科技部補助專題研究計畫成果報告 期末報告

失智症照顧者的主觀與客觀負荷的影響因子

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中 文 摘 要 : 目的: 失智症既為一種退化性的疾病,隨著病情惡化病人需要持續的照顧,對於失智病人的照顧者也造成心理、財務的雙重負荷。本研究的目的比較影響照顧成本與照顧負荷的因素,尤其透過找出可改變的因素,以期減輕失智症照顧者所面對的負荷。除上述追蹤研究之外,計畫主持人也完成兩個相關研究的投稿,首先是以第一波的資料進行ZBI工具的驗證性因素分析,建立短版(12題)的ZBI問卷,用於第二波的收案,經驗證後的短版問卷在發表後,亦可供其他研究使用。其次是以第一波的資料分析失智症家庭使用長期照顧服務的情形,以及影響服務使用的因素,完成第二篇期刊論文投稿。

方法:本研究延續2013年11月在成大醫院失智症門診所召募的231對的失智症樣本組(病患與照顧者為一對),於2015年11月進行追蹤調查,共有167對完成二次面訪。所蒐集之資料包含病患特質、照顧者特質、與患者的關係及照顧者之社會支持,並使用ZBI工具測量主觀照顧負荷。客觀負荷(照顧成本)的估計採全社會觀點,收集直接醫療成本、直接社會照顧成本與家庭照顧成本,三者加總後即為總照顧成本。統計方法先以雙變數分析比較不同類的影響因子分別對於主觀負荷與客觀負荷的相關性,合併兩波的資料後,用線性混合模型(mixed model)分析各類因子對於照顧成本或照顧負荷分數的影響幅度。

結論:本研究比較主觀負荷與客觀負荷的影響因素後,發現影響兩者的因素不盡相同,但透過提供照顧者訓練以解決病患的干擾行為和給予經濟困難的照顧者費用補貼,可以有效減少照顧負荷。對於失智症家庭使用長期照顧服務的情形,建議政府除了提供為失智病人的長照服務之外,也應考慮到照顧者對於支持服務的需要,並加強對照顧者的宣導,才能在傳統雇用看護工的方式之外,提供多元的長照服務來滿足失智症全家照護的需求。

中文關鍵詞: 失智症、家庭照顧者、照顧負荷、照顧成本

英文摘要: Objective: The progression of dementia needs continued care provision and poses both psychological and financial burden

for family caregivers of dementia patients. This is a longitudinal study to find predictors of care costs and caregiver burden and to identify modifiable factors which could alleviate burden. Besides the main study, there are also two related papers: the first one seeks to find an valid short version of the Zarit Burden Interview (ZBI) using caregiver burden data collected at baseline, and the second study examined the use of long-term care services (LTC) by families with a demented elderly person Methods: The follow-up study of 167 dementia patient - caregiver dyads was conducted between 2005/11 and 2016/6 in a dementia clinic at NCKU hospital. Data collected included patient characteristics, caregiver characteristics, relationship to patient, and social support to caregivers. Caregiver burden was measured by Zarit Burden Interview instrument. The association between each predictor variable and cost of care and caregiver burden scores was examined using linear mixed models.

Results: Multivariate analysis on predictors of care costs showed that functional declines measured by ADL had a greater impact on all cost outcomes as compared to behavioral disturbance measured by NPI, which showed no impact on any costs. However, patients' behavioral disturbance was a significant predictor of caregiver burden. If caregiver rated their economic status as having difficulty, they also reported higher caregiver burden; in contrast, caregivers who were better-off reported significantly higher care costs but lower caregiver burden. Results from linear mixed model using two waves of caregiver burden also found patients' behavioral disturbance and caregiver's economic status to be the most significant predictors, while controlling other variables.

Conclusions: Although this study found that predictors of care costs seemed to be different from the predictors of caregiver burden, providing training to caregivers in addressing dementia patient' behavioral disturbance may be an effective way to reduce caregiver burden We recommend the government to consider the need of caregiver support in addition to services targeted at dementia patients and to strengthen educational campaigns to caregivers.

英文關鍵詞: dementia, informal caregivers, caregiver burden, care costs

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摘要

目的: 失智症既為一種退化性的疾病,隨著病情惡化病人需要持續的照顧,對於失智病人的照顧者也造成心理、財務的雙重負荷。本研究的目的比較影響照顧成本與照顧負荷的因素,尤其透過找出可改變的因素,以期減輕失智症照顧者所面對的負荷。除上述追蹤研究之外,計畫主持人也完成兩個相關研究的投稿,首先是以第一波的資料進行 ZBI工具的驗證性因素分析,建立短版(12題)的 ZBI 問卷,用於第二波的收案,經驗證後的短版問卷在發表後,亦可供其他研究使用。其次是以第一波的資料分析失智症家庭使用長期照顧服務的情形,以及影響服務使用的因素,完成第二篇期刊論文投稿。

方法:本研究延續 2013 年 11 月在成大醫院失智症門診所召募的 231 對的失智症樣本組 (病患與照顧者為一對),於 2015 年 11 月進行追蹤調查,共有 167 對完成二次面訪。所 蒐集之資料包含病患特質、照顧者特質、與患者的關係及照顧者之社會支持,並使用 ZBI 工具測量主觀照顧負荷。客觀負荷(照顧成本)的估計採全社會觀點,收集直接醫療成本、直接社會照顧成本與家庭照顧成本,三者加總後即為總照顧成本。統計方法先以 雙變數分析比較不同類的影響因子分別對於主觀負荷與客觀負荷的相關性,合併兩波的資料後,用線性混合模型(mixed model)分析各類因子對於照顧成本或照顧負荷分數的影響幅度。

結果:第一波與追蹤調查的樣本相比,除了女性病患占率增加和照顧者得到家人支持的百分比這兩項有不同之外,其他樣本特質在兩波調查皆無顯著差異。不過失智症病患的身體功能(ADL)變差者,較容易在基期後退出研究。照顧成本的模型顯示費用的主要解釋變數是身體功能,衰退會增加照顧成本,病人的干擾行為(NPI)對於醫療、社會照顧或家庭照顧的成本皆無顯著影響。然而病人的干擾行為對照顧負荷則有顯著影響,此外,照顧者的經濟能力若有困難,會有較多的照顧負荷,經濟能力相當充裕的照顧者相對而言付出較高的照顧成本,但心理負荷顯著較低。照顧負荷的混合模型的結果顯示,病患的干擾行為和照顧者的經濟能力對照顧負荷有最顯著的影響。此外,分析失智症家庭不使用長照服務的原因的研究發現,不使用的主因是不覺得患者有需要使用服務(41%)、其次是因已用看護工故無法申請其他長照服務(35%)。至於未曾使用家庭照顧者支持服務的主因,是照顧者缺少相關服務的資訊(56%)。

結論:本研究比較主觀負荷與客觀負荷的影響因素後,發現影響兩者的因素不盡相同,但透過提供照顧者訓練以解決病患的干擾行為和給予經濟困難的照顧者費用補貼,可以有效減少照顧負荷。對於失智症家庭使用長期照顧服務的情形,建議政府除了提供為失智病人的長照服務之外,也應考慮到照顧者對於支持服務的需要,並加強對照顧者的宣導,才能在傳統雇用看護工的方式之外,提供多元的長照服務來滿足失智症全家照護的需求。

關鍵字: 失智症、家庭照顧者、照顧負荷、照顧成本

Abstract

Objective: The progression of dementia needs continued care provision and poses both psychological and financial burden for family caregivers of dementia patients. This is a longitudinal study to find predictors of care costs and caregiver burden and to identify modifiable factors which could alleviate burden. Besides the main study, there are also two related papers: the first one seeks to find an valid short version of the Zarit Burden Interview (ZBI) using caregiver burden data collected at baseline, and the second study examined the use of long-term care services (LTC) by families with a demented elderly person

Methods: The follow-up study of 167 dementia patient—caregiver dyads was conducted between 2005/11 and 2016/6 in a dementia clinic at NCKU hospital. Data collected included patient characteristics, caregiver characteristics, relationship to patient, and social support to caregivers. Caregiver burden was measured by Zarit Burden Interview instrument. The association between each predictor variable and cost of care and caregiver burden scores was examined using linear mixed models.

