

Effectiveness of a stress-relief initiative for primary caregivers of adolescents with intellectual disability

JUNG HU¹, JIN-DING LIN¹, CHIA-FENG YEN², CHING-HUI LOH³, SHANG-WEI HSU⁴, LAN-PING LIN⁵ & SHENG-RU WU⁶

¹School of Public Health, National Defense Medical Center, Taipei, Taiwan, ²Department of Social Welfare, National Chung Cheng University, Chiayi County, Taiwan, ³Department of Community and Family Medicine, Tri-Service General Hospital, Taipei, Taiwan, ⁴Graduate Institute of Healthcare Administration, Asia University, Taichung County, Taiwan, ⁵Graduate Institute of Life Sciences, National Defense Medical Center, Taipei, Taiwan, and ⁶National Taichung Special Education School, Taichung City, Taiwan

Abstract

Background This study provides a perspective on the mental health status and analyses the effectiveness of a stress-relief program for primary caregivers of adolescents with intellectual disability (ID).

Method Seventy-seven primary caregivers of people with ID were recruited (intervention group, $n = 31$; non-intervention group, $n = 46$) to the study, which involved participation in one stress management workshop (intervention group only) and both groups reading an education booklet on stress management.

Results We found that 22.1% of caregivers in the study were at high risk of depressive stress and in need of mental health consultation; this prevalence was nearly six times that of the general population. The effectiveness of mental health initiatives resulted in a significant reduction in depressive stress for the intervention group.

Conclusions The study highlights that a “face-to-face” workshop is an effective way to decrease levels of depressive stress.

Keywords: caregiver, depression, intellectual disability, mental health, Taiwanese Depression Questionnaire (TDQ)

Introduction

In Taiwan, the national report results revealed that from 2002 to 2007 the prevalence of disabilities increased from 3.69% to 4.45% (an overall increase of 22.8%) of the population. The number of disability institutions also increased from 223 to 254 (12.2%) during this time (Yen, Lin, Wu, & Kang, 2009). Among the disabilities reported, the registered number of people with intellectual disability (ID) increased from 71,012 to 91,004, even though the general population of Taiwan increased only slightly from 22,276,672 to 22,958,360 in the 2000–2007 period. The increase rate in the population with ID was thus 13.67 times that of the general population (ID = 28.15%, general population = 2.06%), and the prevalence of ID increased from 0.318% to 0.396% in this period. The increase in the number of people with ID was particularly significant for school-age children and young adults (Lin,

2009). With regard to the causes of ID, the data illustrated a decrease in the percentage of congenital ID and an increase in disease-caused ID in the previous decade (Lin, Yen, Wu, & Kang, 2009). There are many reasons to explain this increase of demographic changes in people with disability in Taiwan. First, improved medical care has increased the possibility of disability diagnosis. Second, the positive change in society's attitude towards people with disability has encouraged parents to publicly acknowledge having children with disability. Third, individuals diagnosed with dementia or chronic psychosis have added to the numbers of those with disability in recent years (Lin, Wu, & Yen, 2004).

Individuals with ID form one of the most vulnerable sectors of the population. People with ID are more likely to have poor health status, require more medical resources, and experience greater difficulty with healthcare accessibility than the general population (Lin et al., 2006; Lin et al.,

Correspondence: Professor Jin-Ding Lin, PhD, School of Public Health, National Defense Medical Center, Taipei, Taiwan, No. 161, Min-Chun E. Rd., Sec. 6, Taipei, Taiwan. E-mail: jack.lin1964@gmail.com

2007a; Lin et al., 2007b; Lin, Wu, & Lee, 2003; Lin, Wu, & Lee, 2004; Lin, Yen, Li, & Wu, 2005). Approximately 12% of people with ID in Taiwan have psychiatric disorders; namely, attention deficit/hyperactivity disorder, adjustment disorders, anxiety disorders, bipolar disorder, conduct disorder, depression, oppositional-defiant disorder, personality disorder, and psychoses. These individuals are likely to be in poorer health and place greater demands on medical services than individuals with ID without psychiatric disorders (Lin et al., 2005). These disorders have serious consequences for the individuals, their families and carers, and the community as a whole (Einfeld, 1996), and their caregivers tend to experience a high prevalence of depression, burden, and psychological distress (Olsson & Hwang, 2001). Plant and Sanders' (2007) analyses demonstrated that the difficulty parents experienced in completing specific caring tasks, behaviour problems exhibited by their child during these caregiving tasks, and level of the child's disability, were all significant predictors of parental stress levels.

