

行政院國家科學委員會專題研究計畫 成果報告

精神分裂症病患之家庭照顧者與整個家庭正負向照顧經驗 研究成果報告(精簡版)

計畫類別：個別型
計畫編號：NSC 99-2410-H-040-017-
執行期間：99年08月01日至100年12月31日
執行單位：中山醫學大學護理學系(所)

計畫主持人：蕭秋月
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報告附件：出席國際會議研究心得報告及發表論文

公開資訊：本計畫涉及專利或其他智慧財產權，2年後可公開查詢

中華民國 101 年 03 月 30 日

中文摘要：精神疾病不僅影響病患的家庭成員，也影響了整個家庭。多數有關家庭照顧者的研究著重負向的照顧經驗。少數研究探討正向的照顧經驗及家庭照顧者復原力的因素。有關家庭照顧者及家庭整體如何長期照顧一位患有精神分裂症患者的相關知識是需要的。

本研究主要是探討精神分裂症病患之家庭照顧者及整個家庭的壓力與需求、生命凝聚感、相依關係、家庭耐受力及個人適應情形(例如：照顧者的負荷和滿足)與家庭的適應情形(例如：家庭功能)之情況及相關性。共計 97 個家庭參與本研究。皮爾森積差相關、混合線性模型等統計方法加以分析資料。研究結果發現家庭的壓力與需求越少、生命凝聚感越多，家庭照顧者的負荷越少。當家庭照顧者生命凝聚感越多和家庭耐受力越高，其滿足感和家庭功能較高。另外，家庭耐受力顯著地降低家庭照顧者的負荷及增進照顧者的滿足感和家庭功能。

精神分裂症是一種容易導致慢性化的疾病，不論罹病的個人、家庭、社區及社會皆會長期的受到影響。從整體性、連續性的醫療照護觀點，除了提供病患在住院期間疾病的照護外，精神醫療人員能提供以個人為中心、家庭為單位的醫療照護來協助家庭照顧者及整個家庭達到最佳的生活適應情況。

中文關鍵詞：適應、家庭照顧、精神分裂症

英文摘要：Mental illness affects not only the individual family members but also the entire family system. Caring for a family member with schizophrenia can be a demanding, stress-filled experience. Most studies of primary family caregivers to relatives with schizophrenia have focused on negative aspects of family caregiving. Few studies, however, have explored positive aspects of family caregiving and resilient factors that motivate family caregivers to continue to care for their relatives with schizophrenia. Furthermore, little is known about why some families adapt well; other families do not. More knowledge is needed to understand how individual family caregivers and the family as a whole respond to caring for a next of kin with schizophrenia over time.

The main purpose of this study was to investigate

individual and family adaptation in Taiwanese families of persons with schizophrenia, with potential predictors being family demands, sense of coherence, mutuality, and family hardiness. Descriptive statistics, principal component analysis, and a hierarchical linear modeling were used to analyze data. A total of 97 families of individuals with schizophrenia participated in this study. Lower family demands and greater sense of coherence decreased the level of caregiver burden. Greater sense of coherence and mutuality enhanced caregiver satisfaction and family functioning. Additionally, family hardiness significantly enhanced caregiver satisfaction and family functioning and reduced caregiver burden. Schizophrenia is a chronic illness that affects individuals, families, communities, and a whole society as well. From a holistic point of view, it is critical for mental health care providers to identify individual and family strengths and resiliency as well as the development of family-centered interventions to increase individual and family adaptation.

英文關鍵詞： adaptation, family caregiving, schizophrenia

Background and Significance

Mental illness is a leading cause of global burden of disease (WHO, 2010). According to the report of the World Health Organization (WHO) in 2010, one of the top ten diseases leading to disability worldwide is schizophrenia. In Taiwan, in 2008, nearly .88 % of adults had a diagnosable mental illness (Department of Health, Taiwan, Republic of China, [R.O.C.], 2010). Approximately .33 % of these adults are diagnosed as having schizophrenia. However, it is critical to note that the “real” prevalence may underestimate.

