

The Effect of Support Group on the Burden and the Quality of Life of Primary Family Caregivers of Elderly with Dementia

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INFOGRAPHIC

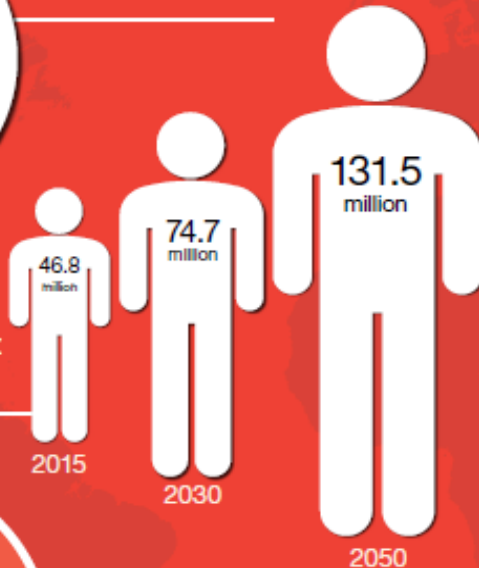
The global impact of dementia



Around the world, there will be 9.9 million new cases of dementia in 2015, one every 3 seconds

46.8 million people worldwide are living with dementia in 2015.

This number will almost double every 20 years.



Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.

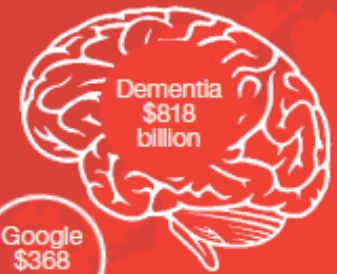


The total estimated worldwide cost of dementia in 2015 is US\$ 818 billion. By 2018, dementia will become a trillion dollar disease, rising to US\$ 2 trillion by 2030

If global dementia care were a country, it would be the

18th largest economy

in the world exceeding the market values of companies such as Apple and Google



(source: Forbes 2015 ranking)

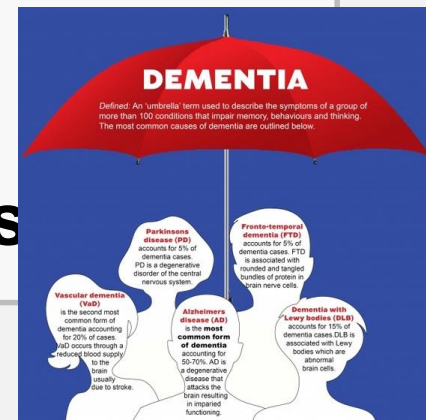


This map shows the estimated number of people living with dementia in each world region in 2015.

We must now involve more countries and regions in the global action on dementia.

Prevalence of Dementia in Taiwan

- Overall prevalence of dementia 8.9%
 - The age-adjusted (aged 65 years or older) prevalence of all-cause dementia was 8.04% (95% CI 7.47–8.61)
 - the prevalence approximately doubled for every 5-year increase in age after 70 years
 - In community is about 2.5%
 - In LTC is about 6-7%
- More than 260K in population are diagnosed with dementia in 2016
- About 85% of elderly people with dementia are cared by family members



Impact of Dementia

Individual with dementia

- **Loss of short term memories, abstract thinking and judgments**
- **Gradually progress to total cognitive impairment**
- **loss of abilities to live independently**
- **Unable to recognize families and friends**
- **psychological and behavioral problems**

Family And Friends

- **Potential victims of disease**
 - **Caregivers are “invisible patients”**
- **Economical burden**
- **Physiological strain**
- **Psychological /emotional stress**
 - **In Taiwan, 1/3 of caregivers are depressed**
 - **Studies indicated 14% ~ 55% of caregivers were diagnosed with depression**
- **Hindered quality of life**

Characteristics of Family Caregivers

- **Female > Male**
- **age > 50**
- **relationship**
 - **Children, mostly**
 - **spouse**
- **Average 16 hrs./day in providing care**
- **About 14% quit their original jobs**
- **About 44% providing care full time**

➤➤ *They also have the right to accept care*

People Who Take Care Of Others Also Need To Be Taken Care Of .

