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The Chinese University of Hong Kong
香港中文大學醫學院



Effectiveness of a Caregiver-centered Empowerment Program for Chinese Stroke Family Caregivers

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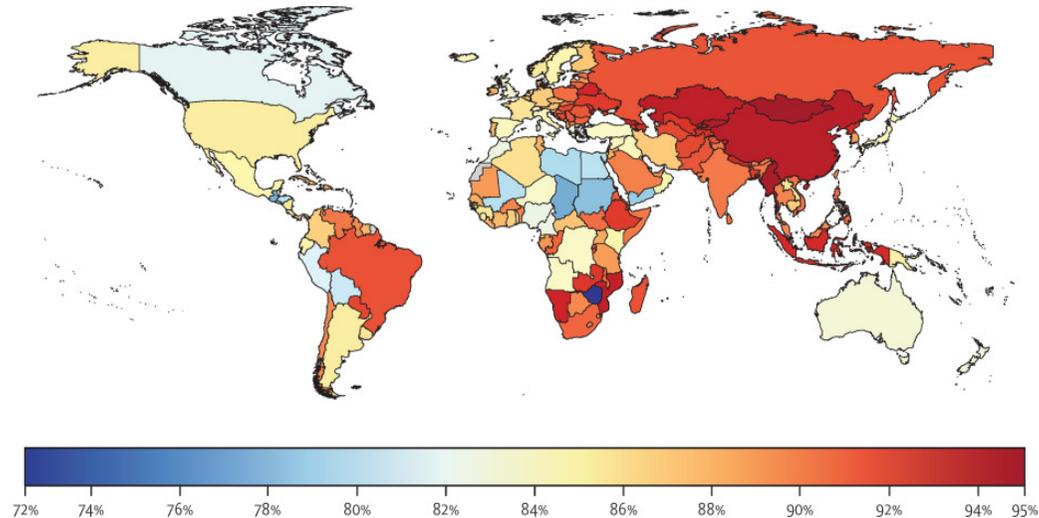
Global Burden of Stroke

Worldwide

- Each year approximately **15 million** people worldwide are diagnosed with stroke:
 - 1/3 died
 - 1/3 become disabled

China

- There are **over 8 million** stroke survivors in China.
- The number of stroke survivors in China can be increased to **31.7 million in 2030** (World Bank, 2011)





Stroke Family Caregivers

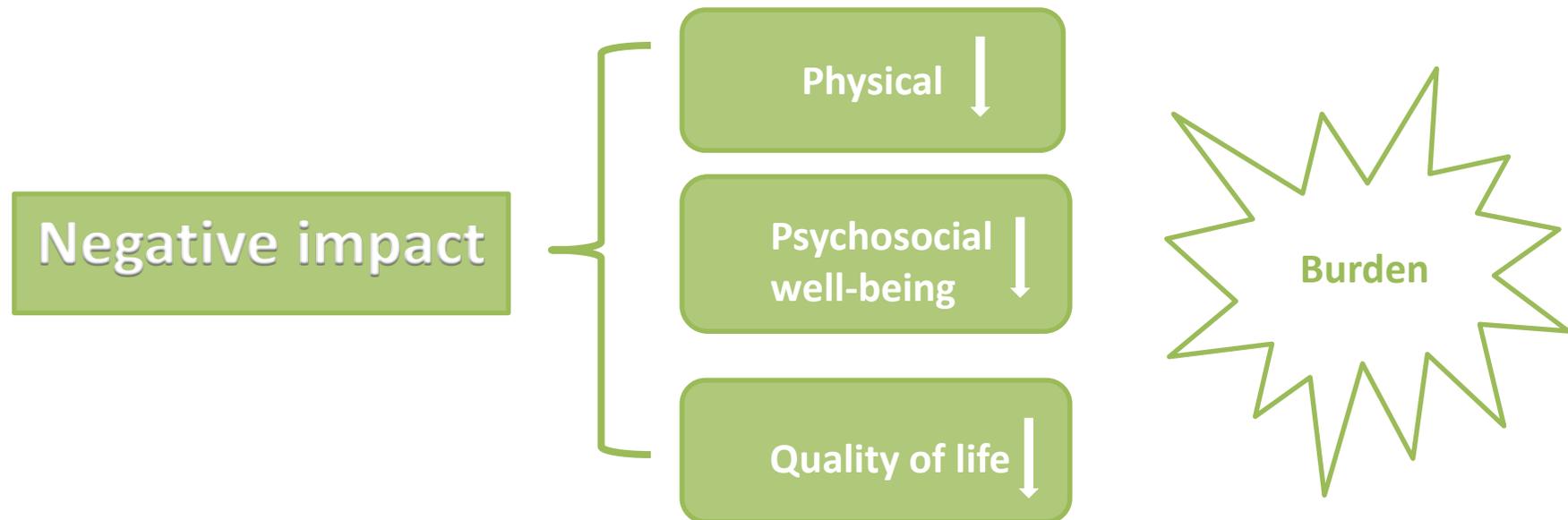
■ Stroke family caregivers

- An estimated **78%** of stroke survivors who subsequently experience persistent impairments (physical, cognitive and emotional deficit) require assistance or are fully dependent on their family caregivers for activities of daily living (Fisher & Norrving, 2011).

