study, the validity study of the CBCL was conducted in Taipei using mothers of 1391 children aged 4-10 years (729 boys and 662 girls). The Chronbach's alpha for internal consistency of each problem syndrome of the CBCL ranged from 0.81 to 0.93 and the intraclass correlation (ICC) for test-retest reliability ranged from 0.52 to 0.87. In this study, the alpha coefficients for the 8 syndromes ranged from 0.60 to 0.84. Raw score of each subscale was transformed to *T* score. *T*-scores are defined as multiplying the *z*-score by 10 and adding 50 with a mean of 50 and a standard deviation of 10 (*T*-score = *z*-score *10 + 50).

Chinese version of the Parental Bonding Instrument (PBI-C). The PBI is a 25-item instrument (item-rated on a 4-point Likert scale from "very likely" to "very unlikely") measuring parenting styles during the child's first 16 years with two principle dimensions, Care (12 items) and Protection (13 items) (Parker, 1979). A high score on the Care subscale reflects affection and warmth, while a low score indicates rejection, or indifference. The Protection scale is further subdivided into Authoritarianism (6 items) and Overprotectiveness (7 items) (Cox, Enns, & Clara, 2000; Kendler, Sham, & MacLean, 1997). The Authoritarianism subscale reflected the degree of parental authoritarian control on child's behavior; and the Overprotectiveness subscale reflected an overprotective parenting and denial of child's psychological autonomy.

The PBI-C was prepared using a representative school-based sample of 1343 junior high students, and 115 for test-retest reliability in 2002. The factor structures of the parental reported PBI-C were similar to those of the English version with the eigenvalues of 4.09 (Affection/Care), 4.25 (Overprotection), and 2.97 (Authoritarianism). The Pearson correlation coefficients (γ), and ICC for test-retest reliability and Cronbach's alpha (α) for internal consistency of the subscales of the maternal reports on the PBI-C demonstrated satisfactory reliability ($\gamma = 0.47$~0.65, ICC = 0.47~0.64, and $\alpha = 0.75$~0.84). The internal consistency of the three subscales of the PBI-C ranged from 0.69 to 0.78 in this study.

Chinese Version of the Family Adaptation and Cohesion Scale (FACS-C). The FACESIII, a 40-item self-reporting scale, was developed to assess family systems with respect to the levels of current and ideal cohesion and adaptability (Olson, 1991). Each item is rated on a 5-point Likert scale: 1 for almost never, 2 for once in a while, 3 for sometimes, 4 for frequently, and 5 for almost always. Accordingly, the sum scores for each of the four subscales (10 items for each) range from 10 to 50. Higher score indicates better family functioning (Green, Harris, Forte, & Robinson, 1991b; Olson, 1991). In addition to the current and ideal conditions, their differences of family cohesion and adaptability were computed. The reliability study of the FACS-C using parents of 653 aged 10-15 children showed good test-retest reliability ($\gamma = 0.63$~0.82, ICC = 0.63 ~0.80) and internal consistency ($\alpha = 0.81$~0.90). The internal consistency of the four subscales of the FACS-C ranged from 0.75 to 0.84 in this study.

Chinese version of the Dyadic Adjustment Scale (DAS-C). The Dyadic Adjustment Scale (DAS) is a 32-item self-report scale developed to measure the quality of adjustment to marriage and similar dyadic relationship. The DAS consists of four subscales: dyadic consensus, dyadic satisfaction, dyadic cohesion, and affectional expression (Spanier, 1976). The reliability study of the DAS-C using parents of 676 aged 10-15 children showed good test-retest reliability ($\gamma = 0.50 \sim 0.70$, ICC = 0.46 ~ 0.79) and internal consistency ($\alpha = 0.58 \sim 0.93$). The Cronbach's alpha values for internal consistency of the subscales of the DAS-C ranged from 0.50 to 0.90 in this study.

Procedures

The IRB of the Taiwan University Hospital approved this study prior to the sample recruitment. Written informed consent was obtained from the parents of children with Down syndrome and control children after explanation of the purpose and procedure of the study as well as reassurance of confidentiality. Thirty-five mothers and 34 fathers of the cases, 50 mothers and 50 fathers of the controls reported on the MPI, BSRS, and DAS-C about themselves, and the FACS-C about their families. Mothers and fathers reported on the PBI-C about their parenting styles (cases: 40 mothers and 37 fathers; their siblings: 32 mothers and 25 fathers; controls: 50 mothers and 50 fathers). The numbers of children with mothers' reports on the CBCL for 4-18 years old were 33 for the cases, 31 for siblings, and 50 for the controls. The numbers of children whose mothers reported on the CBCL for 2-4 years old were 8 for the cases and 4 for siblings.