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Conclusions: Although this study found that predictors of care costs seemed to be different from the predictors of caregiver burden, providing training to caregivers in addressing dementia patient' behavioral disturbance may be an effective way to reduce caregiver burden. We recommend the government to consider the need of caregiver support in addition to services targeted at dementia patients and to strengthen educational campaigns to caregivers.

Keywords: dementia, informal caregivers, caregiver burden, care costs

Measuring burden in dementia caregivers: confirmatory factor analysis for short forms of the Zarit Burden Interview

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Abstract

Introduction: To examine the psychometric properties of different short versions of the Zarit Burden Interview (ZBI), and to find an efficient and valid short version for clinical use among dementia caregivers.

Materials and Methods: A total of 270 Taiwanese dementia caregivers filled out the full form of the ZBI, which contains 22 items. Using the 22-item ZBI, we used confirmatory factor analysis (CFA) to calculate the fit indices of all proposed short versions with various items to determine useful short versions. Additional associations between each useful short version and informal care hours, as well as subjective financial situations, were examined to understand their concurrent validity.

Results: Based on the CFA results, three short versions of the ZBI, performed excellently (4-item version: comparative fit index [CFI]=1.000, Tucker-Lewis index [TLI]=1.035, standardized root mean square residual [SRMR]=0.019, and root mean square error of approximation [RMSEA]=0.000; 8-item version: CFI=0.970, TLI=0.958, SRMR=0.045, and RMSEA=0.065; 12-item version: CFI=0.959, TLI=0.950, SRMR=0.053, and RMSEA=0.075). In addition, the 12-item ZBI, as compared with other versions, had a higher correlation with the number of informal care hours. The 12-item ZBI was also highly correlated with the original 22-item ZBI (r=0.952).

Conclusions: We found the 12-item ZBI to be a promising measure for healthcare providers to assess the burden of dementia caregivers quickly and efficiently.

Keywords: caregiver; confirmatory factor analysis; dementia; validity; Zarit Burden Interview

1.Introduction

Caring for people with dementia, including Alzheimer's disease, is very likely to present a severe burden for caregivers because of the need to provide continuous day-to-day supervision and care, including assistance with the patients' activities of daily living (ADLs) and instrumental ADLs (IADLs) (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005). Moreover, such caregivers need to tolerate and cope with the inappropriate and/or violent behaviors from their relatives suffering from Alzheimer's disease (Zarit, Reever, & Bach-Peterson, 1980). While caregivers often cooperate with healthcare professionals to provide better treatment (Chang et al., 2015), those with severe burden may be less capable to work with healthcare professionals, and in extreme cases this can even jeopardize the health of caregivers (Schreiner, Morimoto, Arai, & Zarit, 2006; Zarit, Todd, & Zarit, 1986). Assessing caregiver burden may thus help healthcare professionals to prevent both caregivers and patients from the worst outcomes in this context.

The Zarit Burden Interview (ZBI) is one of the most commonly used scales that measure caregiver burden. However, the structure of the ZBI has been debated for decades. Some studies propose using a multidimensional structure, ranging from two to five factors (Ankri et al., 2005; Bédard et al., 2001; Cheah, Han, Chong, Anthony, & Lim, 2012; Cheng, Kwok, & Lam, 2014; Knight, Fox, & Chou, 2000; Ko, Yip, Liu, & Huang, 2008). In contrast, others propose a unidimensional structure using short form of the ZBI with the number of items ranging from four to 12 (Arai, Tamiya, & Yano, 2003; Bédard et al., 2001; Ballesteros et al., 2012; Gort et al., 2005; Gort et al., 2010; Higginson, Gao, Jackson, Murray, & Harding, 2010). The various recommendations in the literature make it difficult for healthcare professionals to decide which structure and/or version of ZBI should be used. Some researchers have noted the problem of diverse structures in ZBI, and thus compared the different structures of ZBI (Cheng et al., 2014; Knight et al., 2000).

The benefits of multidimensionality for the ZBI are obvious; for example, measurements of caregiver burden being multidimensional can provide more holistic and precise results, because caregivers with an identical score may have burdens that differ in certain aspects (Cheah et al., 2012). Unfortunately, the debate on multidimensional structures of the ZBI is yet to be resolved, and it is very likely that different structures will be needed in different cultures, especially in Western versus Eastern contexts. Cultural values significantly influence the coping styles of caregivers, their interpretations of social support, and how they express emotional distress (Knight & Sayegh, 2010). That is, culture factors may account for the diverse results of the multidimensional structures of the ZBI, though we still cannot identify which specific culture characteristics are involved. As a result, the current problem is that there is no consistent structure of the ZBI for healthcare providers to utilize. Several studies (Cheng et al., 2014; Knight et al., 2000; Longmire & Knight, 2011; Lu, Wang, Yang, & Feng, 2009; Siegert, Jackson, Tennant, & Turner-Stokes, 2010) have used CFA to compare different ZBI structures, and their results are not comparable. For example, Cheng et al. (2014) finally suggested a 4-factor structure with 18 items, while Knight et al. (2010)

proposed a 3-factor structure with 14 items.

Because of the uncertainty of the structure, we propose to use a short version of unidimensional ZBI measuring the global burden instead. By using a short form of the ZBI, healthcare providers would need significantly less time to evaluate caregiver burden, and this process would also be easier for caregivers. In other words, using a good short version can be premised on ease of administration and possibly screening in busy clinical settings or intervention/population studies. We also justify the reasons of adopting a short version include (1) being a surrogate of role strain, personal strain and total ZBI score; (2) being potentially constituted by few items. Nevertheless, there are currently different versions of unidimensional ZBI and further efforts are needed for version selection.

The main purpose of this study was to compare six proposed unidimensional ZBI in a sample of Taiwan caregivers for dementia patients using confirmatory factor analysis (CFA), and to determine which version was the most suitable in this context.

2. Method

2.1 Participants and procedure

We recruited 286 dementia patient—caregiver dyads at the dementia clinic in a national university hospital in southern Taiwan from November 2013 to April 2015. We included patients whose medical records contained a diagnosis of dementia according to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria. Dementia subtypes included mostly Alzheimer's disease (n=224), but also dementia with Lewy bodies (n=9), vascular dementia (n=6), and other unspecified types. The inclusion criteria required that dementia patients were living in the community and had an informal caregiver. The caregiver of the dementia patient must be a family member who had cared for the patient for at least 12 months, be ≥18 years of age, and fluent in either Mandarin or Taiwanese. After excluding 10 patients who moved to a nursing home, four withdrawals, and two incomplete responses, our final sample included 270 community-dwelling dyads. Ethical approval was obtained from the National Cheng Kung University Hospital Institutional Review Board before this study began (IRB No: B-ER-102-173). Data were collected using telephone interviews with caregivers after obtaining written consent for the study from the caregivers and the patients. For cognitively impaired patients who could not provide their signatures, proxy consent was obtained from their family caregiver.