Mental illness is not only an individual disease but also a family illness (Greeff, Vansteenwegen, & Ide, 2006; Hsiao & Van Riper, 2009; Liu, Lambert, & Lambert, 2007). Caregivers and families play a vital role in the caregiving process of individuals with mental illness (Hsiao & Van Riper, 2009, 2010; Zauszniewski, Bekhet, & Suresky, 2009). To achieve a holistic mental health nursing care, it is vital to expand its focus beyond the individual with mental illness. From a family system point of view, caring for people with mental illness influences not only the adaptation of the affected individual but also the adaptation of other family members. More attention needs to be directed at potential consequences for other family members.

Caring for a family member with mental illness can be a challenging and demanding experience (Hsiao & Van Riper, 2009). Miller and Lawton (1997) asserted that there is a need to examine alternative consequences to build new knowledge in caregiving outcomes. Most caregiving studies in Taiwan have documented the tremendously negative impact that providing care to persons with schizophrenia has on caregiver burden (Hou et al., 2008; Song, 1999) and family caregivers' mental health (Yen & Lundeen, 2006). Yet, results from Western studies indicated that some family caregivers of individuals with mental illness such as schizophrenia have been found to become more resilient over time (Luthar & Brown, 2007; Zauszniewski et al., 2009). Some researchers have noted the existence of positive experiences associated with family caregiving and the potential for personal growth, uplift, reward, increased gratification and satisfaction that may occur with adaptation to providing care for individuals with mental illness (Chen & Greenberg, 2004; Yen & Lundeen, 2006; Zauszniewski et al., 2009). Family caregivers may not only survive the ongoing demanding but also thrive in the face of caring for a family member who is mentally ill (Zauszniewski et al., 2009). Therefore, family caregivers may have positive as well as negative experiences. Although the positive aspect of caregiving has gradually been acknowledged, no research has focused on both the positive and negative aspects of caregiving in Taiwanese family

caregivers living with mental illness. Additional research is needed to examine both positive and negative caregiving outcomes to offer a more holistic perspective of caregiving. By doing this, it will help us understand why some individuals and families adapt successfully to the caregiving experience while others do not.

An extensive literature review of Taiwanese caregiving studies has shown that maladaptation is more likely to be found in Taiwanese families where individuals have more behavior disturbances, social support is perceived as insufficient, and there is less regard for the value of family caregiving (Hsiao & Van Riper, 2010). These contributors of maladaptation have generally been examined from the individual perspective. Other key family components such as mutuality, family hardiness, and family functioning in the context of Taiwanese family caregiving for persons with schizophrenia are still unexplored. By exploring linkages among increased demands, sense of coherence, mutuality, family hardiness, and individual and family adaptation, the findings of this study would help researchers and clinical practitioners develop theory-guided and culture-driven interventions that meet the needs and interests of individual family members as well as the family as a whole.

The main purpose of this study was to investigate individual and family adaptation in Taiwanese families of persons with schizophrenia, with potential predictors being family demands, sense of coherence, mutuality, and family hardiness.

Methods

Design

A cross-sectional, correlational research design was used.

Sample and Setting

A total of 97 families of individuals with schizophrenia (172 individual family caregivers) participated in this study. Inclusion criteria were as follows: (a) a family caregiver lived in the same household or have at least weekly the same household or have at least weekly contact with the patient, who had a diagnosis of schizophrenia according to the criteria in the *Diagnostic and Statistic Manual IV (DSM-IV)*; (b) the participant were at least over 20 years old; and (c) the participant were able to understand or communicate in Taiwanese or Mandarin.

Data Collection

Institutional Review Board approvals were obtained from two hospitals before initiating this study. After eligible criteria of participants have been verified, the principal investigator

(PI) or trained research assistants explained the purposes and procedures of this study to potential subjects. Reassurance of voluntary and confidentiality were given before recruitment. Written consent forms were obtained for participation. Data were collected through an approximately 50-minute face-to-face structured interview.