Results

Demographic characteristics

SAS 8.2 was used for all statistical analyses (SAS Institute Inc, Cary, NC). For demographic differences between children with DS and controls, frequency and percentage were presented and chi-square test was employed for categorical variables; and means and standard deviations (SD) were presented and analysis of variance was used for continuous variables (see Table 1). The pre-selected alpha value was 0.05. There was no difference in gender and age distributions, and number of children in the families between two groups (see Table 1). In terms of maternal characteristics, we found that mothers of children with DS were lower educated and less likely to be employed than mothers of the controls. However, there was no difference in current age and age of childbirth of the index children between the two groups. In terms of fathers' demographics, there was no difference between the two groups in their fathers' ages, education levels, and employment statuses (see Table 1).

Parental Personality Characteristics and Psychopathology

Multivariate analysis of covariance was used to compare the mean score of each dimension (continuous variables) the MPI and the BSRS between parents of children with DS and their counterparts and between mothers and fathers for the two groups controlling for children's age and gender, and parents' age and educational levels (see Table 2). Our results showed that compared to mothers of controls, mothers of children with DS had significantly higher score in obsession, depression, anxiety, psychoticism, general symptom severity index, and total number of positive symptoms; and had marginally higher score in somatization, interpersonal sensitivity, phobia, and additional symptoms. Fathers of children with DS had significantly higher score in neurotic personality characteristics, somatization and hostility, and marginally lower score in depression and general symptom severity index.

In terms of difference between mothers and fathers, there was no difference in personality characteristics and parental psychopathology for both groups with some exceptions ($p = 0.104 \sim 0.907$). For the control group, mothers showed less social desirability in personality characteristics, greater hostility, and higher positive symptom distress index than fathers.

Behavioral Characteristics of Children with Down Syndrome, Siblings, and Controls

Multivariate analysis of covariance was used to compare the mean *T*-score of 8 behavioral syndromes derived from the CBCL among children with DS, siblings, and controls controlling for subjects' gender and age (see Table 3). The post hoc Duncan's multiple range test was used to adjust the p value for multiple comparisons among the three comparison groups. Results showed that children with DS had greater severity in attention problems, social problems, somatic complaints, thought problems, and withdrawn than their siblings and controls. Besides, children with DS had more delinquent behaviors than their siblings. However, children with DS had fewer anxious/depressive symptoms than controls. There was no difference between siblings and controls in behavioral problems.

Parenting Styles among Children with DS, Siblings, and Controls

Multivariate analysis of covariance was used to compare the mean three subscales of mother’s and father’s parenting styles by the three child comparison groups controlling for subjects’ gender and age (see Table 4). The post hoc Duncan's multiple range test was used to adjust the p value for multiple comparisons among the three comparison groups. In terms of maternal parenting style, we found that siblings of children with DS significantly obtained less maternal affection/care than controls did. There was no difference in maternal affection/care between children with DS and controls, and between children with DS and their siblings. Siblings of children with DS obtained less protection from their mothers than children with DS and controls. Particularly, siblings with DS got less maternal authoritative control than controls.

Concerning paternal parenting style, siblings of children with DS obtained less protection from their fathers than children with DS and controls. Especially, children with DS tended to be overprotected their fathers than their siblings and controls by encouraging psychological dependence. Furthermore, fathers of children with DS gave more authoritative control on their children with DS than their children without DS. There was no difference among three child comparison groups in terms of paternal affection/care.

Parental Difference in Parenting Styles

We further compare the parenting styles between fathers and mothers by the three comparison groups. For children with DS, their mothers showed greater affectionate/caring attitude toward them than their fathers did ($p = 0.026$) (see Table 4). Their fathers showed greater protection toward them than their mothers ($p = 0.027$), particularly in the encouragement of psychological dependence ($p = 0.025$). For control children, their mothers displayed greater affection/care to them than their fathers ($p = 0.002$). There was no parental difference in parental overprotection and control among control children. Furthermore, for siblings of children with DS, there was no parental difference in parenting styles (p values ranging from 0.147 to 0.997).

