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精神分裂病患社區生活功能與家屬照顧方式順應性之研究

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計畫參與人員:游育瑄、呂桂玲

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執行單位:台灣大學醫學院職能治療學系

中 華 民 國 九十三 年 一 月 三十一 日

中、英文摘要及關鍵詞

摘要

為了減少精神病患對醫院的依賴、使病患在最少限制的環境中生活,我國的精神醫療政策除了強調積極的住院治療,也越來越重視社區復健。然而社區復健設施因為法令過於嚴苛以及社區民眾反彈等因素,增設的數量一直遠低於預估需求量,而既有的設施也因為病患或家屬不知道、以及已有家人照顧等因素而使用率偏低。我國社會的家庭觀向來具備照顧弱小家庭成員的美德,在尋求突破現行社區復健措施之困境的同時,考量我國固有家庭觀是非常必要的做法。

本研究以嚴重精神疾病的代表性診斷--精神分裂症為對象,研究的目的為(1)探討社區精神分裂症病患照顧者的期望、照顧負擔、及教養方式,(2)探討前者與病患社區生活功能之順應情形,(3)建立以家屬照顧為主軸之社區精神病患家居復健方案。本研究為兩年期的計劃,將收錄80對社區精神分裂症病患及其照顧者(計160位)為研究對象,進行間期7個月之追蹤評估,預計完成的任務包括評量工具的建立、病患社區生活功能層級的分類、家屬照顧方式之順應標準的建立、順應情形對於病患功能變化以及家屬負擔和照顧成就感變化的探討、及依據研究結果發展符合我國國情及家庭觀的家居復健方案等。

本研究的結果將可提供精神醫療以及相關領域有關照顧者教養方式與病患社區生活功能之相關性的訊息,作為出院安置計劃以及社區醫療的重要參考。而考量照顧者感受與經驗所建立的家居復健方案,將作為後續研究探討其成效的基礎。此家居復健方案除了試圖提昇照顧者的教養技能、減輕照顧者的壓力、改善病患之社區生活功能,也將為我國成效不彰的社區復健政策提供另一個思考的方向。

Abstract

The purpose of this presentation is to share the results of a qualitative study that explored the occupation-related caring experiences of family members of persons with schizophrenia living in the community. This study was carried out in Taiwan, where institutionalization is never an issue due to insufficient psychiatric services in the past but a substantial proportion of people with psychiatric illness has been hanging around in the community. Previous studies have indicated that psychiatric patients in the community were mostly unemployed and in a state of "idleness". In order to develop community occupational therapy programs that help caregivers to assist their ill family members in participating in meaningful occupations, the researcher used the grounded theory methodology to explore caregivers' occupation-related caring experiences. Caregivers' expectations and needs related to the patient's occupational participation were also investigated. Preliminary results

indicate that caregivers do not have much knowledge about helping the patient to participate in meaningful occupations. Results of preliminary data analysis as well as implications to occupational therapy will be presented.

關鍵詞:精神復健、需求評估、社區基礎職能治療、應用性科學探究

<u>Key words</u>: psychiatric rehabilitation, needs assessment, community-based occupational therapy, applied scientific inquiry

前言

避免精神病患者長期住院及倡導社區照顧是國內外近代精神醫療的重要政策(楊素端 & 楊佩琪,1992;行政院衛生,1997; United States General Accounting Office, 2000)。文獻指出,一部份的精神病患是可以在社區生活的。以加拿大為例,如果提供適切的支持,60%以上的精神病患可以獨立地在社區生活,只有10%的病患需要住院接受治療(Durbin, Cochrane, et al., 2001)。宋麗玉對台灣中部地區精神病患的研究結果顯示,功能程度不佳、需要長期養護的精神病患約佔1/4;另有1/3的精神病患功能程度中等,但在15至20年後其照顧者年老、沒有其他支持系統,也會需要長期的安置;其餘40%的精神病患則功能程度良好,適合長期生活於社區之中,但需要協助維持其社會功能(宋麗玉,1998)。對社區精神病患及其照顧者來說,成功的社區生活是需要適切的支持或協助的。

行政院衛生署於民國七十八年起推展精神病患之「社區復健計畫」,內容包括社區復健中心、康復之家、庇護工廠、及居家治療等四種模式;民國八十六年起衛生署以「加強積極治療與復健、減少消極收容與養護」為精神疾病防治之政策導向,推展社區復健及社區心理衛生是此政策的重點之一(行政院衛生,1997)。社區復健之立意雖獲得肯定(余伍洋,陳明哲, et al.,1995;陳快樂,呂孟穎, et al.,1999),然而國內社區復健設施至今仍然不足(宋麗玉,1998;行政院衛生,1997),其原因包括法令規定的室礙難行、社區民眾的阻力、及醫療與福利給付之誘因不足等(宋麗玉,1998;楊素端 & 楊佩琪,1992),至於現有的社區復健服務之使用情形,則因為病患及其家屬一無所知、服務可近性不夠、及已有家人可以照顧等原因,亦不盡理想(楊素端 & 楊佩琪,1992;黃梅羹,胡海國, et al.,1994)。

家庭在我國社會文化中有強烈的情感聯繫,當家中有罹病的弱小成員,其他健康的成員便會承負起照顧的義務與責任(成和玲 & 楊美賞,1997;余伍洋,陳明哲, et al.,1995;邱淑貞 & 蕭淑貞,1998)。國內的研究結果指出,出院精神病患和家屬同住的比例高達 86.3%(鄭泰安,1985),由此可見家屬是社區精神病患的主要照顧者。然而,有學者指出家屬所承負的照顧責任是其無可選擇的結果,在精神科床位不足、分布不均、以及社區復健服務尚未健全的情形下,病患一旦出院,照顧的責任也只能落在其家庭成員的身上(宋麗玉,1998;楊素端 & 楊佩琪,1992)。檢討我國精神社區復健計畫推行成效的同時,如何發展符合我國社會文化特有的家庭觀、又能顧及精神病患照顧者之需要與選擇權的社區復健服務模式,似乎是未來推展相關計畫的一大課題。