McCarthy, Cuskelly, van Kraayenoord, and Cohen (2006) examined parental and family stress and functioning in families where there is a child with fragile-X syndrome. The researchers identified that the strongest predictor of maternal stress was the level of marital satisfaction, while the strongest predictor of paternal stress was the level of the child's adaptive skills. Neece and Baker (2008) reported similar findings, and noted that when examining parental stress, child social skills are an important variable to consider, especially in the context of a child with behaviour problems. Hassall, Rose, and McDonald (2005) indicated that most of the variance in parenting stress could be explained by the parental locus of control, parenting satisfaction, and any child behaviour difficulties. Although there was also a strong correlation between family support and parenting stress, stress was mediated by the parental locus of control.

Given that caregiver stress is clearly an important issue in the provision of services for people with ID, there are many existing measures for examining caregiver perceived stressors in services for people with ID (Devereux, Hastings, Noone, Firth, & Totsika, 2009; Folkman & Lazarus, 1985; Guralnick, Hammond, Neville, & Connor, 2008; Hatton & Emerson, 1995; Hatton et al., 1999; Lin et al., 2009; Lee et al., 2009; Nachshen, Woodford, & Minnes, 2003; Rose, 1999; Saloviita, Itälänne, & Leinonen, 2003). The stress experienced by family caregivers who raise children with ID is affected by many factors such as the child's conditions (levels of disability and of maladaptive behaviour) and

available family resources or social support (Abbeduto et al., 2004; Baker et al., 2003; Beck, Hastings, & Daley, 2004; Ben-Zur, Duvdevany, & Lury, 2005; Hodapp, Ricci, Ly, & Fidler, 2003). However, there are few initiatives in place that focus on stress-relief programs to improve the quality of life of the caregivers of people with ID. The aims of the present study were to examine the levels of stress experienced by caregivers of people with ID using the Taiwanese Depression Questionnaire (TDQ), and to evaluate the effectiveness of a stress-relief initiative currently in use in Taiwan.

Methods

The stress-relief program offers a variety of opportunities for caregivers to explore stress management strategies and relaxation techniques that may meet their individual needs. The goal of the program is to help caregivers remain comfortable and confident in dealing with daily stress, particularly in coping with the demands of caring for people with ID. The stress-relief initiative of the present study included a 2-hour stress management workshop and participants were provided with a booklet on stress relief. The workshop was led by a senior psychiatrist who provided lecture information and facilitated face-to-face discussion. The purpose of the workshop was to identify the cause and symptoms of stress for caregivers. The workshop also focused on stress management tips and techniques, such as rational and positive thinking, physical relaxation techniques, emotional management, and the use of social support systems. The stress-relief booklet provided a range of health information handouts addressing stress management and wellness, which included a definition of stress, stress management tips, information on behavioural problems of children with ID and respite care, and an introduction to social support resources. We recruited 77 primary caregivers of people with ID (intervention group, $n = 31$; non-intervention group, $n = 46$) to participate in the study. The intervention group participated in workshops conducted in 3 different locations (Taipei County, Taichung City, and Yuling County) and studied the stress-relief booklet, whereas the non-intervention group studied only the stress-relief booklet.

The study employed the TDQ to measure the depressive stress levels of primary caregivers of adolescents with ID. The TDQ is a 4-point scale with 18 items and has a satisfactory sensitivity of 0.89 and a specificity of 0.92. Lee, Yang, Lai, Chiu, and Chau (2000) and Lee et al. (2008) reported that the validity of the TDQ was superior to the Beck

Depression Inventory (BDI) in detecting depression in individuals in Taiwan. Therefore, TDQ is a culturally specific self-rating instrument for the effective detection of depression in Taiwanese people. Participants are guided to self-rate each item on a scale from 0 to 3 on the basis of "how often you felt the physical and emotional aspects during the past week." TDQ scores range from 0 to 54, with a cut-off point above 19 indicative of depressive states. A score of less than 8 indicates a lack of depressive stress, 9–14 is moody or unhappy, 15–18 indicates mildly depressive stress, 19–28 signifies moderately depressive stress, and higher than 28 denotes severely depressive stress and a need for medical consultation for this (Lee et al., 2000; Lee et al., 2008). The definition of depressive stress in the study was the presence of physical and emotional symptoms associated with depressive symptomatology or stressful circumstances. The authors received approval from the John Tung Foundation to use the TDQ in this study.