■ Defining family caregiver

- As defined by Caregiver Coalition (2011), a family caregiver is an individual who provides ongoing care and assistance, without pay, for family members who are in need of support due to physical, cognitive, or mental health conditions (Lum et al. 2011).

Impact of Stroke Caregiving



- Research has shown that caregiving burden can result in negative impact on physical, psychological and quality of life for caregivers.
- Caregivers have been linked to high rates of depression, cardiovascular disease, poor QOL, and high mortality.



Impact of Stroke Caregiving



(Greenwood, 2012)

Empowerment can motivate caregivers

- to gain a dynamic awareness in taking a proactive role in the caregiving context
- in adaptive coping with caregiving demands and self-care needs.

(Schulz & Nakamoto, 2013; Anderson & Funnell, 2010; Shearer, 2009; Falk-Hage & Lorensen, 2005; Rafael, 2001).



Empowerment in the context of family caregiving

Empowerment among family caregivers can be defined as

“positive control of one's mind and body, cultivating a positive attitude, proactively attempting to understand one's role as a caregiver to improve caregiving capabilities, supporting the independence of the care receiver, and creating constructive relationships.”

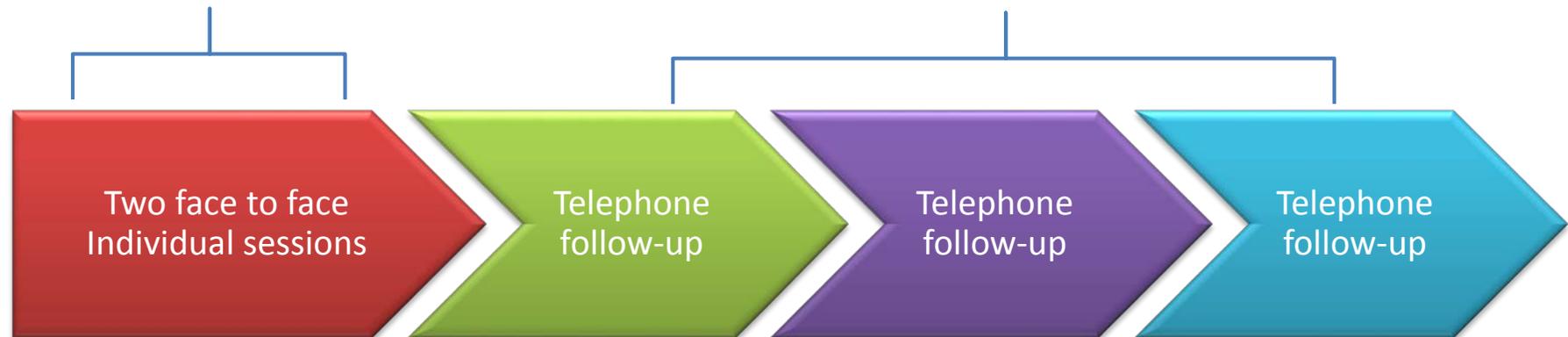
(Sakanashi et al., 2016)

A brief description of the intervention

■ The CEP includes:

Part I: Inpatient period

Part II : Post-discharge period

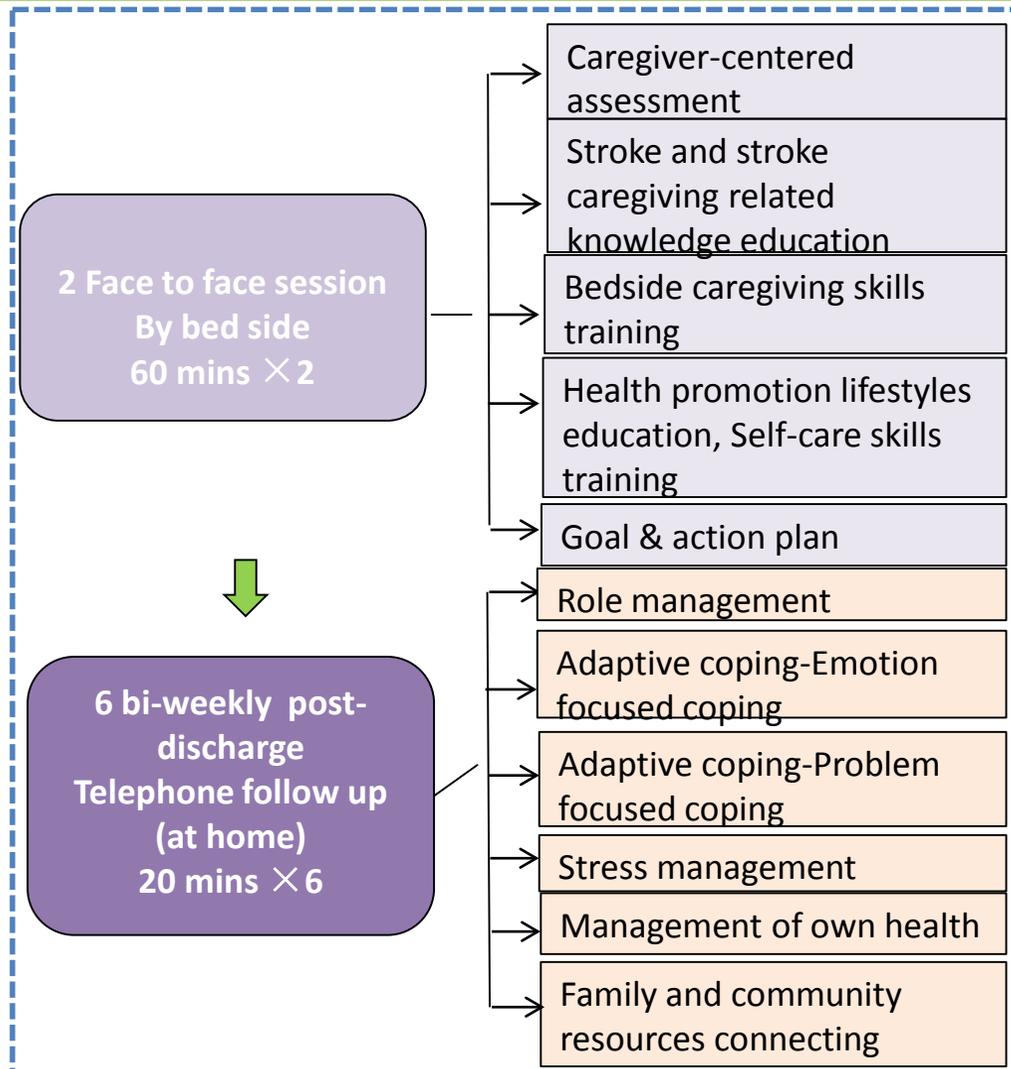


(During 1 week before discharge day) (6 bi-weekly post-discharge telephone sessions)

A 13-week Caregiver-centered Empowerment Program (CEP)

Empowerment Process Model (Cattaneo & Chapman, 2010)

A brief description of the intervention





Study aim and hypothesis

■ Aim

- To evaluate the effectiveness of the Caregiver-centered Empowerment Program (CEP) on stroke caregivers' health outcomes.

■ Hypothesis

- Comparing with the control group, participants in the intervention group will have significant:

Caregivers' Outcome:

- ① improvement in the **self-efficacy** (General Self-Efficacy Questionnaire);
- ① improvement in the **caregiving competence** (Caregiving Competence Scale)
 - improvement in **health-promoting behavior** (Health-Promoting Lifestyle Profile C)
 - improvement in **coping** (Brief COPE)
 - improvement of perceived **social support** (MSPSS)
 - reduction in **caregiving burden** (Zarit Burden Interview)
 - improvement of the **quality of life** (SF-12v2);

Study design

■ Design:

- A two-arm RCT

■ Randomized method:

- Block randomization: Block of 4 , CG:IG =1:1

■ CG: receive usual care

■ IG: receive usual care + CEP intervention

■ Usual care:

- Unstructured health education on needed basis
- Routine discharge instruction of health advice on needed basis
- Telephone call for general social chatting *

* The purpose is to balance the psychosocial effects of professional contact.



Participants

Inclusion criteria

Primary caregivers of a stroke family member who had been discharged home with post-stroke functional disability (Barthel index < 80/100)

Exclusion criteria

Caregivers of stroke survivors have:

1. a diagnosis of mental health problems or known cognitive impairments
2. co-existing severe diseases



Sample

■ Sampling size planning

- Primary outcome measures: self-efficacy
- Effect size at 0.447 (Powell et al., 2015)
- $\alpha=0.05$ (5% level of significance), $\beta=0.2$ (a power of 80%, to detect difference between two groups)
- Attrition rate =20%
- $n=72$ for each group **total number=144**

■ Sampling method

- All consecutive participants who met the selection criteria were recruited during hospitalization.



Data collection procedure

Data collection	T0 (Baseline data collection)	T1 (Immediately after the CEP)	T2 (1-month after the CEP)
Demographic data	√		
Self-efficacy(GSE)	√	√	√
Caregiving competence (CCS)	√	√	√
Health-promoting behaviors (HPLP-C)	√	√	√
Coping (COPE)	√	√	√
Social support (MSPSS)	√	√	√
Caregiver burden (ZBI)	√	√	√
Quality of life (SFv2-12)	√	√	√



Data analysis

- Descriptive statistics were used to summarize the socio-demographic characteristics and caregiver-centered outcomes.
- The effectiveness of the intervention was assessed based on the **intention-to-treat (ITT) principle**.
- The **Generalized Estimating Equation model (GEE)** was used to estimate the intervention effect over time.