國內的研究指出,社區精神病患有從事職能活動方面的障礙,例如:病患在懶惰行為的因應效能最差(蕭淑貞,楊秋月,et al.,1999) 對其生活品質最不滿意的是缺乏活動(成和玲 & 楊美賞,1997),而病患的照顧者最希望病人能在社區中正常地工作,對休閒及復健治療的需求最高(崔秀倩,楊延光,et al.,

1998 》就精神病患社區生活復健的立場而言,個案的社交技巧、日常生活活動(activities of daily living, ADL 》工作、及休閒的功能是迫切需要被重視的四個領域。

綜此,精神病患者之社區生活復健,有兩項重要的問題:(一)社區復健 設施不足、使用率不理想 (二)病患個人生活技巧與社區生活能力不佳。此兩 個不同層面的問題,對長期提供照顧的家屬而言,是很嚴重的問題。此兩個問題 未能解決,家屬的負擔會加重,甚至會放棄病患的照顧與復健,造成社會負擔的 增加。第一個有關社區復健設施的問題,有賴醫療與福利措施之增加;而第二個 有關病患個人生活技巧與社會生活能力的問題,則是精神醫療專業人員可以加強 著力之處,該問題包括兩個病理因素:(1)精神病患者神經心理功能降低,(2) 生活環境學習機會降低或錯誤學習的因素。為改善精神病患之社區生活品質,免 除社會干擾事件, 化解社會對精神病患之偏見, 並增加精神病患之生產力, 降低 社會成本,下列三項工作值得深入探討:(1)照顧病患之家屬對病患社區生活表 現的期待、瞭解、與病後教養方法,(2)以神經心理障礙為基礎,患者病後之社 交技巧、ADL、工作潛能與休閒活動之功能程度 (3)家屬之期待、瞭解、與病 後教養方法是否順應患者社區生活功能障礙之程度與性質。是否有利患者社區生 活功能之再發展與再成長。目前精神病患家屬照顧者之責任重、負擔重,精神病 患在社區生活之復健設施不足,如果有這三方面的資料,將有助於設計社區精神 病患家居生活之復健方案。本研究企圖驗證之假設是(1)家屬對患者之期待若 順應於病患之社區生活功能,則家屬之負擔、壓力會減少:(2)家屬對患者之教 養方式若順應於病患之社區生活功能,則家屬之負擔 壓力及照顧成就感會增高。 精神分裂症是精神科疾病中較為嚴重的一種診斷,由於疾病往往呈慢性化,病患 在工作能力、人際關係、及社區生活適應等方面出現障礙,為病患本人、家庭、 以及社會帶來沉重且長期的負擔(崔秀倩,楊延光,et al., 1998)。以精神分裂症 為主題儘探討精神病患之社區生活功能,有下列幾點考量:(1)減少研究樣本之 異質性,使研究結果的解釋,免除樣本異質性引致之污染效應(confounding effects);(2)精神分裂症是嚴重精神病之代表性疾病,該疾病患者是社區中為 數最多之嚴重精神病患 ;(3)精神分裂症已有相當豐富之精神病理研究,可資運 用之研究素材較足夠;(4)精神分裂症患者之主要照顧家屬的負擔是精神病患家 屬中最嚴重者;(5)精神分裂症是一種慢性疾病,其長期病程中所需要的家屬照 顧與教養是持續且長期的。因此本研究將以精神分裂症為研究樣本,有相當研究 經驗之後,當可以發展到其他精神病,如雙相情感疾病(bipolar affective disorder) 之研究。

研究目的

本研究的目的有三:

- 1. 瞭解負責照顧之家屬對社區精神分裂症病患家居生活功能之需求、期待、與教養方法。
- 2. 檢視本研究的兩個研究假設(如下),以探討家屬主要照顧者負擔、壓力、成就感與患者社區生活功能程度之相關性。
 - 假設(1) 家屬對患者之期待若順應於病患之社區生活功能程度,則家屬之 負擔會減少;
 - 假設(2) 家屬對患者之教養方式若順應於病患之社區生活功能程度,則家屬之照顧成就感會增高。
- 3. 依據此實證資料,本研究結果將建議發展合乎國情(亦即缺少社區復健措施之情境)之「居家職能治療方案」,以增強承擔病患照顧之家屬對情境之掌控性與成就感,減少家屬之負擔,並有效提昇病患家居生活之表現。

文獻探討

一、精神分裂症的社區復健相關政策、問題與困境

在歐美國家,1960年代以前的精神分裂症患者大多集中收容於公立的療養院,由於人數眾多,給政府財政帶來極大的負擔,又因為人力不足,照顧品質不佳,使得病患長期被機構收容照顧的結果造成「機構化」現象:生活功能喪失、對機構依賴、與正常社會脫節等(成和玲 & 楊美賞,1997;郭峰志,2001),因而有「去機構化」運動的倡導,鼓勵精神病患回到社區。「去機構化」立意雖好,卻因為社區復建設施尚未完善(成和玲 & 楊美賞,1997;邱淑貞 & 蕭淑貞,1998;郭峰志,2001)尊重精神病患有拒絕接受治療的權利(United States General Accounting Office,2000)等因素,導致許多病患重複住院或淪為流浪漢,造成更多的醫療與社會問題,「去機構化」的做法因此遭致了嚴厲的批評(成和玲 & 楊美賞,1997;郭峰志,2001)。

在我國,精神醫療資源長期以來一直處於不足的情況,所以精神病患並沒有如國外那樣有「機構化」的問題,也就沒有「去機構化」的必要性(宋麗玉,1998)。近年來,由於健保制度的實施,精神醫療給付強調住院治療,因此我國精神科床位數已有明顯增加,然而,我國社區精神醫療的發展是要避免未來精神病患之機構化,我國精神病患仍有住院治療以外之相關精神醫療照顧(如社區復健)的需求。行政院衛生署自民國七十八年起推行社區復健計劃,包括康復之家、庇護性工廠、社區復健中心、及居家治療四種服務設施,康復之家預期需求量為3561 床,庇護性工廠及社區復健中心需求量為4122 床(宋麗玉,1998),衛生署除了提撥經費增設社區復健設施,也研訂精神復健機構設置標準及鼓勵辦法,鼓勵民間設置社區復健機構(行政院衛生,1997)。民國九十年六月衛生署醫政處的