Results

Table 1 shows the characteristics of the caregivers of adolescents with ID in the sample. There were no statistically significant differences between the intervention and non-intervention groups in terms of the relationship to the individual with ID being cared for. Differences in age, household income, or employment history of the caregivers were also not significant. We used number, percent, mean, and standard deviation (*SD*) to describe the level of depressive stress reported by the caregivers of adolescents with ID based on the TDQ scale (Table 2). In the TDQ's 4-point scale (0–3 score) with 18 items, a score of 0 is given if the caregiver felt

the physical and emotional symptoms of stress less than 1 day per week, a score of 1 if the feelings were present 1 to 2 days per week, a score of 2 if the feelings were present 3 to 4 days per week, and a score of 3 if the feelings were present 5 to 7 days per week. The mean distribution of scores for each aspect was 0.3–1.06 (*SD* = 0.66–0.94).

Table 3 shows that the mean \pm *SD* of the total TDQ score of the caregivers was 12.51 ± 11.10 , which is significantly higher than in the general population (3.26 ± 5.92) ($p < .001$). Based on a comparative analysis, the data indicate that 22.1% of caregivers of adolescents of ID were in the high-risk group for depressive stress and in need of medical consultation regarding their mental health (TDQ score ≥ 19); the prevalence of depressive stress for the high-risk group was nearly six times higher than that of the Taiwan general population (3.7%) (Yen et al., 2005). The self-rated prevalence of depressive stress of the caregivers was significantly higher than that of the general population ($p < .001$).

Table 4 shows a comparison of the TDQ score distribution between the intervention and non-intervention groups. Prior to the introduction of a mental health workshop, results of the TDQ test showed that 22.6% of intervention group caregivers and 21.7% of non-intervention group caregivers were in need of professional help for their depressive stress status (TDQ ≥ 19). Forty-two percent of the intervention group and 50% of non-intervention group participants had scores indicating that they were free from depressive stress. In the test carried out following completion of the stress management program, 12.9% of caregivers in the intervention group and 30.4% of caregivers in the non-intervention group still had a TDQ score higher than 19 indicating that they were still under depressive stress.

Table 1. Personal characteristics of the caregivers of adolescents with ID

Variable	Intervention (<i>n</i> = 31)	Non-intervention (<i>n</i> = 46)	Statistics
	<i>n</i> (%)	<i>n</i> (%)	
Relation to individual with ID			$\chi^2 = 0.814$ ($p = .666$)
Father	8 (25.8)	11 (21.2)	
Mother	23 (74.2)	39 (75.0)	
Other	0 (0)	2 (3.8)	
Age (Mean \pm <i>SD</i>)	47.60 \pm 6.71	46.61 \pm 7.52	$t = 0.578$ ($p < .565$)
Marital status			$\chi^2 = 4.291$ ($p = .117$)
Married	26 (83.9)	42 (91.3)	
Divorced/widowed	5 (16.1)	4 (8.7)	
Household monthly income (New Taiwan dollars)			$\chi^2 = 2.207$ ($p = .531$)
$\leq 20,000$	15 (48.4)	16 (34.8)	
20,001–40,000	8 (25.8)	15 (32.6)	
40,001–80,000	5 (16.1)	12 (26.1)	
$\geq 80,001$	3 (9.7)	3 (6.5)	