Ethical considerations

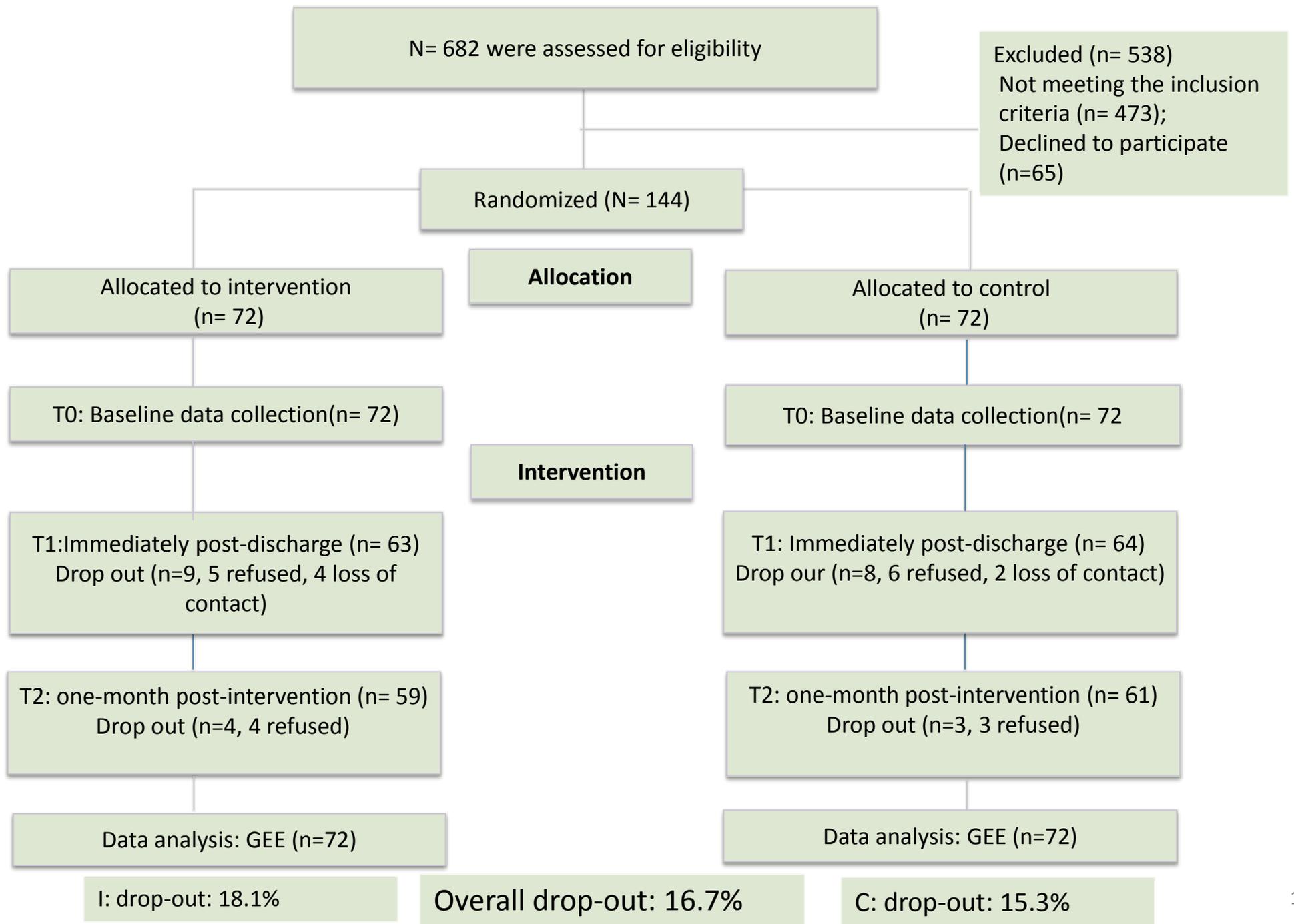
- Ethical approval from the Joint CUHK-NTEC Clinical Research Ethics Committee.
- Data collection was commenced after obtaining informed consent from each eligible participant.



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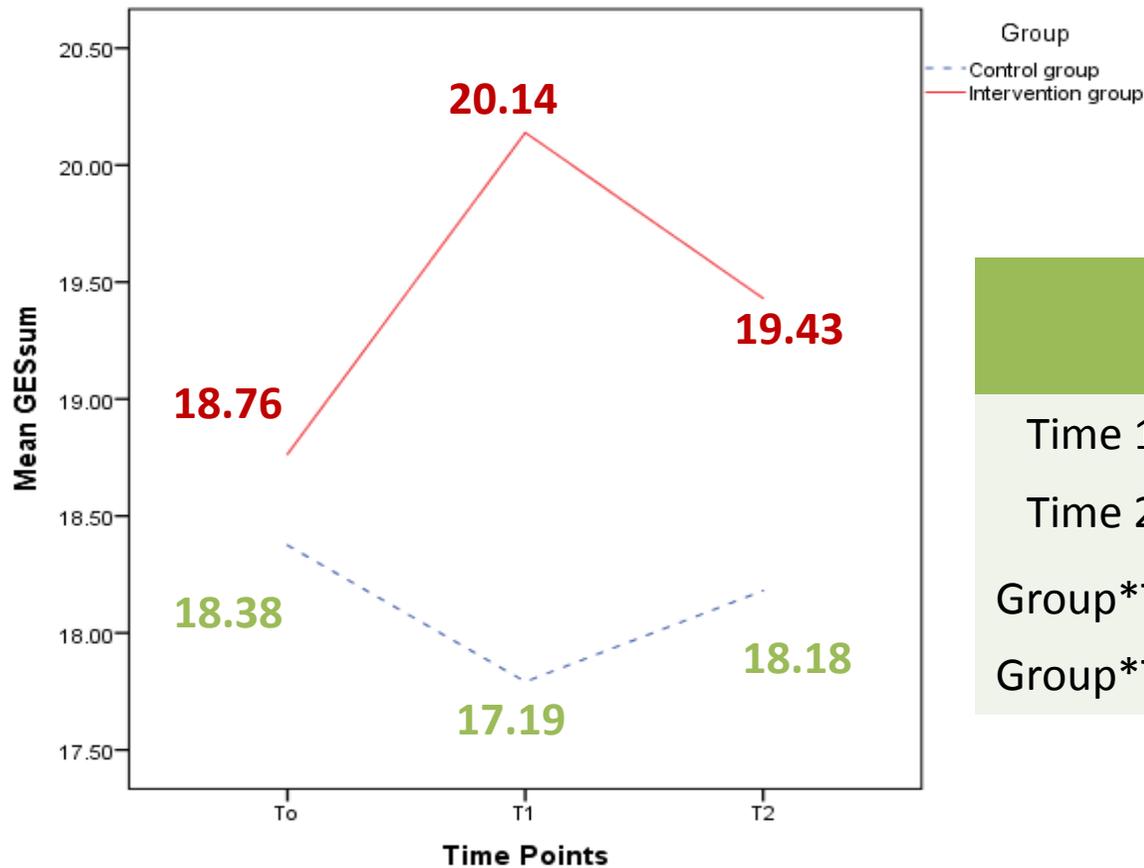
RCT Results