Family Functioning and Parental Marital Relationship

The difference in the subscales of the *FACS-C* and *DAS-C* between the families of DS children and controls was tested using the multivariate analysis of covariance. Our results revealed that mothers of children with DS reported lower score of ideal family cohesion than mothers of control children ($F_{(1,82)} = 4.41$, $p = 0.039$). Among control children, mothers reported marginally higher difference between ideal and current family cohesion than fathers did ($F_{(1,98)} = 3.27$, $p = 0.074$). In addition, there was no difference in maternal reports on current and ideal family adaptation and current family cohesion (p value ranging from 0.437 to 0.842) and paternal reports on current and ideal family adaptation and cohesion between the case and control groups (p value ranging from 0.126 to 0.506). Moreover, there was no parental difference in reports on current and ideal family adaptation and cohesion between mothers and fathers for the control (*p* value ranging from 0.074 to 0.952) and case groups (*p* value ranging from 0.336 to 0.643).

With regards to parents' marital relationship, there was no difference in parents' reports on dyadic consensus, dyadic satisfaction, dyadic cohesion, and affectionate expression between the case and control group and between mothers and fathers. However, mothers of children with DS showed marginally lower marital satisfaction than mothers of controls ($F_{(1,83)} = 3.48$, $p = 0.066$) and fathers of children with DS ($F_{(1,66)} = 3.54$, $p = 0.064$).

Discussion

Literature has been questioning whether parents of children with DS or other disabilities encountered more stress from child-rearing than those of normal children. Results from this study indicate that parents of children with DS suffered from more psychopathology without difference between mothers and fathers but they did not report more impaired family and marital relationship than parents of normal children. Despite the evidence that children with DS demonstrated more behavioral problems in this study as expected, we found that children with DS was treated similarly by their parents as the way that parents of normal children treated their children except that fathers of children with DS tended to overprotect these children. The unique finding of this study is that siblings of children with DS obtained less care and control from their mothers than children with DS and normal children.

Parental Adjustment

Our findings that mothers of children with DS were more likely than their counterparts to take care of their children full time without employment may be explained by that extra medical care and early educational intervention for these children prevent their mothers to maintain a regular, full-time job.

Similar to the findings of some previous studies in Western countries (Cummings, et al., 1966; Miller, et al., 1992; Pelchat, et al., 1999), and Chinese families (Cheng & Tang, 1995), this study found higher level of somatization and depression in both parents of children with DS, obsession, anxiety, and psychotic tendency in mothers of children with DS, and hostility in fathers of children with DS than parents of normal children. Although these parents suffered from more emotional distress, our findings did not support that having a disabled child, like a child with DS in this study, cause adverse effect on family and marital functioning as revealed by some previous studies (Bristol, et al., 1988; Dyson, 1997b; Pelchat, et al., 1999). In contrast, similar to some other studies (Bennett & DeLuca, 1996a; Dyson, 1991; Ferguson, 2002; Fisman & Wolf, 1991), Chinese parents of children with DS seem to adapt well to their children's disabilities in terms of maintaining good family and marital interaction.

Although mothers play the major role of child rearing of these children with DS, consistent with some studies (Dyson, 1997b; Krauss, 1993) yet inconsistent with others (Beckman, 1991b; Goldberg, et al., 1990b), we did not find that mothers suffered from more severe psychopathology than fathers.

Parenting and Behavioral Characteristics of Children with DS

Our hypotheses regarding more behavioral problems among children with DS (Cuskelly & Dadds, 1992; Stores, et al., 1998) received support. Due to the presence of mental retardation in children with DS, more severe problems in attention, social ability, and thoughts, and increased withdrawn and delinquent behaviors among these children as compared to normal developed children are under anticipation. As literature has shown that children with DS are generally friendly, and easy-going in characteristics (Gibbs & Thorpe, 1983; Gunn & Berry, 1985), it may explain that our finding of less severe anxious/depressed symptoms among children with DS than normal children. This study also contributes to our understanding of parenting style among children with DS, which has been neglected in literature. Findings from this study suggest that the attitude of mothers of children with DS toward these disabled children is similar to that of mothers of normal children. However, fathers of children with DS tend to overprotect these disabled children. This differential pattern of parenting between fathers and mothers need to be examined in different populations.