Measures

Measures for this proposed study include the following: (a) a demographic information sheet of the family caregiver, (b) Family Stressors Index, (c) Family Strains Index, (d) 13-item Sense of Coherence (13-item SOC), (e) Mutuality Scale, (f) Family Hardiness Index (FHI), (g) Carer's Assessment of Satisfaction Index, (h) Caregiver Burden Scale-18 items, and (i) Family APGAR Score. Three of the measures used in this study, the Family Stressors Index, Family Strains Index, and Carer's Assessment of Satisfaction, had not been translated into Chinese, which is the target language for the participants in Taiwan. Therefore, these three instruments were translated and back-translated by the principal investigator and another bilingual PhD-prepared nursing faculty member. The final Chinese versions of Family Stressors Index, Family Strains Index, and Carer's Assessment of Satisfaction were pilot tested with ten Chinese-speaking families of individuals with schizophrenia to estimate the understanding of each item.

Data Analysis

SAS version 9.1 was applied to analyze data. Descriptive statistics were conducted for characteristics of individual family members and the family unit. Principal component analysis was selected to analyze the linear combination of a set of components (i.e., family stressors and strains). The outcome of this set of components was defined as family demands. Hierarchical linear modeling (HLM; Raudenbush & Bryk, 2002) were undertaken to examine the relationships of variables (i.e., family demands, sense of coherence, mutuality, family hardiness, caregiver burden, caregiver satisfaction, and family functioning) in families living with schizophrenia.

Results

The final sample consisted of 97 families of individuals with schizophrenia (172 individual family caregivers). The age of family caregivers ranged from 22 to 86 years with a mean age of 57.64 years. The majority of family caregivers were female (55.2 %), married (72.7 %), living with relatives with schizophrenia (85.5%), had at least a junior school degree (58.7%), and currently employed (61.63%), and a household income more than 25,000 NTD per month (58.72%). The duration of family caregiving ranged from 1 to 50 years with a

mean of 22.47 years.

Means, standard deviations, and ranges of study variables for parents and the family as a whole are described in Table 1. Lower family demands ($\beta = .23, p < .01$) and greater sense of coherence ($\beta = -.31, p < .001$) decreased the level of caregiver burden. Greater sense of coherence ($\beta = .13, p < .05$) and mutuality ($\beta = 12.36, p < .001$) enhanced caregiver satisfaction. Greater sense of coherence ($\beta = .05, p < .001$) and mutuality ($\beta = .93, p < .001$) increased family functioning. Additionally, family hardiness significantly enhanced caregiver satisfaction and family functioning and reduced caregiver burden.

Discussion and Conclusion

This study is the first to investigate both positive and negative consequences in Taiwanese families of individuals with schizophrenia. In general, findings indicated that family caregivers with greater mutuality and family hardiness enhanced their individual and family adaptation. Results provide tenable explanations for why some family caregivers experience negative consequences while other families are resilient and thrive.

Given the nature and extent of the demands of family caregiving, an increased awareness of issues of family caregiving and concerns in mental illness may help mental health nurses and other health care providers consistently collaborate with families to identify their unique needs as well as acknowledge and amplify their strengths. Supportive interventions need to include interventions designed to help decrease the effect of demands of family caregiving on adaptation in families of individuals with schizophrenia. These interventions need to help enhance the family's ability to provide ongoing care to the family member with schizophrenia. That is, the implications for provision of successful family interventions need to focus more on tapping into a resiliency factor (e.g., family hardiness) than on family demands and develop strategies for assisting family caregivers.

Contemporary nursing education in psychiatric mental health nursing in Taiwan is primarily driven by the traditional medical model that targets illness-oriented and patient-centered medical care. Psychiatric mental health nursing programs designed to educate nursing students and practicing nurses about integrated knowledge of family-centered nursing into clinical practice are scarce in Taiwan. By virtue of acknowledgement of the ongoing role of families in the health care delivery, findings from this study serve as a reference for mental health professionals to incorporate caregiving issues within the context of family-centered health care into the content and curriculum of psychiatric and mental health nursing education in Taiwan.