Comparisons of **socio-demographic characteristics** between groups at baseline

	Intervention Group (n=72)	Control Group (n=72)	t/x ²	p
	Mean (SD)/n(%)	Mean (SD)/n(%)		
<u>Patient characteristics</u>				
Age (years)	71.38 (12.95)	67.88 (14.55)	0.17	0.13
MBI	52.99 (33.43)	57.78 (32.27)	-0.88	0.38
Sex				
Male	46 (63.9%)	42(58.3%)	0.47	0.50
Female	26(36.1%)	30(41.7%)		
<u>Caregiver characteristics</u>				
Age (years)	55.32 (14.33)	51.92 (13.13)	0.49	0.14
Sex				
Male	27 (37.5%)	29 (40.3%)	0.12	0.73
Female	45 (62.5%)	43 (59.7%)		
Educational level				
Primary or below education	16(22.2%)	13(18.1%)	0.75	0.69
Secondary school education	34(47.2%)	39(64.2%)		
Tertiary education	22(30.6%)	20(27.8%)		
Job statuses				
Full time job	22(30.6%)	25(34.7%)	3.54	0.17
Part time job	9(12.5%)	16(22.2%)		
Retired	41(56.9%)	31(43.1%)		
Yearly income (RMB)				
< 62000	60(83.3%)	63(87.5%)	0.50	0.48
≥62000	12(16.7%)	9(12.5%)		
Relationship with the patient				
Spouse	29(40.3%)	26(36.1%)	1.21	0.37
Adult-children	40(55.5%)	38(52.8%)		
Other family member	3(4.2%)	8(11.1%)		
Living with the patient				
Yes	46(63.9%)	54(75%)	2.10	0.15
No	26(36.1%)	18(25%)		
Presence of helper				
No helper	30(41.7%)	32(44.4%)	2.78	0.25
Unpaid helper	37(51.4%)	39(54.2%)		
Paid helper	5(6.9%)	1(1.4%)		
Hours of caregiving per day(hours)	16.07 (8.81)	16.28 (8.34)	-0.15	0.88