Table 2. TDQ score distribution among the caregivers of adolescents with ID

TDQ items	0 (less than 1 day per week)	1 (1 to 2 days per week)	2 (3 to 4 days per week)	3 (5 to 7 days per week)	Mean	SD
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		
1. I often felt like crying.	50 (64.9)	22 (28.6)	3 (3.9)	2 (2.6)	0.44	0.70
2. I felt blue and depressed.	26 (33.8)	43 (55.8)	7 (9.1)	1 (1.3)	0.78	0.66
3. I felt more agitated than before.	38 (49.4)	26 (33.8)	9 (11.7)	4 (5.2)	0.73	0.87
4. I had trouble sleeping.	31 (40.3)	28 (36.4)	13 (16.9)	5 (6.5)	0.90	0.91
5. I had a poor appetite.	59 (76.6)	13 (16.9)	5 (6.5)	0 (0)	0.30	0.59
6. I frequently had chest tightness.	40 (51.9)	25 (32.5)	7 (9.1)	5 (6.5)	0.70	0.89
7. I felt uneasy, uncomfortable.	30 (39.0)	34 (44.2)	10 (13.0)	3 (3.9)	0.82	0.81
8. I felt tired and weak.	30 (39.0)	34 (44.2)	8 (10.4)	5 (6.5)	0.84	0.86
9. I felt upset.	24 (31.2)	40 (51.9)	8 (10.4)	5 (6.5)	0.92	0.82
10. I had poor memory.	21 (27.3)	37 (48.1)	12 (15.6)	7 (9.1)	1.06	0.89
11. I could not concentrate when doing things.	35 (45.5)	32 (41.6)	5 (6.5)	5 (6.5)	0.74	0.85
12. I was slower in thinking and doing things than before.	35 (45.5)	29 (37.7)	9 (11.7)	4 (5.2)	0.77	0.86
13. I felt less confident than before.	39 (50.6)	25 (32.5)	8 (10.4)	5 (6.5)	0.73	0.89
14. I tended to look at the dark side of everything.	37 (48.1)	25 (32.5)	9 (11.7)	6 (7.8)	0.79	0.94
15. I felt miserable and even wanted to die.	60 (77.9)	13 (16.9)	1 (1.3)	3 (3.9)	0.31	0.69
16. I lost interest in everything.	52 (67.5)	18 (23.5)	2 (2.6)	5 (6.5)	0.48	0.84
17. I felt sick (headache, dizziness, palpitation, or abdominal distress).	37 (48.1)	30 (39.0)	5 (6.5)	5 (6.5)	0.71	0.86
18. I felt worthless.	55 (71.4)	14 (18.2)	1 (1.3)	7 (9.1)	0.48	0.91

Table 3. TDQ comparison between the general population and caregivers of adolescents with ID

TDQ score	Taiwan general population (<i>N</i> = 1487) ^a	Caregivers in the present study (<i>N</i> = 77)	Statistics
	<i>n</i> (%)	<i>n</i> (%)	
<19	1432 (96.3)	60 (77.9)	$\chi^2 = 56.311$ (<i>p</i> < .001)
≥19	55 (3.7)	17 (22.1)	
Mean ± SD	3.26 ± 5.92	12.51 ± 11.10	<i>t</i> = -7.259 (<i>p</i> < .001)

Note. ^aYen et al. (2005).

In relation to the prevalence of a lack of depressive stress (TDQ < 8 scores) among participants, the intervention group numbers increased from 41.9% to 64.5% and the non-intervention group numbers decreased from 50% to 47.8%.

A paired *t*-test was used to compare the effectiveness of mental health initiatives between the intervention and non-intervention groups that aimed to improve the depressive stress status of caregivers of adolescents with ID. Table 5 shows that the initiatives (workshop and stress-relief booklet) had a significant impact on the intervention group (*p* = .040), but in the non-intervention group (stress-relief booklet alone) there was no difference (*p* = .387). For the intervention group, the mean score of the TDQ test was 13.2 ± 11.3 prior to implementation of the help initiatives and 9.4 ± 9.0 after their

completion. For the non-intervention group, the TDQ score increased from 12.0 ± 11.1 prior to the help initiative to 13.3 ± 12.5 after its implementation.

Discussion

The aims of the present study were to provide an overview of the mental health status (evidence of depressive stress) and effectiveness of mental health initiatives for primary caregivers of adolescents with ID. To our knowledge, this study was the first in Taiwan to explore the stress profile of caregivers for people with ID using the TDQ instrument. The results demonstrated that 22.1% of caregivers were in the high-risk group for depressive stress and were in need of mental health consultation (TDQ score ≥ 19). These results are similar to those of a previous cross-sectional survey in which we compared the Taiwan national norms of SF-36 (Lin et al., 2009). In that study we found that 1,243 staff working with people with ID had significantly lower physical and mental component scores than the general population. Thus, carers of people with ID may experience higher levels of stress and depression than those in the general population.