資料顯示,康復之家的床數為 1803 床,為預估床數的 51%,社區復健中心的服務人數只有 564 人,為預估床數的 14%,顯示我國社區復健設施仍然嚴重不足。有學者指出,社區復健設施增設速度緩慢的原因包括:

- 1. 法令規定過於嚴苛:精神復健機構設置辦法規定社區復健中心必須符合 合甲級消防安全之標準,一般都市住宅房屋難以通過此規定。
- 2. 社區民眾的阻力:精神疾病「污名化」的結果,社區復健中心的設置 往往招致民眾的反彈,甚至有社區復健機構因此歇業。
- 3. 醫療與福利給付誘因不足:社區復健現已納入健保給付範圍,然而參與社區復健的病患必須自行負擔交通費與伙食費,對於多數無業的社區精神病患是一項龐大的支出;此外,目前社區復健之健保給付太低,不敷成本,民間設置意願不高。

這些都是社會福利與精神醫療政策層面之問題,在此政策性問題未解決以前,應以負責照顧病患最著力之家屬為研究與關心的重點。本研究企圖就精神分裂症患者之社區生活功能與主要照顧者之期待與教養方式之相應性來探討當前情境中可行之病患家居生活的職能復健方案。

二、社區精神分裂病患的功能層級及社區復健目標

責:

我國政府對精神病患之病情狀態分成六大類,並據此劃分照顧體系之權

病患性質	服務類別	服務項目	服務機構	權責劃分
一、嚴重精神病症狀,需急性	精神醫療	急診	精神醫療機構	衛生醫療單位
治療者。		急性住院治療		
二、精神病症狀緩和但未穩		慢性住院治療		
定,仍需積極治療者。		日間住院治療		
		居家治療		
三、精神病症狀繼續呈現,干		長期住院治療		
擾社會生活,治療效果不彰,				
需長期住院治療者。				
四、精神病症狀穩定 , 局部功	精神醫療	日間住院治療	精神醫療機構	衛生醫療單位
能退化,有復健潛能,不需權	社區復健	社區復健治療	精神復健機構	
日住院但需積極復健治療者。		社區追蹤管理	衛生所	
	就業安置	就業輔導	職業訓練及就	勞政單位
			業服務機構	

病患性質	服務類別	服務項目	服務機構	權責劃分
五、精神病症狀穩定且呈現慢性化,不需住院治療但需長期生活照顧者。 六、精神病症狀穩定且呈現慢性化,不需住院治療之年邁者、癡呆症患者、智障者、無家可歸者。	居家服務	養護服務 居家服務		社政單位(主辦) 衛生醫療單位(協 辦) 衛生醫療單位

從上表可以看出只有第四類精神病患是社區復健服務的對象,其餘五大類的病患需要積極的住院治療或是長期的安置,讓人懷疑如此之權責劃分的結果,是否精神病患可以在最少限制的環境中生活?為了方便政府相關單位對精神病患的照顧有清楚的權責界定,精神病患似乎在政府權責劃分的過程中被「去人性化」(depersonalized)了。每一位精神病患的問題都有其獨特性,從臨床經驗來看,精神病患的症狀狀態似乎無法很容易地被歸到上表的某一分類之中,在如此的照顧體系下,病患及家屬的需要很有可能繼續被當成皮球,在不同政府單位間踢來踢去。

宋麗玉(1998)對台灣中部地區社區精神病患(多數為精神分裂症患者)之社會功能進行研究,透過叢集分析(cluster analysis)及區辨分析(discriminant analysis)統計法,將病患之社會功能程度做區辨性的分級,並藉各程度分級之病患特徵做出社區復健目標的建議。研究結果顯示病患之社會功能可區分為四個等級,各等級之病患特徵與社區復健目標的建議整理如下表:

社會功能層級	病患特徵	社區復健目標	
全面高度功能組	罹病時間較短。	維持病患的功能、避免退化。	
(16%)	行為問題較輕微。	維持病患的支持網絡。	
高度獨立性與職能組	年紀較大。	協助維持職能功能。	
(約 1/4)	罹病時間較長。	協助就業。	
	行為問題少。	增進社交技能。	
	適合生活於社區。	提昇病患的娛樂與社會性。	
全面功能平均組	整體功能狀況不佳,但家庭支持系統	透過各種社區社復健服務增進	
(約 1/3)	仍能使病患生活於社區。	其功能,尤其是「獨立」「社	
	照顧者平均年紀較大,未來仍需考量	會性」、「職業」三方面。	
	長期安置問題。		
全面低度功能組	罹病時間最長。	不適合留在社區,需要長期養護	
(約 1/4)	多數人教育程度不高。	的機構。	
	行為問題最嚴重。		
	照顧者負荷程度高,勉強照顧病人。		

研究結果顯示,「全面高度功能組」及「高度獨立性與職能組」適合長期在社區生活,合計約佔 40%,另有 1/3 之「全面功能平均組」在其照顧者能夠提供支持的情形下,也能在社區生活 15 至 20 年。不論其社會功能程度為何,需要提供病患及照顧者必要的協助以避免病患的功能退化、提升其功能(宋麗玉,1998)。

宋麗玉的研究提供了一個思考的方向,亦即社區復健宜設計不同功能程度之專屬復健目標,然而研究者所建議的社區復健目標,在各功能層級似乎有重疊,且各不同功能分組是否具備層級上相對應的復健目標,似乎也有待探討。

國外探討以精神病患或照顧者需求為依據的社區安置計畫文獻指出,叢集分析法固然能將病患能力做統計學上合理的分組,其分組的結果可能缺乏臨床的意義,病患及其照顧者的需求在病患之社區安置是不可忽略的考量要素(Durbin, Cochrane, et al., 2001)。以下將接著回顧有關社區精神分裂症病患照顧者之需求的文獻。

三、社區精神分裂症病患照顧者的負擔及需求

胡海國等(2000)對國內社區精神分裂症病患照顧者的研究指出,超過一半的照顧者認為沒有獲得足夠的社會支持(包括病患照顧、訊息提供、感覺分享等方面),最令照顧者憂心的項目有:「疾病治不好」, 盛行率佔整體照顧者的 3/4;「經濟損失」, 盛行率 1/2;「生活常規受干擾」, 盛行率約 1/3。長期生病及社會支持不足與照顧者所感受的負擔程度有密切的關係。