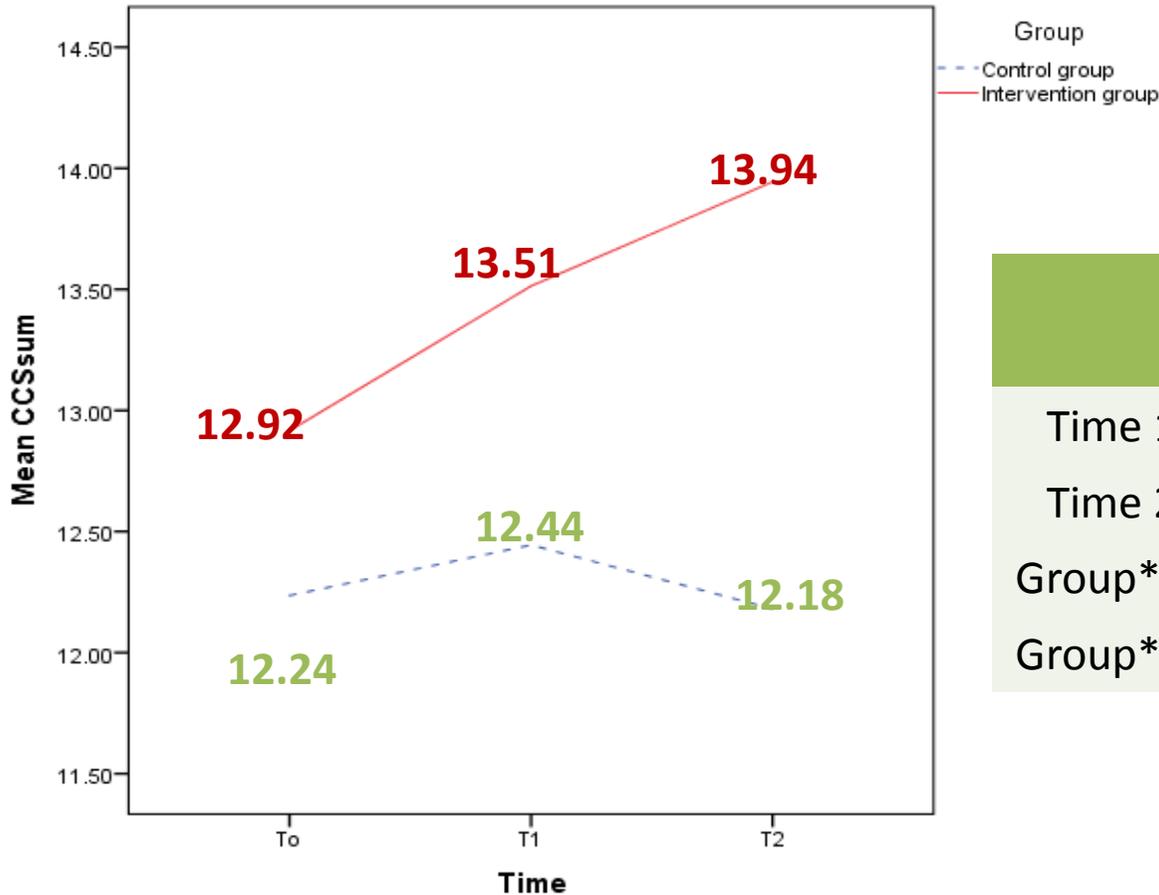
CEP effect on self-efficacy



	β (95%CI)	p
Time 1	-0.583 (-0.797, -0.370)	<0.001
Time 2	-0.194 (-0.378, -0.011)	0.037
Group*T1	1.958 (1.554, 2.362)	<0.001**
Group*T2	0.861 (0.533, 1.189)	<0.001**

General Self-Efficacy Questionnaire (GSE)

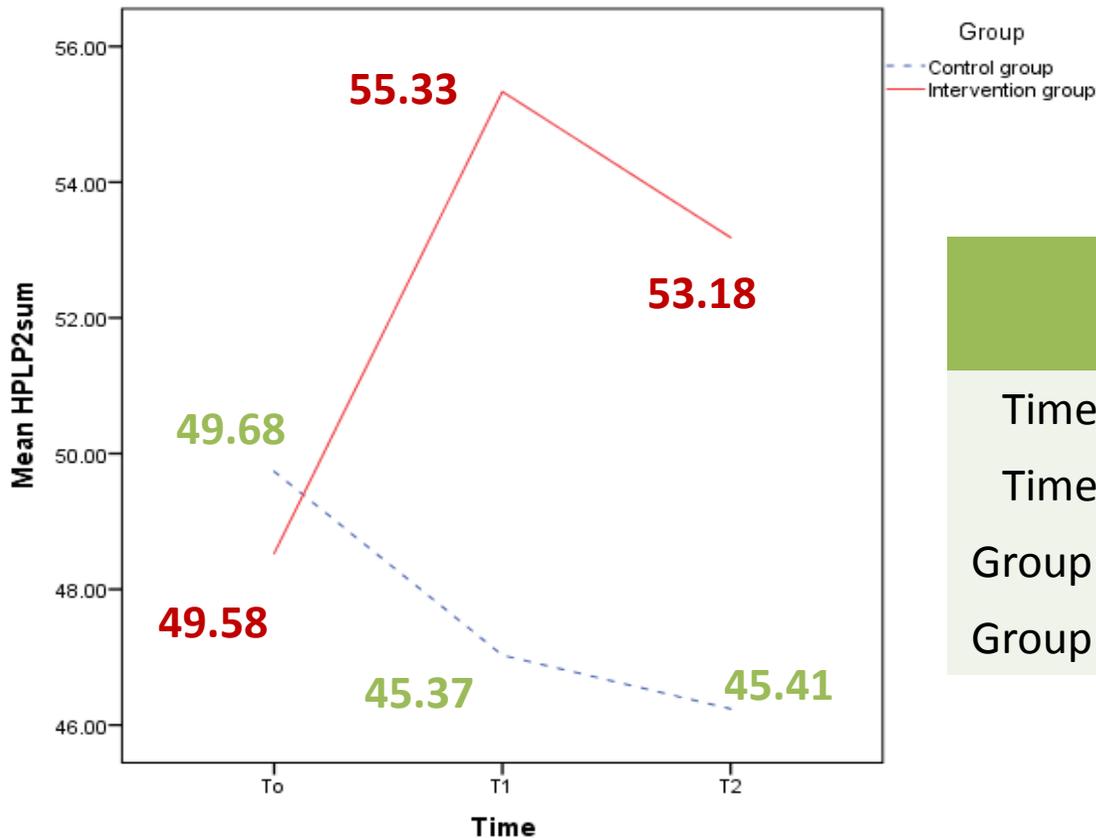
CEP effect on caregiving competence



	β (95%CI)	p
Time 1	0.208 (0.041 ,0.376)	0.015
Time 2	-0.056 (-0.204 ,0.093)	0.464
Group*T1	0.389(0.110, 0.668)	0.006*
Group*T2	1.083 (0.764 ,1.403)	<0.001**

Caregiving Competence Scale (CCS)