Needs of Caregivers

- **70 % of caregivers' needs are not met.**

Personal Needs

- Allow time to run errands
- Allow time to take a break
- Provide information on caring for dementia

Systematic Needs

- Opportunity to share experiences
- Subsidy of medical expense will be provided by government
- Meeting of support group

Definition of Support Group

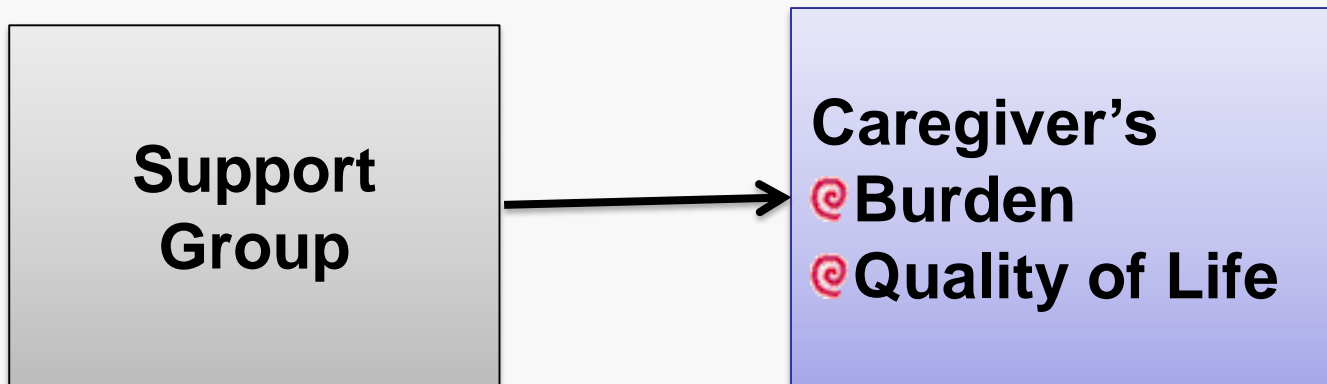
- **A support group is a group of people with common experiences and concerns who provide emotional and moral support for one another**

Benefits of Support Group

- **Learn problem solving skills**
- **Share experience, exchange ideas and support each other**
- **Explore, vent and adapt to one's emotions**
- **Discuss strategies of of working with family members to face the challenge of disease**
- **Linking social support systems to reduce stress to improve the quality of life.**

Purpose of Study

- The purpose of this study was to investigate the effect of a support group on both the caregiver's burden and the quality of life for primary family caregivers of elderly with dementia



Study Design

- A 2-group quasi-experimental study, using a pre-and post-test repeated measure method, was conducted to investigate the study outcomes.

	Pretest	Intervention	Posttest 1	Posttest 2
Experimental	O_{E1}	X	O_{E2}	O_{E3}
Control	O_{C1}		O_{C2}	OC3

Participants

Inclusion Criteria

- **Primary family caregivers of individuals who had been diagnosed with dementia**
 - ≥ 20 y/o
 - Live with patients
 - No previous participation at a support group for dementia

Exclusion Criteria

- **No mental illness**
- **No employment relationship**

Participants

- **Referred by physicians**
- **Group assignment was based on participants' choices**
 - **Experiment Group (n = 35)**
 - **Attrition rate 2.86 (n = 1), decease of patient**
 - **Control Group (n = 38)**
- **Participants included in final analysis**
 - **Experiment Group (n = 34)**
 - **Control Group (n = 38)**

Setting

- **Group meetings were held at a conference at a hospital**

Instruments

- **A demographic questionnaire**
 - Including information on the patients and the caregivers
- **Chinese version of Caregiver Burden Inventory** ◦
 - Including five dimensions: (a) time-dependence, (b) developmental, (c) physical, (d) social and (e) emotional burden
 - A total of 24 items
- **Taiwan version of WHOQOL-BREF**
 - Comprised of 28 items
 - Including physical health, psychological health, social relationships, and environment