崔秀倩等(1998)的研究也有類似的結果,社區精神分裂症病患照顧者負荷最重的項目依序為:對疾病的擔心、影響家庭經濟及干擾家庭互動。在照顧者需求方面,85%的照顧者希望病患能擁有正常的社區休閒,約3/4的照顧者希望能給予病患就業保障。

綜合上述的研究結果,社區精神分裂症病患照顧者在病患長期生病、自已未獲得足夠的社會支持情況下,承受沈重的照顧負擔,如何分擔照顧者的負擔、 提升其照顧的技巧、提供相關的訊息等是值得加強的部份。

四、一個實驗性居家照顧模式

國內文獻曾有社區精神分裂症患者居家照顧模式的報導(楊延光, 牟秀善, et al., 1991)。這個位於台南的居家照顧團隊由一位神精科醫師、兩位住院醫師、兩位社工師組成,此團隊的治療內容包括:心理衛生教育、醫療資源運用諮詢及職業輔導、危機處理、以及居家復健(包括規律化家居生活或工作之推行)。由社工師做每週一次的居家訪視,為期三個月,之後改為二至四週一次,但每週仍有一次電話追蹤,除了主動訪視,病患及其家屬在危機時也可隨時以電話向團隊成

員求助。參與研究的病患分實驗及對照兩組,各 15 人,均接受九個月的追蹤,期間重複測量兩組病人的精神症狀、整體功能、藥物副作用、社區生活狀態、工作適應、家庭關懷等。在社會及家庭功能方面,研究結果發現實驗組的病患在社區生活及家庭關懷的得分較對照組有顯著的改善,在工作適應的得分改變則與對照組沒有顯著的不同。研究者指出,居家治療的成本所費不貲,但病患獲得無形的生活品質的改善,建議此項高成本的居家治療宜以高危險群病患之藥物與症狀監控為優先目標(楊延光,牟秀善, et al., 1991)。

由於這是一個 pilot study,參與研究的個案數也不多,研究結果發現實驗組病患在工作適應方面未獲明顯改善,有可能是個案數太少的關係,有較高的機率觸犯統計學上第二型錯誤(Type II error),因而偵測不到實際存在的差異(Cohen, 1988);另一種可能是工作相關的復健治療需要提供居家治療的人員具備工作能力評估、工作分析等的專業背景,這個居家照顧團隊的成員正好都沒有這方面的專業背景,因此可能因此導致病患的工作適應能力未能獲得統計學上有意義的改善。

綜而言之,社區生活功能的四大領域:社交技巧、ADL、工作及休間,是精神分裂症患者在社區生活中,急需精神復健的重大項目。基於上述文獻分析與評述,應針對此生活功能之潛能、既有水準進行評估,且應對主要照顧之家屬的期待、教養方式、壓力等進行瞭解。家屬情境與病患能力程度之順應性應是發展家居復健之主要信息。有這些資料,未來當可發展順應台灣國情之家居生活功能復健方案。本研究之研究架構以圖一表示,附於文後。

研究方法

一、前五個月(91年8月-91年12月): 研究評估表之建立

本研究所欲使用之評估工具有一部份有待建立,包括:家屬期望評估量表、家屬教養方式評估表、家屬照顧成就感量表等。此階段評估量表的建立將借重病患照顧者的經驗,依據照顧者的經驗建立由照顧者自行填寫之量表的內容。量表建立的步驟陳述如下:

- 1. 訪談 10 位病患家屬的經驗,包括期望、教養方式、及照顧成就感等。
- 2. 依據所取得的資訊列出量表項目。
- 3. 尋求專家意見,建立量表之專家效度。
- 4. 進行量表之信效度測試。
- 二、後7個月(92年1月-92年7月): 資料收集

此階段將收集資料探討社區精神分裂症病患之社區生活功能程度,以及病患

照顧者之期望、負擔、教養方式與照顧成就感,藉以瞭解兩者之順應情形。預計收集80對門診精神病患及其照顧者、計160位研究參與者的資料,計畫每個月收集10至12對病患及其照顧者的資料,七個月預計完成80對研究參與者的資料。病患的篩選標準為:1)診斷必須符合第四版心理疾病診斷及統計手冊(Diagnostic and Statistical Manual for Mental Disorders, 4th edition, DSM-IV, American Psychiatric Association, 1994)所定義之精神分裂症診斷,2)年齡介於18至65歲,3)規律接受門診之追蹤治療;照顧者的篩選標準為:1)與病患同住至少6個月,2)負責照顧並支持病患的社區生活。此階段將使用的評量工具除了前階段所建立的三種評量表,還包括下列已發展之評量表:

- 1. 活性與負性症狀量表(Positive and Negative Symptoms Scale, PANSS, 鄭若瑟, 何海, et al., 1995):是一種中譯的精神症狀評量表,包含7題活性症狀、7題負性症狀、16題一般精神病理,每一題項均需在7分量表上做評分,分數越高,代表症狀越嚴重。有研究顯示,此一量表經因素分析法可得出六個結構因素,包括負性因素、解組性、精神病性、相關負性因素、焦慮/憂鬱、及激動性,解釋66.2%的變異量(劉絮愷,葉玲玲, et al., 1996)。
- 2. 社交互動評量表(Social Interaction Scale, SIS, Williams & Bloomer, 1987): 是灣區功能表現評估(Bay Area Functional Performance Evaluation, BaFPE)的一部份,透過對個案於五種特定社交情境(一對一會談、用餐、無結構的團體情境、結構的活動團體、結構的口語團體)之表現的觀察或他人的描述,評估其口語及非口語的社交互動行為。治療師在每一種情境中分別就7個功能指標(口語溝通、心理動作行為、社交適切行為、對權威者的反應、獨立/依賴、與他人共事的能力、團體參與)對個案評分,每一個功能指標各獲得1至5分的評分,總分的計算是將五種社交情境之得分加總之後求其平均值。
- 3. 日常生活功能評量表(褚增輝, 1997):內容包括衛生習慣、健康情形、獨立能力、休閒生活、生活品質、文字數學、一般常識、金錢交易、交通通訊、應變能力。前五項屬自我照顧,後五項屬生活常識,每項計分 10分,量表總分為 100分。由受試者填寫,治療師依評分標準評定分數。
- 4. 賈氏職前技巧評量(Jacobs Prevocational Skills Assessment, JPSA, Jacobs, 1991):是一種標準化的工作表現評估工具,包括 15 項工作相關任務,治療師藉由觀察個案操作這些任務,分別從身體能力(physical capacity)工作行為(work behavior)及工作性向(work aptitude)等三個向度去評估每一項任務的表現,如果個案的表現不符合所要求的標準,則在該項任務的相對向度做圈選記號,圈選的項目數量越多,表示該向度越需要改進。