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Table 1

Descriptive Statistics of Study Variables for Individuals (N=172) and Families (N=97)

| Variables | Parents (N =172) | | | Families (N = 97) | | |
|------------------------|------------------|-------|--------------|-------------------|-------|-------------|
| | Mean | SD | Range | Mean | SD | Range |
| Family Demands | 13.93 | 11.23 | 0.00 - 45.96 | 14.01 | 10.17 | 0.00-41.72 |
| Mutuality | 2.14 | 0.75 | 0.00-4.00 | 2.20 | 0.67 | 0.47-3.67 |
| Sense of Coherence | 67.77 | 16.04 | 33.00-91.00 | 67.10 | 14.62 | 33.00-91.00 |
| Family Hardiness | 39.35 | 7.58 | 14.00-57.00 | 39.10 | 6.32 | 24.00-57.00 |
| Caregiver Burden | 25.70 | 12.36 | 3.00-64.00 | 26.19 | 11.92 | 3.00-64.00 |
| Caregiver Satisfaction | 55.23 | 14.81 | 7.00 – 90.00 | 56.36 | 12.76 | 18.50-90.00 |
| Family Functioning | 6.51 | 2.63 | 0.00-10.00 | 6.47 | 2.38 | 1.00-10.00 |

國科會補助專題研究計畫項下出席國際學術會議心得報告

日期：99 年 11 月 01 日

| | | | |
|--------|--|---------|-----------------------------|
| 計畫編號 | NSC99-2410-H-040-017- | | |
| 計畫名稱 | 精神分裂症病患之家庭照顧者與整個家庭正負向照顧經驗 | | |
| 出國人員姓名 | 蕭秋月 | 服務機構及職稱 | 中山醫學大學 助理教授 |
| 會議時間 | 99 年 10 月 13 日至 99 年 10 月 16 日 | 會議地點 | Louisville, Kentucky USA |
| 會議名稱 | (中文) 第 24 屆美國精神科護理學會議 (英文) APNA 24 th Annual Conference | | |
| 發表論文題目 | (中文) 台灣精神病患者家庭之精神疾病家族史家庭照護的意義和家庭功能 (英文) Family history of mental illness, meaning of family caregiving, and family functioning in Taiwanese families living with mental illness | | |

一、參加會議經過

此次的研討會分別以教育、臨床、政策及研究為主題方向，內容相當豐富。大會特別在 preconference 針對 online course design、building advocacy skills、evidence-based assessment, diagnostic and treatment strategies 等安排了工作坊。為了瞭解學員的需求，美國精神科護理學會分別由一位 chairperson 邀請學員針對其所 focus 的領域(如：教育、臨床、政策及研究) 進行討論，並提出相關因應方針及未來努力方向

二、與會心得

此次的研討會在美國的路易斯維爾舉行，主題：「Psychiatric Nurses: Champions of Advocacy-Advancing Practice, Policy, Education and Research」。Drs. Eric Arauz 和 Ronald Manderscheid 為此次研討會所邀請的 Keynote speakers，並針對此次大會的主題分別進行演講。從兩位學者精采的演講中，讓我對於現今精神衛生護理學在教育、臨床、政策及研究方面之重要議題與趨勢有更進一步的瞭解。

此次，個人是以 poster presentation 的方式發表論文。為了增加與會學者能參與 poster sessions 及增進與每位 presenter 的互動，大會特別要求每位參與研討會的學員必須針對每一張 poster 進行評分，並向每位 presenter 進行發問。整體而言，學員們及 presentors 的反應相當熱絡。另外，在為期 4 天的研討會中，除了有機會能針對與本身研究領域相關之國際知名學者請益外，也能夠與其他學者進行學術交流與經驗分享。