We collected data on baseline demographics (age, gender, and educational level), marital status, and relationship to the patient from caregivers using questionnaires. The ZBI (Zarit et al., 1980) assessed subjective caregiver burden, while unpaid caregiver (informal care) time was collected using Resource Utilization in Dementia (RUD) instrument (Wimo et al., 2013). Informal care time was categorized into hours spent on Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), and supervision for the person with

dementia in the past week before the interview. Moreover, one survey question on financial burden ("Does your family have difficulty paying living expenses every month?") was used as a criterion for testing known-group validity.

2.2 Zarit Burden Interview (ZBI)

All 22 items on the ZBI are rated on a 5-point scale from 0 (not at all) to 4 (extremely), and a higher ZBI score indicates a higher level of caregiver burden. The internal consistency of the ZBI has been reported as satisfactory (α =0.92; Hébert, Bravo, & Préville, 2000), including the Chinese version for Taiwanese subjects (α =0.89; Ko et al., 2008). Moreover, the test-retest reliability for a two-week interval is excellent for the Chinese version of the ZBI (intraclass correlation coefficient=0.88; Ko et al., 2008). The most used two domains of the ZBI are personal strain and role strain. In the current study we also found that the internal consistency was adequate for 22 items (α =0.855), and the item descriptions are presented in the Appendix. In addition, we compared the psychometric properties of the following six short versions: 4-item (Bédard et al., 2001; Gort et al., 2005), 6-item (Higginson et al., 2010), 7-item (Gort et al., 2010), 8-item (Arai et al., 2003), and 12-item (Ballesteros et al., 2012). The reason of not including other existed short ZBI (e.g., Cheng et al., 2014; Longmire & Knight, 2011) is we tried to compare the versions with 12 or fewer items and derived using the uni-dimensional approach.

2.3 Statistical analysis

We examined six CFA single-factor models and performed their fit statistics. All models were estimated using maximum likelihood estimation based on absolute skewness (0.027 to 1.979) and kurtosis (0.297 to 3.089) values of less than 3 and 8, respectively, suggesting a normal distribution(Kline, 2015; Lin, Luh, Cheng, Yang, & Ma, 2014). The χ^2 should be nonsignificant to indicate a good data-model fit, but we did not use this statistic to assess the fit of any model, as it is too sensitive to a large sample size (Wu, Chang, Chen, Wang, & Lin, 2015). Therefore, we used the following fit indices instead: comparative fit index (CFI), Tucker-Lewis index (TLI), standardized root mean square residual (SRMR), and root mean square error of approximation (RMSEA). The values of CFI and TLI that are > 0.95, and of the SRMR and RMSEA that are < 0.05 suggest excellent data-model fit, while alternatives of > 0.90 and < 0.08 suggest acceptable fit (Cheng et al., 2014; Tsai et al., 2015).

Using the above fit statistics, we aimed to determine which model had all indices that were acceptable and/or excellent. If the results showed that there were several acceptable models, we then compared their factor loadings, internal consistency using Cronbach's α , and their correlations with the average scores of the 22-item ZBI and its two domains. In addition, the correlations between the acceptable models and informal care hours were computed. The known-group validity was also assessed using a one-way analysis of variance (ANOVA) with Bonferroni correction to determine the sensitivity of acceptable models.

LISREL 8.8 (Scientific Software International, Lincolnwood, IL, USA) was used for all

CFA models, and SPSS 16.0 (SPSS Inc., Chicago, IL, USA) was used for descriptive analyses, internal consistency, correlations, and known-group validity.

3. Results

The mean (SD) age of the caregivers was 59.99 (13.22) years, and most of them were married (81.5%). More than half of the caregivers were female (63.0%) and two-thirds of them had an educational status of senior high school or above. Most of their relationships to the care-recipient were spouses (40.4%) or children (45.9%), slightly less than half of them had a full-time job (43.7%), and most of them lived with the care-recipient (77.8%). The caregivers seemed to spend more time taking care of their care-recipients' IADL (mean=14.91 hours/week) than their ADL (mean=6.58 hours/week), while the average total informal care hours, including supervision, was 48.83 per week. In addition, the average duration of care was 4.63 years (Table 1).

Table 1. Characteristics of the caregivers (N=270)

Age (years), M±SD	59.99±13.22					
Gender (women), n (%)	170 (63.0)					
Marital status, n (%)						
Married	220 (81.5)					
Single	42 (15.6)					
Divorced	8 (3.0)					
Educational status, n (%) [†]						
Illiterate	12 (4.4)					
Primary school	45 (16.7)					
Junior high school	29 (10.7)					
Senior high school	93 (34.4)					
College or above	90 (33.3)					
Employment (yes), n (%)	118 (43.7)					
Relationship to care-recipient, n (%)						
Spouse	109 (40.4)					
Child	124 (45.9)					
Child-in-law	32 (11.9)					
Others	5 (1.9)					
Living with care-recipient, n (%)	210 (77.8)					
Financial situation						
Have more than enough money	52 (19.3)					
Have enough money	167 (61.9)					
Have some difficulty	41 (15.2)					
Have great difficulty	10 (3.7)					
Informal care hours per week, M±SD						
Care for activity of daily living (ADL)	6.58±8.93					
Care for instrumental ADL (IADL)	14.91±9.90					
Care for ADL and IADL	21.49±15.71					
Care for ADL, IADL, and supervision	48.83±41.23					
Care duration (years), M±SD ^a	4.63±3.10					

[†]With one missing value

Table 2 summarizes the fit statistics for all the proposed ZBI frameworks. If not considering the significant χ^2 , four unidimensional models had the remaining four fit indices that fulfilled the requirements: these were the 4-item (Gort et al., 2010) and the 7-item (Gort et al., 2005) models proposed by Gort et al., the 8-item model from Arai et al. (2003), and the 12-item model of Ballesteros et al. (2012). In addition, the 6-item model proposed by Higginson et al. (2010) had fit statistics close to requirements. As a result, we only removed the 4-item model from Bèdard et al. (2001), which had unsatisfactory fit indices, for the following analyses.

Table 2. Reliability and fit statistics for different structures of the Zarit Burden Interview

Study	No. of item	Cronbach's α	CFI	TLI	SRMR	RMSEA
Bédard et al. (2001)	4	0.663	0.925	0.774	0.063	0.160
Gort et al. (2010)	4	0.463	1.000	1.035	0.019	0.000
Higginson et al. (2010)	6	0.790	0.965	0.942	0.044	0.094
Gort et al. (2005)	7	0.827	0.975	0.962	0.042	0.080
Arai et al. (2003)	8	0.768	0.970	0.958	0.045	0.064
Ballesteros et al. (2012)	12	0.842	0.959	0.950	0.053	0.075

Note: CFI = comparative fit index; TLI = Tucker-Lewis index; SRMR = standardized root mean square residual; RMSEA = root mean square error of approximation