Sibling of Children with DS

Although the influence of having a sibling with DS on parenting and behavioral problems has not been well-studied among those who have siblings with DS, we anticipated that siblings of children with DS should have more behavioral problems than normal children and that rearing a child with disability such as DS in this study should influence parenting not only to children with DS but also the other child (or children) without DS in the same family. Surprisingly, our findings did not support that siblings of children with DS suffered from more emotional or behavioral problems as shown by previous studies (Lavigne & Ryan, 1979b; Poznanski, 1969b). This study found that although siblings of children with DS were not reported to have more behavioral problems but they did not get enough affectionate care from their mothers and they were relatively neglected by their parents, who encouraged them to have behavioral freedom. This differential parenting toward siblings of children with DS was not only observed when compared to children with DS but also to normal children. As family value with strong family ties has been emphasized in Chinese families in Taiwan, which is substantially influenced by the traditional Confucian principles (Bond & Huang, 1986), mothers play the major role of child-rearing and are responsible for children’s performance (Chao, 1994). The relative neglect of siblings of children with DS by their mothers in terms of care and monitoring can be explained by that mothers may pay their full attention to taking care of disabled children and either leave other normal children alone or give them responsibility of taking care of their disabled siblings. Accordingly, despite no increased behavioral problems among siblings of children with DS in this study, finding from this study indicates that the importance of issues regarding the parenting and rearing of siblings of disabled children is not less than that of disabled children.

Among the strengths of this study were that this study was the first comprehensive study on parental personality and adjustment, family functioning, marital relationship, and parenting style, and child’s behavioral characteristics among DS children in non-Western population, the first study to investigate parental attitude and behavioral characteristics among siblings of children with DS, which has been neglected in previous studies, in addition to studying the mother’s role, father’s contribution was also investigated, and wealth of self-administered measures with good reliability and validity, which have been established before the implementation of this study.

Despite these strengths, this study is limited by small sample size of case and control families, lack of recruitment of children with other disability as the control group, and no consistent measures of child's behavioral problems due to the wide range of age distribution. First, this study has tried its best to recruit all the eligible subjects by extensively searching children with DS through hospitals, a DS foundation, early educational intervention centers, kindergartens, and primary schools in northern Taiwan. There is no information about the total number of children with DS younger than 10 years old in this area; we, therefore, cannot confirm the representative of the subjects with DS in this study. However, the controls were recruited according to the age, gender, and school distribution of the case group. Second, the distribution of the majority of measures was not against the assumption of normal distribution despite the small sample size. Accordingly, we used the analysis of covariate to conduct the statistical analysis. The drawback of the small sample size is decreased power to detect the true difference. Hence, the significant finding in this study is believed to be convincing. Third, a lack of recruitment of children with other disabilities such as autism prevent us to replicate previous studies to test whether parents of DS children report fewer problems in their children and encounter less stress than parents of children with other disability. Lastly, because the age range of the index subjects were from 1 to 10 years, different versions of CBCL was used resulting decreased sample size for comparison between the two groups. Future research might recruit children with other disabilities to investigate the difference between children with DS and with other disabilities in terms of parental and child measures.

Implications

The take-home message of this study is that in addition to the emphasis on physical, educational, and psychological cares of children with DS, the prevention of mental health of their parents and siblings should not be less emphasized. Perhaps the most important lesson to learn from this study is that the siblings of children with DS were relatively neglected by their parents, who demonstrated differential parenting to their children without DS from their disabled children. Therefore, parenting counseling for this population should not only focus on children with DS but also their siblings as well. Moreover, different age and development of children with DS may need different cares, thus that the sources of stress for mothers change over time according to children's age (Lam & Mackenzie, 2002). Therefore, different strategies according to child's developmental stage should be developed to help parents to cope with the stress.

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Table 1 *Sample Characteristics*