Mental health management initiatives are vital health strategies for improving the quality of care and the well-being of caregivers of people with ID. Our study found that a “face-to-face” professional

Table 4. TDQ score between the intervention and non-intervention groups

TDQ score	Intervention (<i>n</i> = 31)		Non-intervention (<i>n</i> = 46)	
	Pretest <i>n</i> (%)	Posttest <i>n</i> (%)	Pretest <i>n</i> (%)	Posttest <i>n</i> (%)
<8 (Lack of depressive stress)	13 (41.9)	20 (64.5)	23 (50.0)	22 (47.8)
9–14 (Moody, unhappy)	5 (16.1)	4 (12.9)	8 (17.4)	7 (15.2)
15–18 (Mild depressive stress)	6 (19.4)	3 (9.7)	5 (10.9)	3 (6.5)
19–28 (Moderate depressive stress)	5 (16.1)	3 (9.7)	7 (15.2)	8 (17.4)
>28 score (Severe depressive stress)	2 (6.5)	1 (3.2)	3 (6.5)	6 (13.0)

Table 5. Paired *t*-test of TDQ score between the intervention and non-intervention groups

Depression scale	Intervention (<i>n</i> = 31)			Non-intervention (<i>n</i> = 46)		
	Pretest	Posttest	Statistics	Pretest	Posttest	Statistics
Mean ± <i>SD</i>	13.2 ± 11.3	9.4 ± 9.0	Paired <i>t</i> = -2.144 (<i>p</i> = .040)	12.0 ± 11.1	13.3 ± 12.5	Paired <i>t</i> = 0.873 (<i>p</i> = .387)

workshop in mental health intervention significantly decreases depressive stress as measured by the TDQ test. Such workshops provide opportunities for participants to discuss issues pertaining to stress, time management, self-esteem, and assertiveness in relation to the provision of care to adolescents with ID. The mental health intervention of a psychiatrist at the workshop in addition to access to an educational booklet was more effective than the educational booklet alone. For the non-intervention group, although the TDQ score increased from 12.0 to 13.3, this was not statistically significant, and further analysis is required to explore why the score for depressive stress increased. Our results suggest that further mental health initiatives for caregivers should take into account their mental health status and provide services based on their identified needs.

To relieve the stress experienced by caregivers of people with ID, it is important to consider optimal use of respite care and psychosocial intervention to encourage positive appraisal and problem-solving for the caregivers (Lam, Giles, & Lavander, 2003). Duvdevany and Abboud (2003) noted that the higher the amount of the informal support resources available to mothers of children with ID in Saudi Arabia, the lower the level of stress and the higher the sense of well-being they experienced. Guralnick et al. (2008) conducted a longitudinal study of 63 mothers, for which the results of multiple regression analyses revealed that parenting support during the early childhood period, irrespective of source, consistently predicted most dimensions of parental stress assessed during the early elementary years and contributed uniquely to the variance of outcomes. General support from various sources had other, less widespread effects on parental stress.

Reinforcement of positive thinking in a mental health workshop is an effective way to relieve the stress of the caregivers of people with ID. Positive thinking tips and techniques included interaction among participants, breathing exercises, visualisation, and scheduling activities for time management. Devereux et al. (2009) also found this relationship between positive thinking and stress relief in a cross-sectional regression analysis they conducted of 96 staff members from a UK National Health Service residential hospital site and a small community-based unit for adults with ID. In that study, the data revealed a relationship between work demands and emotional exhaustion burnout that was reduced when positive coping strategies were introduced as a predictor. To improve the level of effective mental health management for caregivers of people with ID, health authorities need to develop awareness, understanding, and education relating to the experiences of caregivers in their work settings, so that these caregivers can gain access to resources and maintain good mental health while caring for people with ID.

The limitations to be considered in interpreting the findings presented in this study are, first, that the TDQ scale may be too generic to focus on the specific stress-health issues that can be reduced by earlier intervention from the public health system. Second, the ongoing effectiveness of both interventions is unknown, as the study did not conduct any follow-up beyond a posttest. The third limitation is the possibility that demographic, family, and social factors can influence caregivers' depressive stress, but these factors were not controlled in the present study. A future study could give consideration to the multidimensional aspects of caregivers' depressive stress.

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