- 5. 角色活動表現量表- 休閒活動領域(Role Activity Performance Scale, RAPS- Leisure activities domain, Good-Ellis, Fine, Spencer, & DiVittis, 1987):是一種半結構式的評分量表,共評量 12 種角色領域,每個領域均由下列五個面向進行會談,包括背景資訊、角色環境及責任、所遭遇的困難、個案的優點及應變策略、個案及他人對個案於該角色領域之表現的看法,治療師依據評分標準,就會談所取得的資訊對每一個角色領域做1至6分的評分。本研究只採用休閒活動這個領域的評分,就研究參與者最近三個月之休閒活動表現做評分並取其平均值。
- 6. 艾倫認知階層測試 (Allen Cognitive Level Test, ACL, Allen, Earhart, & Blue, 1992): 為一個標準化之評估認知功能、專門為精神病患而發展的工具,由職能治療師施測,受試者在指導之下從事三種難易度不同的皮革縫法,根據標準化的評分標準給受試者的表現評定認知階層,範圍由階層 1 至階層 6。研究報告指出,ACL 具有良好的信效度,與 Wisconsin Card Sorting Test (WCST) 的得分有顯著的關聯,被認為是評定與操作能力有關之認知功能的良好指標 (Allen, 1985)。修訂版的 ACL 在階層 3 至階層 6 之間加入更細微的等級,對認知層級做更精確的辨識 (Allen, Earhart, & Blue, 1992)。本研究將採用修訂版的 ACL,以所得的認知階層探討其與動機缺陷之現象的關連性。
- 7. 家屬負荷量表(Family Care-giver Burden Scale, FCBS, 吳就君, 1995):是一中譯的版本,將家庭過去一年照顧精神病患的壓力歸納為八方面:病情、生活、休閒、婚姻、情緒、經濟、藥物濫用、家人健康等項,以半結構會談法評估精神病患照顧者之負荷。

三、最後二個月(92年6月-92年7月): 資料分析

病患的社區生活功能程度初步將以叢集分析法(cluster analysis)及區辨分析法(discriminant analysis, Glass & Hopkins, 1996)將病患的功能程度做分類,在考量每一層級照顧者的期望與負擔的情形下,訂出各層級的合宜教養方式,並據此判定病患社區生活功能程度與照顧者教養方式之順應情形。

預期第一年將會遭遇的困難是研究工作項目繁多,研究者過去雖有從事評估量表之信效度研究的經驗,但本研究之工作進度密集,需要持續投注較多的時間與心力,解決的途徑是擬聘用一位專任研究助理(已編列此項人事費用),依照所訂之進度協助執行本研究之各項任務,包括協助整理病患照顧者之訪談資料、量表項目的整理與維護、量表信效度研究之相關資料鍵入與分析、收集並組織研究參與者之基本資料、評量資料之鍵入與分析等。

結果與討論

Thirteen participants took part in the study. They were either from the psychiatric department of the university hospital which the researcher is affiliated with, or from a local family group. Eleven (85%) of the participants were female and only two were male. Among them, nine were mother to one or more patients; two, sibling; and the other two, spouse (one of them was also a father to a sick child).

As the theory of occupation-related caring experience is still under construction, the remaining section of this paper presents the main themes that are currently extracted from the data.

Chaotic Stage

Most of the study participants have been caring for their sick family members for ten years or more. The caring process could be summarized into three stages. The chaotic stage started with the first episode of psychiatric disorder and followed by attitudes of avoidance and inefficient coping. The participants reported a common experience of shock when the family was first struck with psychiatric illness.

"When I realized what my daughter told me could not be true, I started to worry…and I didn't know where to seek for medical help.(…那一定沒有這回事。我那時候才在急。急的話不曉得我從哪邊去…去就醫…)"

When recall the first sign of their sick family members' psychiatric illness, many participants commented on their lack of knowledge about this illness, mixed with feelings of regret or blaming the system.

"Back then, I had not much knowledge about all the related information. In fact, he needed not to do the military services (due to the illness). I thought the school work required too much thinking in the brain. Going to the military services did not require much thinking and maybe he would get better. So...he joined the military when he was called upon. But the situation got worse... When I went to visit him (two months after joining the military), I felt he had become a totally different person...(crying...)...How could my intact boy become like this...so disoriented...Now I'm very regretful...I had no knowledge about the illness back then, not at all... (那個時候對這一類的知識是不了解那麼多,實際上他根本不要去服兵役...可是我們想讀書是費腦筋,如果這個當兵,也許不用頭腦,會好一點,所以就...等服兵役通知來了,就去好了。那結果一去就更糟了。...[兩個月之後]我去看他的時候,我就覺得這個人變得不一樣了...[哭]...怎麼好好的

整個人就這個樣子,恍惚的不得了...現在非常後悔的就是對...疾病 的常識好像從前也沒有聽說過,也不了解...)"

"In the early days, my son was treated at VGH and NTUH (both medical centers) without any insurance or subsidiary. It was until we moved to the east area [of the city] that we learned about the city psychiatric institute [in which the treatment was less costly to the family]. Hidden in the mountain, who would know the existence of such a psychiatric institute? Many years had already passed by when my son was treated at the city psychiatric institute. (那個時候都是自費在、在榮總看病在台大也看過,後來,最後我搬家搬到東區去了,才發現市立療養院,在那山裡面誰也不知道。後來到市立療養醫院看病時候就已經拖了很多年。)"

During this stage, many participants had the experience of seeking religious help. Caregivers or other family members believed that the God they worshiped would cure the patient in magic ways. They were convinced that drugs were not good to the human body and should be abandoned. Patients and the family believed in alternative forms of "therapy" such as meditation and drinking holy water.