三、建議

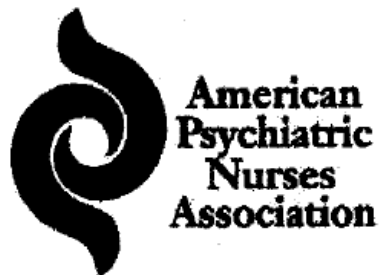
未來台灣應該積極爭取舉辦精神衛生護理國際學術研討會，邀請國際知名學者來台與國內專家學者及研究生針對當前精神衛生護理之重要議題進行討論及學術交流。

四、攜回資料名稱及內容

研討會內容指引、報告者所發表研究摘要及相關資料。

五、其他

寄件者: "Lisa Nguyen" <LNguyen@APNA.org>
收件者: <chsiao@csmu.edu.tw>
傳送日期: 2010年4月13日 上午 02:36
主旨: APNA Annual Conference Abstract Notification



April 12, 2010

Dear Chiu-Yueh,

Thank you for submitting an abstract for the APNA 24th Annual Conference, October 13-16, 2010 in Louisville, KY. We are happy to inform you that your abstract #184288 has been accepted as a **poster presentation**. Congratulations!

The following is what we have listed for your session:

Title: *Family history of mental illness, meaning of family caregiving, and family functioning in Taiwanese families living with mental illness*

Primary Presenter: Chiu-Yueh Hsiao

Please email us at lnguyen@apna.org by **Friday, April 16th** to confirm whether the above information is correct and if you will be participating as a poster presenter. Please email any changes to your title or presenter(s) as soon as possible.

We will contact you in June with detailed instructions regarding conference registration, set-up and take-down times, etc.

Thank you,
APNA Scholarly Review Committee

Abstract

Background: Although there has been an increase in the public's awareness of importance of a family history in terms of the provision of a source of genetic information, little attention has been paid to the relationships between family history of mental illness and family functioning in families living with mental illness.

Aims: To examine the relationships among family history of mental illness, meaning of family caregiving, and family functioning in Taiwanese families of individuals with mental illness.

Method: A mailed survey was used to collect data from 157 family caregivers in 84 families. The survey included demographic information sheet, meaning of family caregiving scale, and family functioning scale.

Data analysis included descriptive statistics, principal component analysis, and a mixed model.

Findings: Family caregivers with more positive interpretation of caregiving significantly improved family functioning. Meaning of family caregiving mediated the relationship between family history of mental illness and family functioning.

Implications: Results shed light on what strengths families possessed to deal with the effect of family history of mental illness regarding caring for individuals with mental illness.

國科會補助計畫衍生研發成果推廣資料表

日期:2012/03/30

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|-----------|---|
| 國科會補助計畫 | 計畫名稱: 精神分裂症病患之家庭照顧者與整個家庭正負向照顧經驗 |
| | 計畫主持人: 蕭秋月 |
| | 計畫編號: 99-2410-H-040-017- 學門領域: 臨床與諮商心理學 |
| 無研發成果推廣資料 | |