We further examined the internal consistency of the six short forms of the ZBI (i.e., 4-item, 6-item, 7-item, 8-item, and 12-item ZBI), and found that only the 4-item ZBI had unsatisfactory reliability (α =0.463 and 0.663). In addition, the correlations between the five short forms, the full form ZBI (i.e., 22-item ZBI), and informal care hours were calculated. The results showed that the 12-item ZBI had the highest correlation with the 22-item ZBI (r=0.952) and with informal care hours (r=0.232 to 0.386; Table 3). We found a similar trend that the 12-item ZBI outperformed the 4-item and 8-item ZBIs with regard to the known-group validity. Table 4 shows that the 6-item, 7-item, 12-item and 22-item ZBIs distinguished the levels of caregiver burden based on different financial situations. Caregiver burden was significantly heavier for caregivers who had some or great difficulty in paying living expenses than for those who had enough or more than enough money. On the other hand, both the 4-item and 8-item ZBIs did not detect a significant difference in caregiver burden between caregivers who had some difficulty in paying expenses versus those who

were better-off financially. Moreover, the between-group differences for the 6-item, 7-item, and 12-item ZBIs were larger among caregivers in different financial situations (difference=1.00 to 1.21 between those who had more than enough money and those had great difficulty in paying their expenses) as compared with those of other ZBI versions' scores (difference=0.80 to 0.85 between family who had more than enough money and those had great difficulty in paying their expenses). The burden score of caregivers in each financial situation was more centered in the 12-item ZBI rather than that in the 4-item, 6-item, 7-item, and 8-item ZBIs.

Table 3. Correlations among three short forms of the Zarit Burden Interview (ZBI), 22-item ZBI, and informal care hours

	4-item ZBI [†]	6-item ZBI	7-item ZBI	8-item ZBI	12-item ZBI [‡]	22-item ZBI
22-item ZBI	0.789	0.890	0.913	0.871	0.952	
Informal care hours on ADL and IADL	0.210	0.278	0.304	0.255	0.323	0.311
Informal care hours on ADL	0.180	0.332	0.365	0.299	0.383	0.366
Informal care hours on IADL	0.232	0.216	0.223	0.217	0.232	0.246
Total informal care hours [§]	0.323	0.346	0.373	0.307	0.386	0.385

Note: ADL = activity of daily living; IADL = instrumental ADL; All p-values < 0.01

[†]Proposed by Gort *et al.* (2010)

[‡]Proposed by Ballesteros *et al.* (2012)

[§]Including care hours on ADL, IADL, and supervision

Table 4. Known-group validity for three short forms of the Zarit Burden Interview (ZBI) and 22-item ZBI

-	Does your fami	F	Group comparison [↑]			
	1. Have more than enough money	2. Have enough money	1, 00, 1, 1, 00, 1,			
	M±SD (n)	M±SD (n)	M±SD (n)	M±SD (n)	-	
4-item ZBI [‡]	0.88±0.80 (52)	1.00±0.79 (166)	1.20±0.98 (41)	1.68±1.09 (10)	3.19*	1<4
6-item ZBI	0.79±0.88 (52)	1.09±0.90 (166)	1.61±0.89 (41)	1.93±1.04 (10)	9.22***	1,2<3,4
7-item ZBI	0.90±0.89 (52)	1.24±0.89 (165)	1.83±0.82 (40)	2.11±1.00 (10)	11.33***	1,2<3,4
8-item ZBI	0.81±0.90 (46)	0.93±0.72 (150)	1.26±0.78 (36)	1.66±1.12 (10)	4.81**	1,2<4
12-item ZBI§	1.11±0.87 (51)	1.38±0.80 (159)	1.90±0.74 (38)	2.11±0.95 (10)	9.30***	1,2<3,4
22-item ZBI	1.12±0.70 (46)	1.28±0.62 (143)	1.74±0.65 (34)	1.96±0.88 (10)	9.39***	1,2<3,4

^{*}p<0.05; **p<0.01; ***p<0.001

[†]Using Bonferroni adjustment

[‡]Proposed by Gort *et al.* (2010)

[§]Proposed by Ballesteros et al. (2012)

Moreover, the factor loadings shown in the Appendix indicate that the 6-item, 7-item, and 12-item ZBIs had adequate loadings (i.e., >0.3). In contrast, the 4-item ZBI of Gort et al. (2005) and the 8-item ZBI had one low factor loading each (loadings=0.155 and 0.235, respectively).

4. Discussion

This study compared six short versions of the ZBI in a sample of Taiwanese caregivers caring for a family member with dementia. Our results showed that the 12-item structure outperformed other unidimensional structures in terms of the fit statistics in CFA, factor loadings, internal consistency, and the correlations with informal care hours.

Using a validated ZBI could help healthcare professionals to better understand the caregiver burden, and to take appropriate actions more quickly, such as providing respite care (Greenwood, Habibi, & Mackenzie, 2012). While the reliability, including internal consistency and test-retest reliability, of the ZBI is good (Hébert et al., 2000; Ko et al., 2008), a concern was that different studies have recommended various structures for the ZBI (e.g., (Ankri et al., 2005; Bédard et al., 2001; Cheah et al., 2012). At the present, healthcare providers cannot confidently use the ZBI with a clear structure to assess caregiver burden, although the trend was towards using multidimensional ZBI (Ankri et al., 2005).

Because of the uncertainty with regard to the multidimensional structure of the ZBI, we recommend an alternative ZBI to be used; that is, adopting a short form of unidimensional ZBI with satisfactory psychometric properties. Our results showed that the 12-item ZBI proposed by Ballesteros et al. (2012) was the best candidate for this use, based on the following reasons. First, the results of two statistical methods (item response theory and CFA) used by Ballesteros et al. (2012) suggested that a unidimensional structure should be used for the 12-item ZBI. Our CFA results (CFI=0.975 and RMSEA=0.067) are comparable to the CFA results (CFI=0.959 and RMSEA=0.075) in Ballesteros et al. Second, our results showed that the 12-item ZBI score was highly correlated with the score of the full form ZBI (r=0.952). Although the 12-item ZBI score had the best internal consistency among all the short forms of ZBI, this may be due to the property of the Cronbach's α . Cronbach's α is sensitive to the number of items and is not an independent measure (Sijtsma, 2009); the more items there are in an instrument, the higher Cronbach's a will be. Third, the known-group validity of the 12-item ZBI score was similar to that of the full form ZBI, and outperformed the 4-item and 8-item ZBIs. In other words, the 12-item ZBI was able to assess the burden to nearly the same extent as the 22-item ZBI. Fourth, the 12-item ZBI was significantly and moderately correlated with caregiving hours. Because previous research has shown that caregiver burden increased with informal care hours (Kim, Chang, Rose, & Kim, 2012; Yu, Wang, He, Liang, & Zhou, 2015), the correlations indicated that the 12-item ZBI is valid. The main benefit of using the short form of the ZBI was that it can assess caregiver burden precisely in a short period of time, which is especially important in clinical environments (Bédard et al., 2001).

Although we found other four satisfactory short forms (4-item, 6-item, 7-item, and 8-item ZBI) based on the CFA results, we recommend only using the 6-item or 7-item ZBI for quick screening. The main reason for not using the 4-item and 8-item ZBIs is their worse psychometric properties as compared with those of the 12-item ZBI (Tables 2 and 3). In contrast, both 6-item and 7-item ZBIs shared satisfactory results in internal consistency and factor loadings. However, their correlations with informal care hours were slightly poorer than that of the 12-item ZBI. Nevertheless, the 6-item and 7-item ZBIs have the advantage of fewer items, and thus may be suitable for rapid screening. In addition, given the only different item between 6-item and 7-item ZBIs is the global item, using 6-item may be more preferable than using 7-item. However, future studies are needed to corroborate our suggestion.