"… he didn't want to take the medicine. My mother heard about a Taoist group in the south [of Taiwan] which claimed that the God would cure my brother without medicine. This group got lots of witness. During the gatherings, people were told not to take any medicine because they would be cured [by God]. (後來就是因為他不想吃藥,就我媽媽聽說有一個宗教,南部有一個宗教,一個道教的團體,它是鼓勵人家不要吃藥的,甚至就是神會幫助他,不要吃藥就會恢復。他們很多見證人,很多聚會也都是告訴人家不要吃藥就會好。)"

"At that time, an aunt from my husband's side, who was a Buddhist, said that my daughter was possessed, whatever, whatever...We paid her to fly to Hua-Lian everyday, with the plane fare of two thousand something each round, to request for [holy water] and bring it back for my daughter to drink. (那個時候,就是我...老公的一個阿嬸 [台語:舅媽],他們就比較...信佛...就跟她講說犯沖了,什麼什麼,她說...每天都到花蓮,一天要花兩千多塊的那個飛機,那個嬸婆每天都要坐飛機過去那邊求什麼來給她喝)"

Whatever efforts the caregivers and the family had taken, all participants of

the study resumed the responsibility of caring for the sick family member. One of the participants shared her family's experience of refusing welfare at this stage, because traditionally welfare was only accepted by those without family or those being abandoned by the family.

"A volunteer [at the hospital] told my husband that the medical services were free. He replied, 'this child has parents of her own. Why would we receive the services for free?'(那個時候那邊的志工就有跟她爸爸講說…這個醫療方面不用錢,她爸就說「孩子我自己的,我為什麼要免錢[台語]?」)"

Back-on-track Stage

The next stage, back-on-tract stage, was the time when the caregivers realized that the medical treatment was essential for their sick family members. Entering this stage was usually signaled by the caregivers' witness of worsening of illness in the patient, or by the exhaustive state in the caregivers after combating with the psychiatric symptoms by themselves for a period of time.

"He had another episode, which was worse than before. In the earlier days, he would only experience auditory hallucination or become suspicious. But that episode was out of control. My mother even refused to take him to the hospital...I indeed witnessed his illness getting worse and worse. Therefore I took all possible actions to...lead him to the hospital... to be hospitalized. (那一次的發作比較厲害,就 跟以前的狀況...以前的狀況只是幻聽,覺得疑神疑鬼之類的,結果 那一次是不能控制,甚至要送到醫院,我媽媽都反對......這個中間 確實我看到他是越來越惡化。所以我才想盡辦法採取行動,...然後 引導他要去接受醫院的治療... 去住院。)"

"After three months of this [kind of life], I was really exhausted. I was all worn out. I could not watch her all day any longer...I dared not to go to sleep when she was awake, not even when she was in sleep. She could run out at any time. (那個時候我就真的很累了,我說這樣我很累我沒有辦法跟妳整天...她睡覺的時候我也不敢睡,她不睡的時候我也不敢睡,整天就這樣從外面衝出去)"

Many participants reported conflict experiences with the patient during this stage. Such conflict seemed to be related to the caregivers' awareness about the problematic state in the patient or the family, but they had not yet become skillful in

handling the encountered situations.

"Although we consider ourselves as taking care of him, he perceives we are picking at him. He relates it as we are about to take him to the hospital. Sometimes when we had a quarrel, he took it as I was trying to take him to the hospital again. He would have this kind of thought. In fact, it was not true. We had tried to talk to him with calm and peace. But he would not remember this. All he remembers were those experiences about us forcing him to the hospital. (雖然我們是照顧他,但是他的心態上他覺得說我都是在找他麻煩...他現在都會在想說我是不是要送他去醫院。有時候譬如說我們發生口角的時候,他會想說我是不是想辦法要送他去醫院。都會有這樣一個心理。事實上不是啊。我們雖然是跟他講了很多,也是和顏悅色的去跟他溝通這些問題,他不會去記這些問題,他會去記我們對他強制性的部分)"

One other participant reported similar experience about the patient's "selective memory" on the moments he was treated badly by the caregiver, which seems to demonstrate the fragile nature of the caregiver-patient relationship.

"Frankly speaking, I am not God. I could not take care of him without any regret. Sometimes I got mad or talked back to him. And he...He would not respond immediately. He would not have quarrels with me. He could not respond so quickly. But he kept all these in mind. Things get exploded after a while. He perceives I treat him badly. Once he had been thinking about getting married with another woman and moving out of the house. (因為坦白說我不是說...我不是神啊,我不可能對你無怨無悔的這樣照顧你,我有的時候也會生氣、也會罵他、也會跟他吵。那他...他就是反應不會那麼快,他不會你跟他吵他馬上跟你吵,他沒有辦法那麼快的反應,可是他都積壓在心裡,隔一段時間他就爆發。那他有的時候可能就會覺得我對他不好。所以他要去跟別的女孩子結婚,搬到別的地方住,也有過這個經驗。)"

In Chinese families, it is very common for the family caregiver to express his or her affection and concerns to the patient by checking on his or her medicine routines, instead of using words such as "I love you" or physically hugging the patient. When there is a psychiatric patient in the family, conflict could be arisen from such usual interaction between the caregiver and the patient. It could take a lot of efforts for the caregiver to get back-on-track.

"Then, I didn't know what to do... 'Annie, Annie, get up. Time to take

your medicine.' I woke her up every morning. 'Annie, get up. Time to take your medicine.' 'Oh.' 'Annie, hurry up. Time to take your medicine.' 'Ok, ok.'...But one day she got mad when I asked her to take the medicine. 'You have said the same thing all the time. You treat me as a psycho. So what if I do not take the medicine?' (那個時候真的是不知道...不曉得...應該要怎麼辦,沒有辦法...「安妮、安妮,起來吃藥了![台語]」每天早上叫她起來,「安妮起來吃藥了![台語]」「好。」...但是那天就是我叫她吃藥她生氣:「每次都這樣講,把我當成神經的,沒吃藥會怎樣...。」)"

The back-on-track stage was characterized with one other feature: information seeking. The caregivers would seek for information in relation to the caring of the patient from any sources they had access to. Information seeking would later lead to behavior change or more adopted reaction in the caregiver.