99 年度專題研究計畫研究成果彙整表

| 計畫主持人：蕭秋月 | | 計畫編號：99-2410-H-040-017- | | | | 計畫名稱：精神分裂症病患之家庭照顧者與整個家庭正負向照顧經驗 | |
|-----------|-------------|-------------------------|-----------------|------------|------|-------------------------------------|---|
| 成果項目 | | 量化 | | | 單位 | 備註（質化說明：如數個計畫共同成果、成果列為該期刊之封面故事...等） | |
| | | 實際已達成數（被接受或已發表） | 預期總達成數（含實際已達成數） | 本計畫實際貢獻百分比 | | | |
| 國內 | 論文著作 | 期刊論文 | 0 | 0 | 100% | 篇 | 目前正在整理研究資料結果，準備投稿 |
| | | 研究報告/技術報告 | 0 | 0 | 100% | | |
| | | 研討會論文 | 0 | 1 | 100% | | |
| | | 專書 | 0 | 0 | 100% | | |
| | 專利 | 申請中件數 | 0 | 0 | 100% | 件 | |
| | | 已獲得件數 | 0 | 0 | 100% | | |
| | 技術移轉 | 件數 | 0 | 0 | 100% | 件 | |
| | | 權利金 | 0 | 0 | 100% | 千元 | |
| | 參與計畫人力（本國籍） | 碩士生 | 2 | 2 | 100% | 人次 | 此研究計劃之研究對象為精神分裂症患者之家屬，不易找尋曾於臨床上從事精神護理之碩士生 |
| | | 博士生 | 0 | 0 | 100% | | |
| | | 博士後研究員 | 0 | 0 | 100% | | |
| | | 專任助理 | 0 | 0 | 100% | | |
| 國外 | 論文著作 | 期刊論文 | 0 | 1 | 100% | 篇 | 目前正在整理研究資料結果，準備投稿 |
| | | 研究報告/技術報告 | 0 | 0 | 100% | | |
| | | 研討會論文 | 0 | 2 | 100% | | |
| | | 專書 | 0 | 0 | 100% | | |
| | 專利 | 申請中件數 | 0 | 0 | 100% | 件 | |
| | | 已獲得件數 | 0 | 0 | 100% | | |
| | 技術移轉 | 件數 | 0 | 0 | 100% | 件 | |
| | | 權利金 | 0 | 0 | 100% | 千元 | |
| | 參與計畫人力（外國籍） | 碩士生 | 0 | 0 | 100% | 人次 | |
| | | 博士生 | 0 | 0 | 100% | | |
| | | 博士後研究員 | 0 | 0 | 100% | | |

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|--|--|-------------------------------------|---|---|------|--|--|
| | | 專任助理 | 0 | 0 | 100% | | |
| | 其他成果 (無法以量化表達之成果如辦理學術活動、獲得獎項、重要國際合作、研究成果國際影響力及其他協助產業技術發展之具體效益事項等，請以文字敘述填列。) | 本研究計劃成果預計至少可以發表一篇護理類之 SCI 或 SSCI 期刊 | | | | | |

| | 成果項目 | 量化 | 名稱或內容性質簡述 |
|---|-----------------|----|-----------|
| 科 教 處 計 畫 加 填 項 目 | 測驗工具(含質性與量性) | 0 | |
| | 課程/模組 | 0 | |
| | 電腦及網路系統或工具 | 0 | |
| | 教材 | 0 | |
| | 舉辦之活動/競賽 | 0 | |
| | 研討會/工作坊 | 0 | |
| | 電子報、網站 | 0 | |
| | 計畫成果推廣之參與(閱聽)人數 | 0 | |

國科會補助專題研究計畫成果報告自評表

請就研究內容與原計畫相符程度、達成預期目標情況、研究成果之學術或應用價值（簡要敘述成果所代表之意義、價值、影響或進一步發展之可能性）、是否適合在學術期刊發表或申請專利、主要發現或其他有關價值等，作一綜合評估。

1. 請就研究內容與原計畫相符程度、達成預期目標情況作一綜合評估

達成目標

未達成目標（請說明，以 100 字為限）

實驗失敗

因故實驗中斷

其他原因

說明：

2. 研究成果在學術期刊發表或申請專利等情形：

論文： 已發表 未發表之文稿 撰寫中 無

專利： 已獲得 申請中 無

技轉： 已技轉 洽談中 無

其他：（以 100 字為限）

3. 請依學術成就、技術創新、社會影響等方面，評估研究成果之學術或應用價值（簡要敘述成果所代表之意義、價值、影響或進一步發展之可能性）（以 500 字為限）

因計劃主持人在研究及經費申請上經驗較不足，收案對象為精神分裂症病患之家庭（每一位患者至少需有一位照顧者參與本研究），在資料收集方面較困難，因而延長半年完成此研究。

整體而言，本研究旨在探討精神分裂症病患之家庭照顧者及整個家庭之正向和負向照顧經驗與其影響因素。透過本研究結果，將提供精神醫療人員更深入了解精神分裂症病患之家庭照顧者及整個家庭的適應情況，以期精神醫療人員能提供以個人為中心、家庭為單位的醫療照護來協助家庭照顧者及整個家庭達到最佳的生活適應情況。