An important limitation of the current study is that the study sample came from a single dementia clinic in one university hospital excluding advanced dementia patients living in institutional settings, and thus could not represent all dementia patients in Taiwan. A second limitation is that our sample included 29 patients with younger-onset dementia. Because caregivers of patients with younger-onset dementia may confront different stresses from those caring for those with late-onset dementia (Grønning et al., 2013; van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010), our proposed model may be biased. In order to address this concern, we re-analyzed the ZBI structures after excluding those 29 subjects with younger-onset dementia, and reached similar conclusions (results not shown but available upon request). Therefore, our findings did not seem to be affected by the inclusion of the younger-onset dementia patients. A third limitation is that we assumed a linear relationship between the informal care hours and the ZBI scores when we used informal care hours as our criterion to select the 12-item ZBI. Although previous studies (Kim et al., 2012; Yu et al., 2015) indicated that informal care hours were correlated with caregiver burden, the relationship may not be linear. This might explain our relatively low correlations (r=0.180 to 0.386) between the ZBI scores and informal care hours. In addition, we did not have any standardized or validated instrument as our criteria to test the concurrent validity of ZBI scores. Although the two criteria we used (informal care hours and financial situations) shed some light on the issue, using a validated instrument may provide additional evidence for clinicians. We therefore propose that future studies should work to corroborate our results by using quality of life (e.g., the WHOQOL-BREF) and/or depression instruments (e.g., the geriatric depression scale) to test the concurrent validity of ZBI scores. Lastly, clinicians and researchers should be cautious with the shortcoming of the 12-item ZBI: the 12-item does not incorporate a salient concept (worry about performance) in Asian societies (Lim et al., 2014). Therefore, we suggest future work should be done on comparing the short forms of ZBI across subcultures of Chinese culture (e.g., Hong Kong, China, and Taiwan), or among countries that share similar Confusianism traditions (e.g., Japan, South Korea, and China).

In conclusion, the use of ZBI may help healthcare providers to assess caregiver burden among dementia caregivers and make appropriate clinical decisions in a timely manner. Based on our results, we propose using a short form of the 12-item ZBI that was not only

highly correlated with the score of the full 22-item ZBI but also a more efficient measure of the overall caregiver burden; in addition, we recommend using a shorter version of the ZBI with only six items for rapid screening.

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Appendix. Proposed versions and standardized factor loadings of the Zarit Burden Interview in short versions

Unidimensional structure	4-item	4-item	6-item	7-item	8-item	12-item
Item # and descriptions	Bédard et al.	Gort et al.	Higginson et al.	Gort et al.	Arai et al.	Ballesteros et al.
	(2001)	(2005)	(2010)	(2010)	(2003)	(2012)
1 Asking for more help than needed						
2 Not enough time for myself	0.640	0.337	0.606	0.589		0.591
3 Stressed for caring & other	0.842		0.778	0.765		0.752
responsibilities						
4 Embarrassment over relative's					0.672	
behavior						
5 Angry		0.772			0.677	
6 Negative relationships			0.546	0.524	0.670	
7 Afraid about the future						
8 Relative's dependence on you						0.322
9 Strained by relative	0.353	0.535	0.344	0.340	0.467	0.332
10 Health decrease			0.685	0.708		0.650
11 Lack of privacy						0.702
12 Lack of social life					0.442	0.630
13 Feel uncomfortable having friends					0.235	
over						
14 Expecting to be cared by you		0.155				
15 Lack of money to pay for the						
expenses						
16 Unable to care much longer						0.353
17 Lost control of life			0.718	0.736		0.751
18 Leave the care to someone else					0.525	0.443
19 Uncertain about what to do	0.420				0.615	0.446
20 Should do more for my relative						
21 Could do a better job caring						
22 Overall feeling of burden				0.751		0.771

失智老人及其照顧者之長期照顧服務使用情形與不使用的原因

施姵宇 白明奇 古鯉榕

摘要

本研究分析失智症家庭使用長期照顧服務的情形,以及影響服務使用的因素, 並進一步探討家庭照顧者不使用長照服務的原因。收案對象為台南某醫學中心失 智症門診之病人及家庭照顧者共231組。結果顯示9%的樣本使用長照服務的比 率,遠低於使用看護工的35%,或未使用任何服務的56%。邏輯斯迴歸分析顯 示使用長照服務的照顧者所具備的長照知識顯著高於未使用者(OR=1.67,

CI=1.16-2.40),但病人特性包括認知功能、身體功能嚴重度則是使用看護工的顯著影響因子。由於91%的樣本未曾使用政府提供的長照服務,進一步分析不使用長照服務的原因,發現主因是不覺得患者有需要使用服務(41%)、其次是因已用看護工故無法申請其他長照服務(35%)。至於未曾使用家庭照顧者支持服務的主因,是照顧者缺少相關服務的資訊(56%)。建議政府除了提供為失智病人的長照服務之外,也應考慮到照顧者對於支持服務的需要,並加強對照顧者的宣導,才能在傳統雇用看護工的方式之外,提供多元的長照服務來滿足失智症全家照護的需求。

關鍵字:失智症、長期照顧、外籍看護工、服務使用

一、前言

國際失智症協會(ADI) 2013 年的報告針對失智症的長期照顧的研究顯示,全球各國 65 歲以上的失智症老年人口約有一半需要提供長期照顧,且照顧服務隨老年人年紀增長而增加(Prince, Prina, & Guerchet, 2013)。隨著照顧者負荷越重,其生理和心理健康也顯著較差(Buyck et al., 2011; Etters, Goodall, & Harrison, 2008; Mahoney, Regan, Katona, & Livingston, 2005)。高齡社會中失智症家庭照顧者扮演很重要的角色,同時也需要周圍的社會支持,來維持照顧者能長期投入照顧的工作(Prince et al., 2013),我國家庭照顧者也面臨相同的問題(呂, 2005;陳, 2013)。然而,在失智症漫長的病程中,因病人疾病特性不同,所需的照顧服務也不同,但其需求是否能獲得滿足卻無不疑問,因此需正視失智症照顧資源適時分配的重要性。本研究分析失智症家庭對長期照顧服務的使用情形,以及影響服務使用的因素;並探討在使用者遠低於不使用的情形下,哪些原因影響家庭照顧者服務使用的意願?

2013年1月台灣失智症協會調查統計,全台約計19萬失智症病人,其中機 構失智症病人僅3萬五千人,其他85%的病人在社區照顧,即由家人擔任主要照 顧者(湯、吳、李、洪,2013)。政府推動長照十年計畫歷年以來雖然累積服務個 案人數逐漸上升,據統計至 2015 年底累積服務人數超過 17 萬人,但 2008 年起 始將失智者納入計畫,因此失智症長照服務個案約1萬5千多人,僅占了所有長 照服務個案的 9.7%,顯示失智者病人的長照服務使用率仍遠低於失能人口(衛生 福利部,2016)。先前以全國長期照護需要評估來探討失智症病人社區長照服務 的研究顯示,病人有 39.8%曾使用過一項以上的正式服務,其中以雇用看護工的 比例最高(35%),居家護理為其次(6%),喘息服務使用最少(0.4%),可見進一步 探索為何看護工之外的長照資源無法在社區普及、或是長照服務是否無法符合失 智症家庭的需求是重要問題(陳,2005)。最近的研究顯示,家庭聘請外籍看護照 顧的比率隨著老人的年齡越高、意識狀況越差、失能程度越高而增加(黃、吳、 張、陳,2016),但對於失智症病人使用長照服務的影響因子的國內研究則相對 缺少,因此本文引用美國與新加坡相關的文獻來探討。美國的研究對 241 位失智 症的家庭照顧者進行調查,為瞭解社區式長照服務的使用情形,並將樣本分為三 組來比較使用者的差異:1. 使用照顧支持服務和喘息服務組、2. 僅使用喘息服 務組、3.每週使用服務時數少於2小時者或未使用者合併為一組(Robinson, Buckwalter, & Reed, 2013)。該研究中未使用的第三組人數比例為 46%, 略多於第 一組的 42%,而且有高達 79%的樣本未曾使用喘息服務。使用者比非使用者的