Variables	DS (N = 45) N (%) or Mean (SD)	Control (N = 50) N (%) or Mean (SD)	Chi-square statistics or *F* statistics
Mother			
Age	37.33 (5.38)	37.02 (4.41)	$F_{(1, 93)} = 0.10, p = 0.756$
Age of childbirth	30.84 (4.62)	29.26 (4.03)	$F_{(1, 93)} = 3.19, p = 0.078$
Education level			
≦Junior high school	6 (14.29)	1 (2.00)	$\chi^2 = 14.07$, df = 2, $p < 0.001$
Senior high school	26 (61.90)	19 (38.00)	
≧College	10 (23.81)	30 (60.00)	
Employment status			
Employed	14 (34.15)	28 (59.57)	$\chi^2 = 5.68$, df = 1, $p = 0.017$
Unemployed	27 (65.85)	19 (40.43)	
Father			
Age	40.23 (5.81)	40.20 (4.56)	$F_{(1, 92)} = 0.00, p = 0.980$
Education level			
≦Junior high school	7 (16.67)	4 (8.00)	$\chi^2 = 5.61$, df = 2, $p = 0.061$
Senior high school	20 (47.62)	16 (32.00)	
≧College	15 (35.71)	30 (60.00)	
Employment status			
Employed	41 (100.00)	46 (97.87)	$\chi^2 = 0.88$, df = 1, $p = 0.348$
Unemployed	0 (0.00)	1 (2.13)	
Child			
Age	7.82 (3.08)	8.44 (2.80)	$F_{(1, 93)} = 1.05, p = 0.308$
Gender			
Male	28 (62.22)	27 (54.00)	$\chi^2 = 0.81$, df = 1, $p = 0.369$
Female	17 (37.78)	23 (46.00)	
Number of children in family	2.27 (0.81)	2.00 (0.67)	$F_{(1, 93)} = 3.08, p = 0.082$

Note. DS = Down syndrome; SD = standard deviation.

Table 2 *Psychopathology and Personality by Down Syndrome and Control Parents*

	Mother		Father			
	1.DS (N = 34)	2.Control (N = 50)	3.DS (N = 33)	4.Control (N = 49)		
Variables	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Statistics ($p < 0.10$)	
Personality characteristics						
Neuroticism	8.93 (7.65)	6.72 (6.24)	9.63 (7.77)	6.04 (5.82)	3 vs. 4	$F_{(1,81)} = 5.76, p = 0.019$
Extroversion	16.31 (4.99)	17.48 (4.82)	15.03 (5.53)	15.80 (5.00)	2 vs. 4	$F_{(1,98)} = 2.94, p = 0.090$
Social desirability	4.55 (1.90)	3.99 (2.20)	4.79 (2.50)	4.92 (2.11)	2 vs. 4	$F_{(1,98)} = 4.69, p = 0.033$
Psychopathology						
Somatization	0.97 (0.79)	0.66 (0.66)	0.73 (0.68)	0.47 (0.42)	1 vs. 2	$F_{(1,82)} = 3.94, p = 0.051$
					3 vs. 4	$F_{(1,80)} = 4.57, p = 0.036$
Obsession	1.05 (0.89)	0.71 (0.58)	0.76 (0.57)	0.63 (0.48)	1 vs. 2	$F_{(1,82)} = 4.68, p = 0.033$
Interpersonal sensitivity	0.82 (0.79)	0.55 (0.54)	0.55 (0.46)	0.41 (0.41)	1 vs. 2	$F_{(1,82)} = 3.68, p = 0.059$
					1 vs. 3	$F_{(1,65)} = 3.06, p = 0.085$
Depression	0.72 (0.77)	0.43 (0.42)	0.54 (0.45)	0.35 (0.40)	1 vs. 2	$F_{(1,82)} = 4.99, p = 0.028$
					3 vs. 4	$F_{(1,80)} = 3.93, p = 0.051$
Anxiety	0.65 (0.71)	0.29 (0.37)	0.35 (0.40)	0.31 (0.44)	1 vs. 2	$F_{(1,82)} = 9.21, p = 0.003$
					1 vs. 3	$F_{(1,65)} = 4.62, p = 0.035$
Hostility	0.88 (0.77)	0.77 (0.71)	0.70 (0.48)	0.48 (0.39)	3 vs. 4	$F_{(1,80)} = 5.26, p = 0.025$
					2 vs. 4	$F_{(1,97)} = 6.31, p = 0.014$
Phobia	0.51 (0.58)	0.28 (0.49)	0.26 (0.43)	0.21 (0.29)	1 vs. 2	$F_{(1,82)} = 3.84, p = 0.053$
					1 vs. 3	$F_{(1,65)} = 3.85, p = 0.054$
Paranoid	0.57 (0.64)	0.39 (0.42)	0.48 (0.58)	0.35 (0.37)		
Psychoticism	0.49 (0.54)	0.27 (0.42)	0.43 (0.56)	0.29 (0.37)	1 vs. 2	$F_{(1,82)} = 4.33, p = 0.041$
Addition symptoms	0.58 (0.57)	0.35 (0.51)	0.50 (0.67)	0.39 (0.41)	1 vs. 2	$F_{(1,82)} = 3.78, p = 0.055$
General symptom severity index (GSI)	0.73 (0.65)	0.46 (0.41)	0.53 (0.42)	0.39 (0.32)	1 vs. 2	$F_{(1,82)} = 5.52, p = 0.021$
					3 vs. 4	$F_{(1,80)} = 2.78, p < 0.10$
Positive symptom total number (PST)	23.29 (15.61)	16.48 (11.37)	19.67 (13.78)	16.20 (12.04)	1 vs. 2	$F_{(1,82)} = 5.36, p = 0.023$
Positive symptom distress index (PSDI)	1.41 (0.43)	1.29 (0.35)	1.23 (0.56)	1.07 (0.40)	2 vs. 4	$F_{(1,80)} = 8.55, p = 0.004$