"I had been asking for information everywhere. Someone told me that this illness needs to take the medicine for the rest of the life and that we should not give up. This is why...when she is not well, I would not worry if she does not get up and eat. I would worry a lot if she does not take the medicine. (因為我有去...我有去打聽,有人跟我講說這個可能要終生吃藥,不能放棄。這是我,在她病的時候我就覺得說她沒有起來吃飯,我不會煩惱,她不吃藥我就很煩惱)"

"In the recent years, I went out and took courses, in which I learned a lot. I felt it is necessary to allow my family to share my burden of caring my husband. I had never told my family about my burden until lately. (這幾年我是覺得我也到外面去聽課,也接受不少,我覺得要讓家裡的人來共同負擔我先生的生病的這個情況,我現在才跟他們講。這幾年。)"

Action Stage

The third stage, action stage, was emerged when new learning or strategic behavior come out of the caregiver base on the information sought or the caring experiences.

"Later I found out that this group of patients needed a stage of communication. Psychological rehabilitation is very important, in which friends, instead of psychiatrists, play a very important role. What they need is friends. (後來我發現他們這些學員需要一個溝通的平台, 蠻重要的溝通平台就是心理復健; 心理復健可以促進溝通平台的建立, 那這個心理復健裡面我又發現不是心理醫師, 而是他們這些學員朋友。他們需要的是朋友。)"

"As I have taken care of her for such a long time, I learned that it is very important not to give her too much pressure. I know it. No pressure. The patient could not tolerate much pressure. Societal pressure or family pressure, they are all the same. We can only care about her, guide her, and give her warmth. (因為我這個這麼久了,我就感覺到她,最重要不能給她有很大的壓力,這點我就知道,這個很重要,不要給她壓力。這種病人給她壓力的話,她沒辦法,她沒辦法再承受。不管各方面社會的壓力啊、親屬的壓力,都是一樣,你只能夠來關懷她,給她引導、給她一個溫暖啦)"

Some of the actions taken by the caregiver during the action stage may not necessarily be as efficient or effective.

"Later I tried to guide my brother to become friends with this patient group. He accepted it at the beginning, but could not tolerate it afterwards. Because I become friends with this patient group, he felt distant from me. He felt all of these were arranged by me, and he would not necessarily like those patients anyway. (所以我後來就想帶我弟弟跟這些學員都變成是朋友。初期的時候他還能接受,但是後來他越來越不能接受,因為我後來等於是跟他們這些學員都變成是好朋友,他反而覺得跟我更有距離感。反正他也覺得這些都是我安排的,他也不見得喜歡這些學員。)"

Several participants shared a common difficulty in arranging daily schedule for the patient.

"Originally we thought he could read the historical novels, or play ping-pong. I even bought a ping-pong table, wishing that he would have interaction with us. He did not want to play ping-pong at all. We then thought he is good at hand writing and maybe we could encourage him to write dairies or memos, or practice calligraphy. He didn't want to do any of these... We may talk about this once or twice. But if we talk more, it becomes harassment to him and makes him annoying. (我們本來想嘗試是不是讓他去接觸這方面 [歷史小說]

的,或者是打乒乓球。甚至我還買了一個乒乓球桌,是不是說可以 跟他跟我們互動,打乒乓球,根本都不想。我們想說他字寫得很漂 亮,想說是不是寫寫日記啊、記載一些事情啊,如果說可以的話進 一步再讓他練毛筆,那這個他也不想、他也不做…這些去講他一兩 次可以,第三次可能就…我們就感覺到我們又在騷擾他,又會造成 他的反感。)"

Despite of the conflict experiences and difficulties encountered during the previous stages, some participants experienced sense of achievement in the process of caring the patient.

"This family is over if it has not been me... Because of my stability (in my career), all our three children grew up normally, without the same illness. This is something I am very happy about. (如果沒有我,這個家就完了...因為我的穩定,他們都正常生長,他們三個都沒有病。這是我覺得最高興的事情。)"

As scrutinizing the process of caring among these participants, a theme "hanging there" emerged. It was the phenomena which the caregiver persistently carried on their responsibility to the sick family member, even though they repeatedly encountered physical and psychological stress in the process of caring.

"I think marriage is a commitment. Besides, he has never unfaithful to me. It's just that he is sick. He has never engaged in any extramarital affairs, nor has he been alcoholic or physically abusive to me. There is no reason for me to leave him...I think I am a responsible person. I am responsible to my husband and to my children. (我覺得結婚是一個承諾,而且他沒有對不起我,是他生病了,他不是說到外面去拈花惹草或者是酗酒、或者是弄得我不堪忍受的事情,所以我沒有離開。...我覺得我覺得我是個負責任的人。...我覺得就是因為負責任,我對我先生負責、對我孩子負責。)"

A contrast theme was also noted in one of the participants, which was labeled as "crossroad phenomena". It is the phenomena which the caregiver is considering to terminate his or her responsibility of caring to the patient. The phenomena were emerged as the caregiver got burned out, resulted from such factors as aging, patients' recurrence of illness or intolerable disturbance, and a lack of support. The phenomena were a dilemma to the caregiver, because the patient was still perceived as his or her responsibility. But such responsibility was not able to be carried on, for the situation has gotten out of the caregiver's hands.

"Looking at his situation, I feel it has come to a crossroad. Which way should you take on? He is our child. Of course we have the responsibility (to care him). But now he puts our neighbors in danger...Or, you have to take him to the long-term care (facilities). He is getting worse and worse...I don't know when he will hurt someone with a knife for no reason. I cannot predict. (我覺得說現在這種病的人...像他這樣的情況已經到一個分叉路了,已經到十字路口,你到底要走哪一邊?...是我們的孩子、是我們的責任,我們要擔當。可是現在這樣這種情況的話妳說危險到鄰居...不然,你就是要去那種長期就養。因為...他實在是越來越糟糕...我都不曉得他哪一天像那個什麼...沒事去把人家拿一個刀子去做什麼事,都沒有辦法預期、都沒有辦法預警。)"

Needs

As emerged from the interviews, the followings were identifies by the participants as the assistance that would be needed by caregivers of persons with schizophrenia living in the community: (1) providing education of illness-related knowledge to the family of patients, as well as the common people, (2) assisting in arrangement of daily schedule, including more access to facilities in the community; and (3) assistance in the patient's placement (such as community accommodation and long-term care facilities) when the caregiver can no longer care for the patient.