年齡較大、社會支持較少,但其照顧的病人不論在問題行為和疾病嚴重度上也比

較輕(Robinson et al., 2013)。而新加坡的統計反映其失智症病人使用長照服務比例也不高、僅 39.9%,研究並進一步將長照服務項目區分成為失智症病人的服務 (Services Targeted at PWD)和家庭照顧者支持服務(Services targeted at caregiver),並分別以失智症病人及照顧者特性探討使用長照服務的影響因素(Lim, Goh, Chionh, & Yap, 2012)。該研究顯示失智症病人的服務使用僅和長照資訊的可及性有關—知道者才能使用服務,而影響家庭照顧者支持服務的顯著因素有二:1. 照顧者是否有就業—未就業者使用服務的機率較高;2. 照顧者是否接收到長照的相關資訊,同樣也是知道者才會使用服務。

雖然過去研究發現家庭照顧者自覺需要協助,但多篇相關研究顯示使用正式支持的服務比例低,尤其在亞洲地區僅 24%的家庭照顧者使用正式支持服務,86%家庭照顧者表示依賴家庭其他成員協助照顧工作(Brodaty, Thomson, Thompson, & Fine, 2005; Mast, 2013; Torti, Gwyther, Reed, Friedman, & Schulman, 2004)。由於未使用任何長照服務的比例超過半數,新加坡的研究中 Lim 等人進一步對不使用失智症病人的服務的原因加以分析,歸納出最主要的原因有三:1.已雇用看護工,2.照顧者沒有意識到需要、即缺乏需求,3.病人拒絕;相較而言,照顧者不使用支持服務的原因則依序為:1.沒有時間使用,2.已自行獲得所需資訊,3.因全職照顧而無法參加(Lim et al., 2012)。文獻指出基於華人文化「盡孝道」的觀念,家庭照顧者較難接受正式支持,也不願加入情緒支持團體,顯示照顧者的態度會影響長照服務的使用(Torti et al., 2004),因此上述不使用的原因可進一步分類,將照顧者或病人主觀的因素歸納為需求面,將與長照服務內容有關的因素視為為供給面,以瞭解未來若想提升失智症家庭對於長照服務的利用率,應該從使用者端或服務提供者端著手。

二、材料與方法

(一)、研究對象

本研究收案期間自 2013 年 11 月至 2015 年 4 月,對象為失智症病人及家庭照顧者,共計 231 組病人及其照顧者(dyads)。收案地點為台南地區某醫學中心失智症特別門診,經醫院人體試驗委員會審核通過(IRB No: B-ER-102-173),收案條件如下:1.失智症病人:病人年齡為 65 歲以上,需由神經內科或精神科專科醫師確診為失智症,疾病亞型包括阿茲海默症 (Alzheimer's disease,簡稱 AD)、血管型失智症或混合型失智症,但排除住機構的病人。2.家庭照顧者:年齡為 18歲以上,與病人有親屬關係且持續提供照顧至少一年者,能以國語或台語接受訪談,自願參與本研究並完成簽立受試者研究同意書者。收案流程為在診間邀請符

合納入條件者加入研究,並在其簽署同意書後,與照顧者約定以電話進行問卷訪 談的時間。

(二)、研究工具

本研究參考過去文獻設計結構式的問卷進行調查,問卷內容包含失智症病人 及其照顧者的基本人口學特性、照顧關係、照顧時數與長照服務的使用情形等。 除以問卷蒐集照顧者的資料,也使用病人於醫院失智症中心的神經心理檢查的病 例資料;茲將病人及照顧者兩方的測量分別說明如下:

1. 失智症病人特性:包括患者的人口學特質和疾病特性,前者如年齡、性別、確診年數,疾病特性包含三個部分:認知功能、精神行為症狀以及日常生活功能。認知功能的測量工具包括簡短式智能評估(Mini Mental State Examination, MMSE)或臨床失智評量表 (Clinical Dementia Rating Scale, CDR),以病人最接近照顧者受訪日的檢查分數為準,若有 CDR 分數,認知功能嚴重度的定義是 1.0 為輕度,2.0 為中度,3.0 則為重度 (林、劉,2003)。若病人最接近受訪日的檢查分數為 MMSE 分數,則使用全民健保對於失智症藥品給付的標準(衛生福利部中央健康保險署,2016)來區分嚴重度,並對於教育程度不滿六年者,調整認知功能嚴重度的分組標準如下表:

表 1: 認知功能嚴重度的分組標準

認知功能嚴重度	輕度	中度	重度
教育程度 >=6 年以上	MMSE>=15	14>=MMSE>=1 0	MMSE<=9
教育程度 <6 年以下	MMSE>=12	11>= MMSE>=9	MMSE<=8

病人精神行為症狀的測量工具為神經精神量表(Neuropsychiatric Inventory,NPI-10)(Cummings et al., 1994),測量患者的 10 種神經精神症狀,施測對象為照顧者,需要評估患者症狀的嚴重度以及出現的頻率,將兩者相乘即可得到該分項的分數,本計畫使用的 10 題版本的 NPI 的總分最高為 120 分。身體功能的測量工具使用評估日常生活功能的巴氏量表(Simplified Barthel ADL Index),共有十項功能評估,包括七項為自我照顧能力及三項行動能力。計分方式最低 0 分,最高為 100 分(Mahoney, 1965)。分數越高代表患者獨立執行日常活動的情形越好。

2. 家庭照顧者特性包含其年齡、性別、居住地區、工作與否、婚姻狀況以及經濟狀況,評量個人的長照知識是依據照顧者回答「現在政府有提供很多長期

照顧的資源,請問您知道的有哪些?」,計算照顧者對於(1)社區照顧關懷據點 (2)居家護理 (3)居家服務 (4)日間照顧 (5)喘息服務 (6)家庭托顧共六項服務所知道的項數。研究變項中與照顧關係有關的還包括與病人的親屬關係、與病人同住與否、病人子女數、每週照顧時數。

3. 長照服務使用:針對長照管理中心提供的正式服務項目,由問卷調查逐一詢問照顧者是否有為病人申請包括居家護理、居家服務、家庭托顧、日間照顧、喘息服務任一項目,另外並問家中是否為患者聘有看護工,另外也調查家庭照顧者是否曾使用過由民間團體提供的照顧者支持服務,例如社團法人熱蘭遮失智症協會,近年持續為台南的失智症照顧者提供家屬情緒支持團體和照護技巧等課程。除了調查長照服務的使用情形,本研究亦以複選方式詢問照顧者不使用服務的原因,並將照顧者或病人主觀的因素歸納為需求面原因,而將與長照服務內容有關的因素作為供給面的原因,分類如下:(1)需求面原因:照顧者沒有時間使用、照顧者不覺得需要、患者拒絕、已使用看護工、經濟考量。(2)供給面原因:服務項目不適合、缺乏服務相關資訊、交通不便。