Intervention

- **Support Group Team Members**
 - Multidisciplinary team work
 - Physicians, nurses, social workers, dietian, physical therapist, family members, volunteers
- **Characteristics of support group**
 - Homogeneous, closed ◦
 - Educational, self-help
 - Supportive

Intervention

- **Meet on every other Saturday morning** ◦
- **Three hours per meeting,**
 - **First two hours**
 - **educational session led by health care professionals** ◦
 - **The 3rd hour**
 - **Discussion, clarification and sharing**

Intervention

1

- Introduction To Members
- Overview Of Dementia And Pharmacological Therapy

2

- Skills In Caring For Individuals With Dementia
- Safety Issues In Daily Environment

3

- Strategies Of Managing Problem Behavior

5

- Nutritional Issues Of Individuals With Dementia
- Social Resources Of Individuals With Dementia

5

- Caregivers' Burden, Stress and Coping Strategies

Findings

Pretest

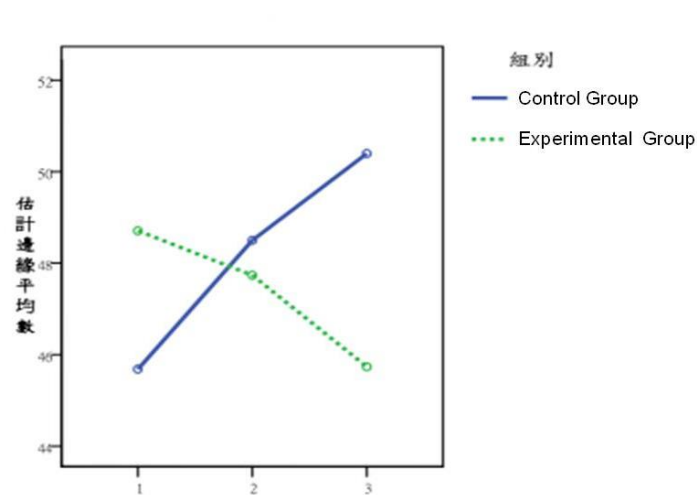
項目	原始得分 分組距	全部 n=72		實驗組 (n=34)			對照組 (n=38)			t 值	p 值		
		平均值	標準差	實測得 分組距	平均值	標準差	排 序	實測得 分組距	平均值			標準差	排 序
Care giver burden											-1.008	0.317	
總分	0-96	47.1	12.70	18-78	48.71	13.74		16-70	45.68	11.70			
時間負荷	0-20	12.76	3.63	5-20	12.62	3.43	1	0-20	12.85	3.85	1		
發展負荷	0-20	10.72	3.98	2-20	11.35	4.29	2	0-20	11.35	4.29	2		
身體負荷	0-16	8.87	2.89	4-16	8.94	3.00	3	4-16	8.94	3.00	3		
社會負荷	0-16	7.40	2.91	3-14	8.09	2.81	4	3-14	8.09	2.81	4		
情緒負荷	0-24	7.35	4.17	0-16	7.71	4.80	5	0-16	7.71	4.80	5		
Quality of life												-1.035	0.304
總分	0-80	50.68	9.08	32.83-74.51	51.81	8.67		30.33-63.11	49.08	9.43			
生理健康	4-20	12.88	2.46	6.86-18.29	12.99	2.18	2	4.57-16	12.78	2.72	2		
心理範疇	4-20	12.07	2.90	6-20	12.27	2.80	4	4-16	11.89	2.80	3		
社會範疇	4-20	13.44	2.52	8-18	13.79	2.46	1	8-18	13.13	2.56	1		
環境範疇	4-20	12.29	2.39	7.11-18.22	12.76	2.22	3	8-16.44	11.87	2.49	4		