Figure 1 depicted the summary of the results.

Discussion

In the results of the preliminary analysis on data of the study, it emerged a process of caring in three stages: chaotic stage, back-on-track stage, and action stage. Qualitative data provided more rich information as how caregivers of persons with schizophrenia progress in the process of caring. Several issues are worthwhile for further discussion.

Values and attitudes of Chinese families

The strong bond in the Chinese families should not be overlooked while planning the future psychiatric services in Taiwan. In fact, living with the family is the best solution for the patient's benefit and is congruent with the current trend of community care. All the study participants resumed the responsibility of caring their family member who has psychiatric illness. It is highly recommended that related policy making should cherish such resources and provide assistance to the family caregiver in all possible ways.

Members of Chinese families seldom express their affections to other members in direct ways. In this study, it has been noted that many of the participants had difficulties maintaining a constructive relationship with the patient, partly due to the indirectly expressed affections. The vulnerability in caregiver-patient relationship was also noted, in which the patient may selectively remember the moments they were badly treated by the caregiver and constructive relationships may not be rebuilt no matter how hard the caregiver have tried. It is implied that the family caregivers need to be educated and supported in establishing and maintaining a constructive relationship with the patient.

Other family roles

During the interviews, many participants mentioned about their other roles in the family, which may be in conflict of caring the patient and adds the burden in the caregiver. One participant shared her experiences with a sense of achievement that after well planning and preparation, she took the patient abroad for two months. Such experience support findings in other study¹³ that planning is very essential in the caring process and may enhance the quality of life in both the caregiver and the patient.

The study results indicated that when evaluating their caring experiences, caregivers do not only look at what they do to the patient, but also what they do in other roles in the family. Managing other family roles was actually interwoven in the caring process for the patient. In the future, related program planning needs to consider caregivers' other family role, in addition to their role in caring for the patient. Needs identified by the caregiver

The study participants identified a few modest needs which could be considered as valuable input to the psychiatric professionals, as well as to the system. For education of knowledge related to the illness, professionals may review their practice and see if related education to the caregiver has been included in the practice routine; while the system may reexamine if related information is available and accessible to the public.

For the need in assisting the arrangement of daily schedule in the community, professionals such as occupational therapists may provide valuable contributions to such request. As the great majority of occupational therapists work in the hospitals, it is recommended that (1) occupational therapists may strengthen their professional competence in philosophies of community care and occupation-based service delivery, and (2) the system may review the current service delivery mechanism and eliminate possible barriers for occupational therapy services to be delivered in the community.

For the need of long-term care facilities, it should be taken as an urgent one. In this study, participants especially those in their sixties and seventies expressed a great concern about the unavailability and inaccessibility of long-term care facilities for their family members with psychiatric illness. The system needs to take such need in a serious manner.

Summary and conclusions

This study explored the caregivers' occupation-related experiences for persons with schizophrenia living in the community. This manuscript presents the result of preliminary data analysis. It is noted that the caring process may be described by three stages: chaotic stage, back-on-track stage, and action stage. The process was also interwoven with the family values and religious culture in the society of Taiwan. Factors such as insufficient knowledge about the illness and conflict experiences with the patient imposed direct impact on the caring process. A few factors were also identified as contributing to the caregiver's sense of achievement in the process. All the study participants expressed a great concern about the future of their sick family member, because the long-term care facilities are unavailable and inaccessible.

The study participants provided valuable input for the planning of further psychiatric services in Taiwan. Certainly, the resource of family caregiver should be cherished. Professionals and the system should provide necessary assistance and support, so that the resource will not die out and patients' greatest benefit will be ensured.

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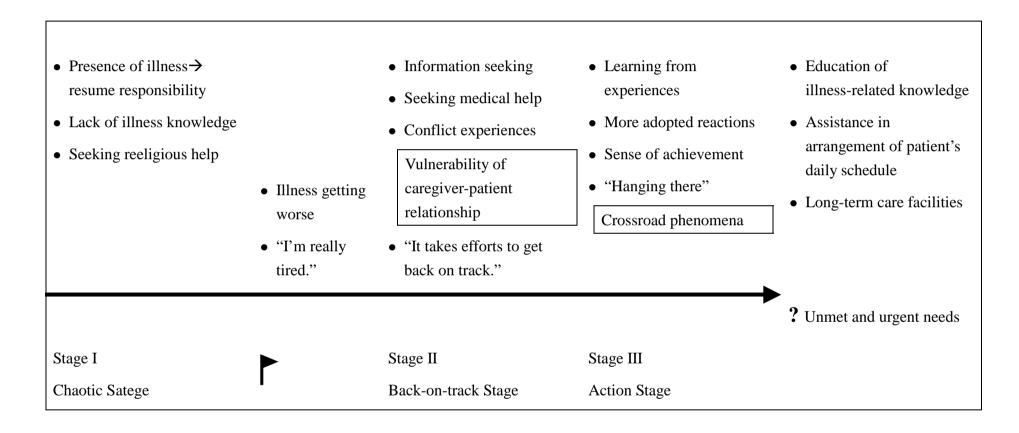
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Figure 1.

Occupation-related Caring Experiences in Caregivers of Persons with Schizophrenia Living in the Community



計畫成果自評

本計畫的設計為兩年期的研究計畫,然只獲得一年的經費補助,本計畫成果乃報告原計畫之第一年的執行情形。本計劃為研究者在取得學位歸國服務之後獲得補助執行的第一個計劃,在計畫經費的規劃使用以及計畫執行上均顯得經驗不足,所幸獲得台大醫學院胡海國教授的指導,得以維持應有的表現。此年度計畫執行期間適逢 SARS 疫情爆發,研究場所位於台大醫院,研究助理曾在醫院規範下暫停上班,原本約定的病人不敢到醫院來參與研究,導致研究計畫執行進度大受影響,後來申請延長執行三個月,才勉強完成。本報告之結果與討論為節錄 2003 年九月於第三屆亞太職能治療學術會議所發表之論文,亦為本計畫之部分結果。