(三)、資料分析

本研究以SAS 9.3 版統計軟體進行資料分析,首先進行描述性統計分析,比較失智症病人特質和主要照顧者特質對長期照顧服務的使用是否具有顯著差異,對於類別變項利用卡方檢定、連續變項則以無母數的 Kruskal-Wallis 檢定來比較使用長照服務、看護工或不使用服務的三群人在哪些樣本特性上有差異。由於本研究將長照服務使用的類型分為三種,進一步以多元邏輯斯迴歸分析(multinomial logistic model),將單變項分析中具統計顯著性的樣本特性放入多變項的迴歸模型,以瞭解在同時考慮失智者的疾病特性與照顧者特性之下,何者為和長照服務使用類型相關的獨立影響因素。然而考量多數的樣本未使用長照服務,故針對未使用任一項長照服務者和任一項照顧者服務者,分別再以描述性分析探討不使用的原因為何。

三、結果

表 2 呈現樣本依照長照服務使用/未使用的情形分為三組後、各組的樣本特性,使用任一長照服務者人數最少,雇用看護工組居次,但未使用任何付費服務的一組人數最多。使用長照服務的 21 人中,使用率最普遍的服務項目是居家服

務(71%),其次依序是日間照顧和喘息服務。使用政府提供的長照服務的失智症病人多為女性、認知功能嚴重度為中度、ADL 平均分數為 70.5 分,確診平均年數將近 5 年,而使用看護工的病人平均年齡最高,為 82.9 歲,女性超過 7 成,其認知嚴重度為重度的比例較高,且 ADL 平均分為 46.1 分,屬於 60 分以下的重度失能族群(衛生福利部社會及家庭署,2016),病人平均確診年數也比使用長照服務組多一年。與上述兩組使用者相比,未使用服務一組病人的年齡顯著較低(78 歲)、女性的比例占 5 成較低,而且不論是認知或身體功能都較好,確診的病史較短。除了上述失智者病人特性的差異,使用長照服務與否的三個族群在照顧者特性上也有顯著差異,例如使用服務的照顧者其長照知識較未使用者高,且配偶照顧者比起子女或其他身分的照顧者,使用長照服務的比例較低。至於每週投入的照顧時數也有顯著組間差異,以未使用者每週平均照顧 24.7 小時最高,其次為使用長照者的 20.9 小時,最低的則是聘有看護工一組的 16.5 小時。

表3呈現以多元邏輯斯迴歸模型分析失智症患者與照顧者的特性與長照服務使用兩者間的關係,結果顯示與使用長照服務相關的因素僅有長照知識,即照顧者對於各項長照服務越熟悉者,使用服務的勝算比顯著高於不使用任何服務,但病人特性則與長照服務的勝算比無關;反觀病人特性卻與使用看護工顯著相關,包括認知功能嚴重度越重、身體功能(ADL)越差和確診年數越長者,使用看護工的勝算比皆高於不使用任何服務,但每週照顧時數越多者使用看護工的勝算比則較低。

圖1顯示失智症家庭不使用長期照顧服務的原因,因為是複選題所以合計超過100%,在將照顧者或病人主觀的原因歸納為需求面,與長照服務內容有關的原因作為供給面的分類之下,需求面的原因明顯比供給面的原因所占的百分比高,例如排名第一的是有40.5%的照顧者不覺得患者有需要使用長照服務、其次是因已用看護工故無法申請其他長照管理中心提供的正式服務,接下的兩個原因才跟服務供給面相關:各有13.3%的照顧者表示服務項目不適合患者或照顧者缺乏與服務相關的資訊,即不知道可以申請使用。也有11%的情形是因為患者拒絕而未使用長照服務。

相較於 91%(N=210)的樣本未曾使用政府提供的五項長照服務中的任一項, 未曾使用民間團體提供照顧者服務者更多達 97%(N=224),圖二分析這群人不使 用照顧者服務的原因,發現和長照服務不使用的原因大不相同,因為排名第一的 是 56.3%的照顧者表示他們缺少相關服務的資訊,其次才是需求面相關的因素, 包括照顧者沒有時間使用服務(22.8%)、或不覺得需要該服務(13%)。

四、討論與結論

(一)、討論

雖然長照十年計畫自 2008 年納入失智症病人已經過多年,而且在 2010 年縣市合併之後,大台南地區有台南市政府照顧服務管理中心作為提供長照服務的單一窗口,但本次調查中的失智症家庭,在 2013-2015 年間使用長照服務的比率僅占總樣本數的 9%,遠低於使用看護工的 35%或未使用任何付費照顧的 56%。雖然研究樣本來自單一醫院失智症門診的立意取樣,但考量國內近年來並無其他失智症病人長照使用率的相關數據,仍然可反映台南的失智症病人在資源利用上的不足。比較使用或不使用長照服務的樣本特性,顯示使用服務與否的組間差異經常反映在病人特性的不同,而且跟過去的研究的結果相似,本研究也發現使用看護工的病人不論在平均年齡、確診年數、認知功能嚴重度和 ADL 失能程度都是最高的一組(黃、吳、張、陳,2016)。相對而言,未使用服務一組的病人在認知或身體功能都較好,也和未使用美國的社區式長照服務的病人是研究族群中的相對健康者的結論一致(Robinson et al., 2013)。

在照顧者特性部分,使用者和非使用者在長照知識和與病人關係這兩個因素上的顯著差異,皆回應先前文獻的發現。例如使用服務的照顧者所具備的長照知識顯著高於未使用者,和新加坡的研究發現不論是失智症病人或照顧者的支持服務,照顧者對於各項長照服務的知識是最重要的影響因素相同(Lim et al., 2012),畢竟使用服務的先決條件是服務對象有機會取得服務。身份為子女的照顧者其年齡既然小於配偶照顧者,使用電子媒體的經驗較多,能掌握長照相關資訊並且加以利用的機會也較高,因此不論在本研究或是美國 Robinson 等人的研究,都發現高齡或配偶照顧者較少使用長照服務(Robinson et al., 2013)。至於家庭照顧時期以未使用長照服務的一組為最高、使用看護工的一組最低,則反應出未使用長照服務的照顧者可能仍需他人協助來分擔照顧責任,由於過去研究也發現提供較多照顧時間的家庭照顧者負荷較高(Kim, Chang, Rose, & Kim, 2012),建議未來研究進一步探討其未使用服務背後的原因為何。

由於上述使用者特性的組間差異是單變項分析的結果,本研究以多元邏輯斯 迴歸同時納入失智症病人與家庭照顧者的特性來探討與長照服務使用類型相關 的獨立影響因素,發現在控制病人疾病嚴重度等因素後,僅長照知識是服務使用 與否的影響因子,這個結果和新加坡 Lim 等人的結果一致,也反映出即便病人 可能出現嚴重的精神行為症狀或者照顧者有意願購買長照服務,但若缺少關於相 關長照資源的訊息,仍然沒有管道取得服務或減輕家庭照顧者的負擔。至於使用 看護工的獨立影響因子也和文獻的結果相同(吳、陳,2014;黃、吳、張、陳, 2016),即失智症家庭雇用外籍看護工主要為了照顧認知退化、身體功能差或久 病多時的病人,而且由於看護工被期待提供「24小時一對一」的照顧,所以家 庭照顧者投入的時數反而和看護工的雇用呈現負相關。