Homogenous
at baseline

**Effects of The Support Group
on Caregiver's Burden &
Quality of Life**

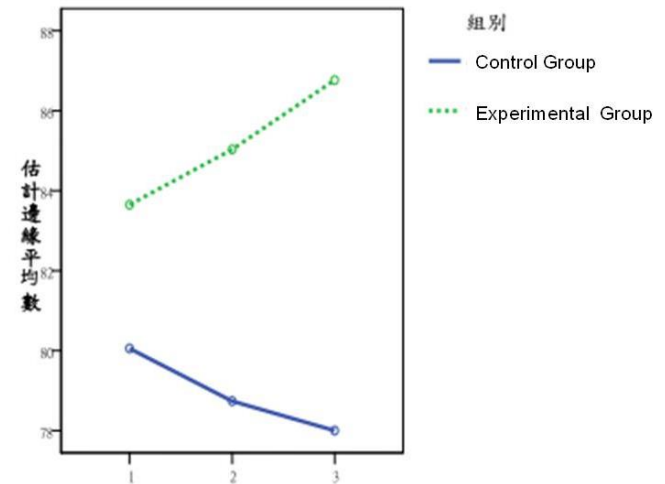
Effects of The Support Group on Caregiver's Burden & Quality of Life

Scores on Caregiver Burden at 3 Data Collection Points



Caregiver's Burden

Scores on Quality of Life at 3 Data Collection Points



Quality of Life

Effects of The Support Group on Caregiver's Burden & Quality of Life

- **Every one point \uparrow in caregiver's burden, there would be a \downarrow of 0.65 in caregiver's burden ($p = .036$)**
- **The caregiver's burden would explain 31.5% variance of caregiver's quality of life ($p = .000$).**

Effects of The Support Group on Caregiver's Burden & Quality of Life

- Length of time was related to the level of caregiver's burden
- every **one month** ↑ in length of time, there would be a **↑ of 0.045 in caregiver's burden** ($p = .036$).

Effects of The Support Group on Caregiver's Burden & Quality of Life

- The support group intervention had a positive impact on the caregiver's burden and the quality of life.**
- Participants at the experimental group had less caregivers' burdens and better qualities of lives than those in control group did at immediate completion of the support group and at 1-month follow up.**

Discussion:

Effects of Support Group on Caregiver's Burden

- **Significant differences were noted on scores of Chinese version of Caregiver Burden Inventory at different data collection points after the intervention indicated **positive effects of support group on caregiver's burden****
- **Findings were correspondent to those findings of and Robinson(1988) and Huang & Tsu (2003))**

Support groups could enable caregivers to increase their skills, gain emotional support, and assist caregivers to take appropriate strategies to address problems related to care for individuals with dementia, and further to reduce care burdens.

Discussion:

Effects of Support Group on Quality of Life

- **Significant differences were noted on scores of Taiwan version of WHOQOL-BREF at different data collection points after the intervention indicated **positive effects of support group on quality of lives of caregivers.****
- **Past literature had suggested that a support group of family caregivers could enhance the quality of life of caregivers.**

With advices of the healthcare team during the course of support group, it is possible for the caregiver to show his/her inner feelings , to share their own experiences and to learn from others. This experience would assist them to meet the ir day to day challenge.

Conclusion

Caregiver's Burden

- Support group could lessen the burden for caregivers of individuals with dementia.

Quality of Life

- Support group could improve the quality of life for caregivers of individuals with dementia.

Based on the findings of this study, a support group is evident to enhance the caregiver's burden and the quality of life among family caregivers of individuals with dementia.

Limitation

Long term effects were not followed up

Caregiver's personal experience was not explored

The study was conducted at one hospital, generalizability may be limited

41.7% of participants hired care-workers to assist their daily care. The effect of care workers was not investigated.

Answering the same questionnaire three times might cause inpatience among participants, this may have an impact on the study result.

Skills learned at the support group were not evaluate.

Recommendations

Policy

Support groups become one of routine health care activities

Implementation of a continuous care model for dementia that integrates the patient as the center, the family as the core and the social support as the network of dementia

Recommendations

Research

Impact of foreign care workers on caregivers' burdens among the family caregivers could be further investigated

Use qualitative approaches to investigate the lived experiences of family caregivers for individuals with dementia.

Other relevant variables can be added to be explored, such as the relationship between burden, coping strategies knowledge, attitudes and behavior of caregivers.

Q & A

THANK YOU FOR YOUR ATTENTION