Note. DS = Down syndrome; SD = standard deviation.

Table 3

Emotional and Behavior Problems by Children with Down Syndrome, Siblings and Controls

	1. DS (N = 33)	2. Siblings (N = 31)	3. Controls (N = 50)	Statistics with Duncan	
T score	Mean (SD)	Mean (SD)	Mean (SD)	F value	Comparisons ($p < 0.05$)
Aggressive behavior	50.03 (8.42)	48.84 (10.60)	50.69 (10.71)	$F_{(2,111)} = 0.32, p = 0.724$	
Anxious/Depressed	47.21 (5.96)	49.69 (10.60)	52.07 (11.34)	$F_{(2,111)} = 2.42, p = 0.093$	1 vs. 3
Attention problems	58.63 (9.82)	45.87 (7.87)	46.87 (7.66)	$F_{(2,111)} = 24.66, p < .001$	1 vs. 2, 1 vs. 3
Delinquent behavior	52.53 (11.63)	47.23 (7.42)	50.06 (10.03)	$F_{(2,111)} = 2.29, p = 0.107$	1 vs. 2
Social problems	60.14 (9.33)	45.03 (6.67)	46.39 (6.99)	$F_{(2,111)} = 41.02, p < .001$	1 vs. 2, 1 vs. 3
Somatic complaints	54.81 (13.11)	47.91 (7.87)	48.12 (7.61)	$F_{(2,111)} = 5.82, p = 0.004$	1 vs. 2, 1 vs. 3
Thought problems	54.55 (12.88)	47.23 (6.10)	48.75 (8.81)	$F_{(2,111)} = 5.43, p = 0.006$	1 vs. 2, 1 vs. 3
Withdrawn	55.00 (11.97)	48.82 (8.38)	47.48 (8.29)	$F_{(2,111)} = 6.55, p = 0.002$	1 vs. 2, 1 vs. 3

Note. DS = Down syndrome; SD = standard deviation.

Table 4

Parental Attitude toward Children with Down Syndrome, Siblings and Controls

	1.DS	2.Siblings	3.Controls	Statistics with Duncan	
	Mean (SD)	Mean (SD)	Mean (SD)	*F* value	Comparisons ($p < 0.05$)
Mother	(N = 40)	(N = 32)	(N = 50)		
Affection	27.53 (4.31)	26.85 (4.78)	29.10 (4.27)	$F_{(2,119)} = 2.85$, $p = 0.062$	2 vs. 3
Protection	14.74 (5.16)	12.26 (4.97)	14.94 (4.64)	$F_{(2,119)} = 3.32$, $p = 0.040$	1 vs. 2, 2 vs. 3
Overprotection	8.03 (3.33)	6.50 (4.13)	7.84 (3.25)	$F_{(2,119)} = 1.95$, $p = 0.147$	
Authoritative controlling	6.71 (2.98)	5.76 (2.80)	7.10 (2.27)	$F_{(2,119)} = 2.50$, $p = 0.086$	2 vs. 3
Father	(N = 37)	(N = 25)	(N = 50)		
Affection	25.27 (4.40)	25.07 (4.26)	26.01 (5.19)	$F_{(2,106)} = 0.42$, $p = 0.661$	
Protection	17.08 (3.79)	12.56 (4.97)	14.48 (4.44)	$F_{(2,106)} = 8.42$, $p < .001$	1 vs. 2, 1 vs. 3
Overprotection	9.65 (2.83)	6.80 (3.19)	7.89 (3.20)	$F_{(2,106)} = 6.90$, $p = 0.002$	1 vs. 2, 1 vs. 3
Authoritative controlling	7.43 (2.81)	5.76 (2.68)	6.58 (2.71)	$F_{(2,106)} = 2.84$, $p = 0.063$	1 vs. 2

Note. DS = Down syndrome; SD = standard deviation