由於本研究不論長照服務或照顧者服務的使用比率皆低於一成,特別針對逾 九成未使用服務者加以分析其不使用的原因,而且參考新加坡 Lim 等人研究的 歸因方式,比較後發現台南和新加坡兩地的照顧者在不使用長照服務的原因高度 相似:即台南的失智症照顧者不覺得有長照服務的需要居首,已用看護工而無法 申請其他長照服務為居次,剛好跟新加坡調查的第一、第二名原因的順序對調, 顯示兩地的失智症照顧者都優先考慮使用看護工,而不覺得對於政府提供的各項 長照服務有所需求。至於兩地在照顧者不使用支持服務的原因的排序上則有很大 差異,僅台南的第二名原因「沒有時間使用」和新加坡排名居首的原因相同,但 台南排名第一的原因是缺少相關服務的資訊,在新加坡的調查的排序中並未出現 在前三名,反而是有多數新國的照顧者表示因為已自行獲得所需資訊,而不使用 特定的照顧者支持團體或教育課程。既然台南有高達 56% 受訪的照顧者表示缺乏 相關資訊,同時僅有逾一成的照顧者表示不覺得需要該服務,可見多數的受訪者 其實有支持服務的需求,只是沒有機會獲得必要的資訊,建議未來政府和民間團 體可以合作加強對民眾的宣導,增加家屬情緒支持團體和家屬照護技巧等課程的 使用率。此外,考量照顧者因擔心不能讓失智症病人單獨在家而無法外出使用照 顧者支持服務,若要能同時滿足照顧者和病人雙重的需求,結合多組家屬與失智 者全程陪伴參與的瑞智互助家庭也是未來值得推廣的長照服務模式(湯、吳、李、 洪,2013)。

(二)、結論

政府自推動長照十年計畫以來雖然服務人數逐漸上升,始終以失能老人為主要對象,失智者的長照服務使用率仍遠低於失能人口。本研究樣本雖僅來自台南單一間醫院的社區失智症病人,不具全國的樣本代表性,仍提供過去少見的資訊,探討南台灣的長照服務使用率偏低的現況。長照十年計畫中排除已使用看護工使用其他服務的資格,固然是造成使用率偏低的重要因素,但本研究也發現照顧者個人的長照知識多寡是服務使用與否獨立的影響因子—使用服務的先決條件是服務對象知道有該服務的存在。至於大多數的未使用服務者之所以認為沒有需要,可能筆因於不清楚長照服務的內容。因此本研究的主要發現,凸顯出對於失智症家庭,政府除了提供為病人的長照服務之外,也該考慮到照顧者對於支持服務的需要,而且應該從服務的宣導做起,先讓照顧者能接收到由政府和民間社團提供

的各項服務的資訊,才能在傳統雇用看護工的方式之外,建立更多元的長照服務模式來滿足失智症全家照護的需求。

表 2 使用/未使用長照服務的失智者病人特性與照顧者特性

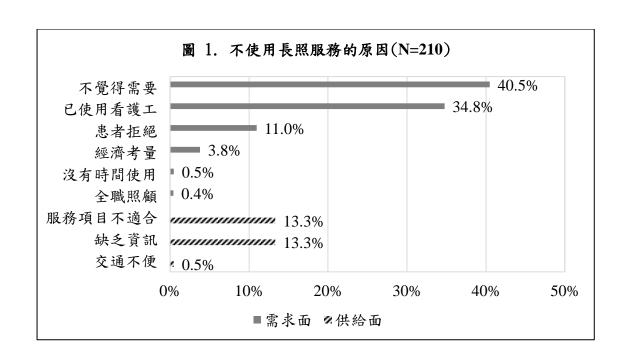
		使用長	照服務	使)	用看護工	未使用	(N=129)	
相關變項		(N=	=21)		(N=81)			P值
10 1991 文·只		平均數 (%)	標準差	平均數 (%)	標準差	平均數 (%)	標準差	1 (E.
失智者病人特	寺性							
年龄		81.05	6.34	82.93	5.79	78.00	6.89	<0.01**
女性		66.67%		72.84%		50.39%		<0.01**
認知功能	輕度	33.33%		18.52%		62.02%		<0.01**
	中度	47.62%		49.38%		29.46%		
	重度	19.05%		32.10%		8.53%		
NPI		27.52	24.04	19.23	20.42	15.75	17.23	0.08
ADL		70.48	31.66	46.91	32.77	82.79	26.09	<0.01**
病人確診。	年數	4.71	3.20	5.91	3.86	3.72	2.59	<0.01**
照顧者特性								
年龄		61.71	11.44	63.80	12.92	62.81	13.62	0.74
女性		23.81%		45.68%		33.33%		0.09
居住地區	原台南市	47.62%		53.09%		58.14%		0.38
	原台南縣	33.33%		35.80%		24.03%		
	其他地區	19.05%		11.11%		17.83%		
工作與否	有工作	42.86%		49.38%		37.21%		0.22
婚姻關係	已婚	71.43%		85.19%		82.17%		0.12
	未婚	28.57%		9.88%		16.28%		
	離婚/分居	0.00%		4.94%		1.55%		
經濟狀況	有困難	19.05%		24.69%		18.60%		0.14
	夠用	57.14%		67.90%		62.02%		
	充裕	23.81%		7.41%		19.38%		
長照知識		3.48	1.50	2.49	1.56	2.36	1.50	0.01*
與病人關	子女/其他	76.19%		71.60%		54.26%		0.02*
係								0.0 2
	配偶	23.81%		28.40%		45.74%		
與病人同位		66.67%		71.60%		79.84%		0.24
每週照顧日	寺數	20.93	15.95	16.48	15.34	24.69	15.22	<0.01**

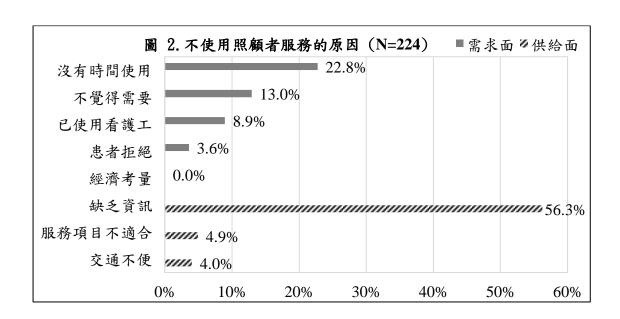
^{*}p<0.05 **p<0.01

表 3. 長照服務使用類型的多元邏輯斯迴歸模型(N=231)

	使用長照	服務(N=21)	使用看護	使用看護工(N=81)		
解釋變項	勝算比	95% 信賴	勝算比	95% 信賴		
		區間		區間		
失智者病人特性						
女性	1.19	(0.38-3.77)	1.72	(0.73-4.05)		
認知功能(輕度)						
中度	3.23	(1.00-10.38)	5.24**	(2.15-12.77)		
重度	2.39	(0.45-12.56)	5.51**	(1.64-18.44)		
NPI	1.02	(0.98-1.05)	1.00	(0.98-1.03)		
ADL	0.99	(0.97-1.01)	0.96**	(0.95-0.98)		
確診年數	1.16	(0.98-1.37)	1.22**	(1.07-1.38)		
照顧者特性						
與病人關係	1.02	(0.28-3.77)	1.57	(0.63-3.88)		
長照知識	1.67**	(1.16-2.40)	1.19	(0.92-1.54)		
每週照顧時數	0.97	(0.94-1.00)	0.94**	(0.91 - 0.96)		

^{*}p<0.05 **p<0.01





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