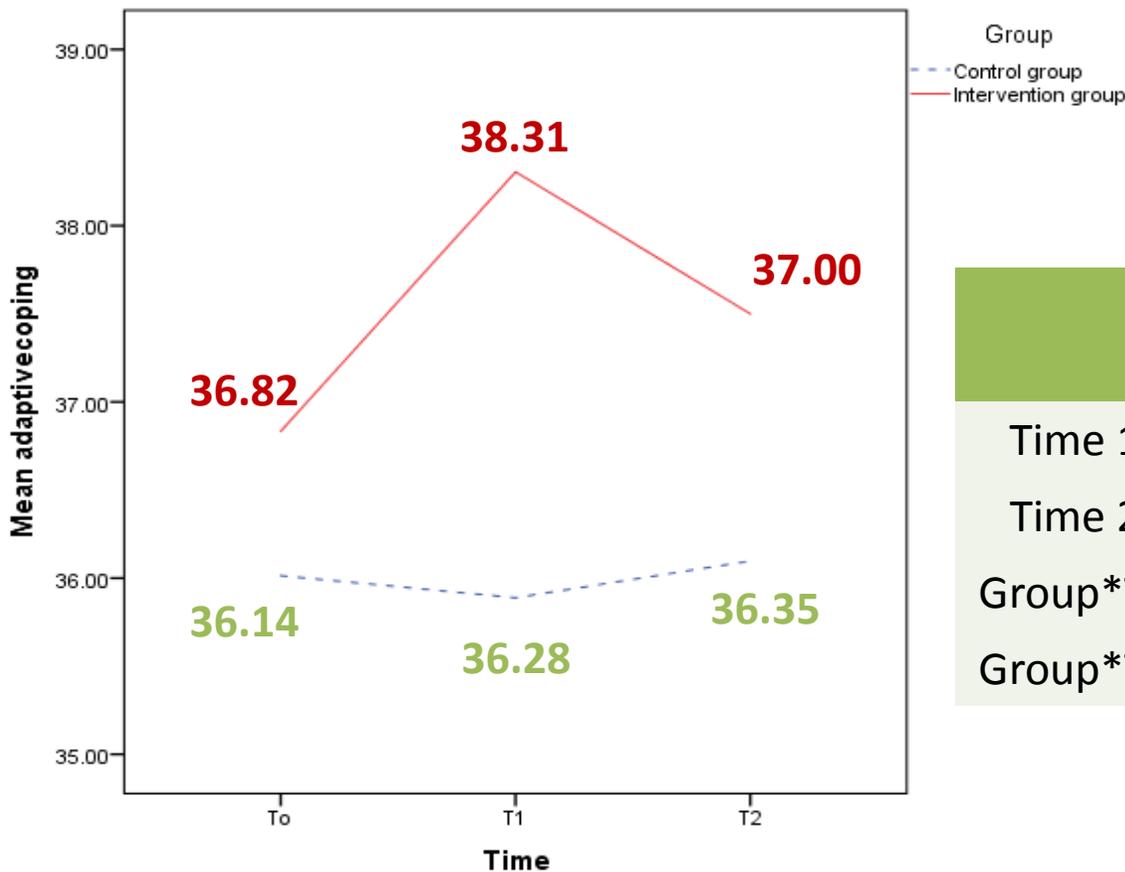
CEP effect on health promoting lifestyle



	β (95%CI)	p
Time 1	-2.693 (-3.662, -1.724)	<0.001
Time 2	-3.541 (-4.307, -2.775)	0.037
Group*T1	9.498 (6.198, 12.798)	<0.001**
Group*T2	8.302 (5.765, 10.839)	<0.001**

Health Promoting Lifestyle Profile (HPLP-C)

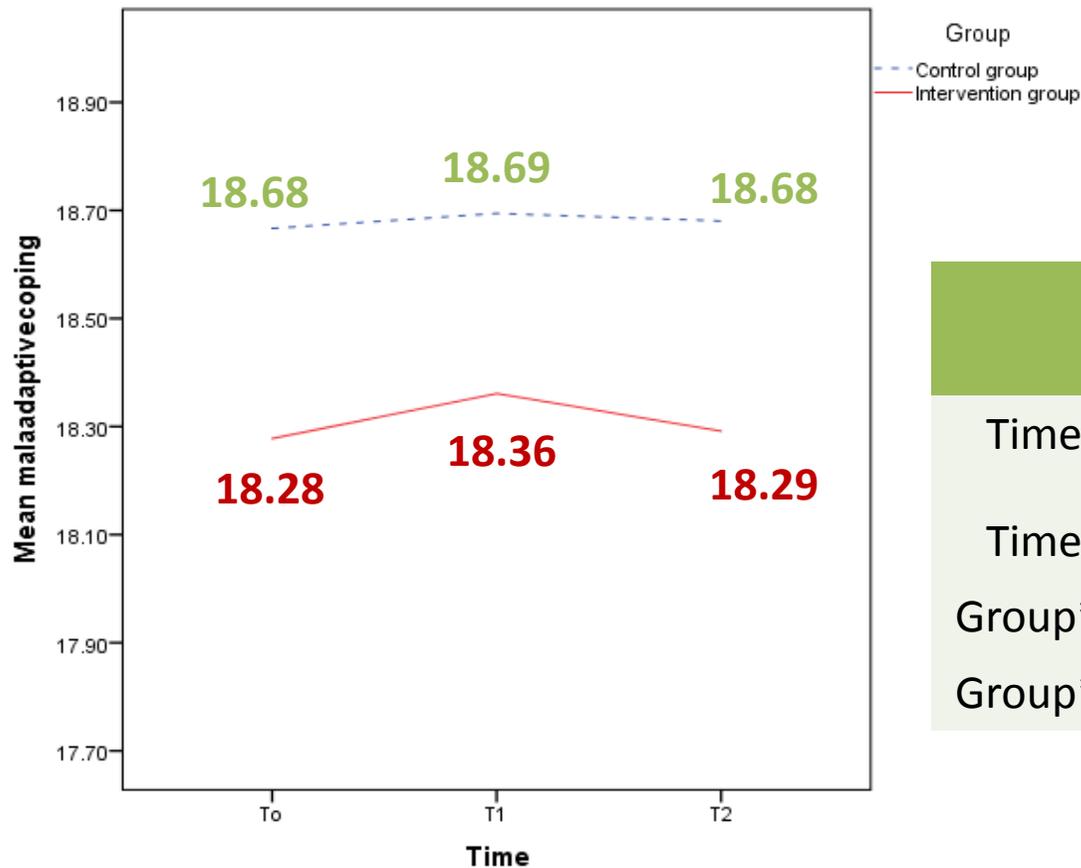
CEP effect on coping strategies



	β (95%CI)	p
Time 1	-0.125 (-0.328, 0.078)	0.229
Time 2	0.083 (-0.144, 0.310)	0.472
Group* T_1	1.597 (1.118, 2.076)	<0.001**
Group* T_2	0.583 (0.240, 0.927)	0.001*

Adaptive coping
Brief COPE Inventory (BCI)

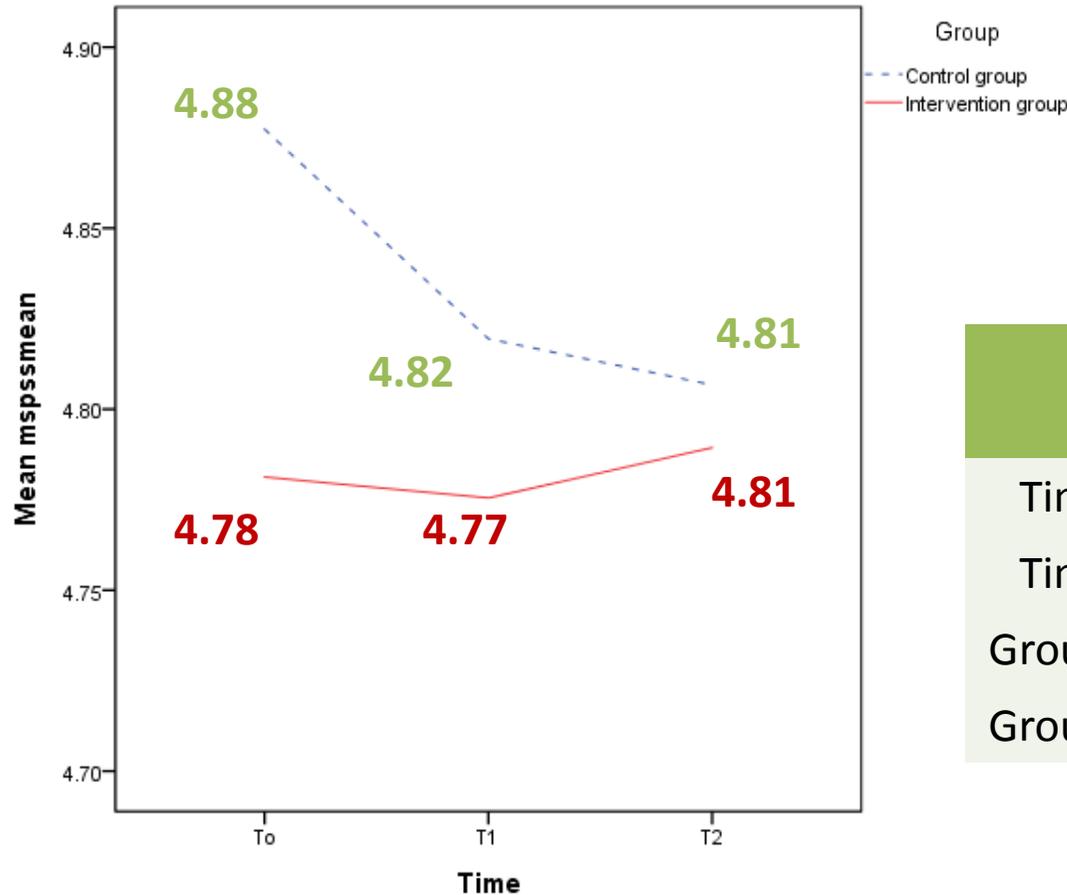
CEP effect on coping strategies



	β (95%CI)	p
Time 1	0.028 (-0.088, 0.143)	0.637
Time 2	0.014 (-0.058, 0.086)	0.705
Group*T1	0.056 (-0.128, 0.239)	0.553
Group*T2	0.048 (-0.102, 0.102)	0.990

Maladaptive coping
Brief COPE Inventory (BCI)

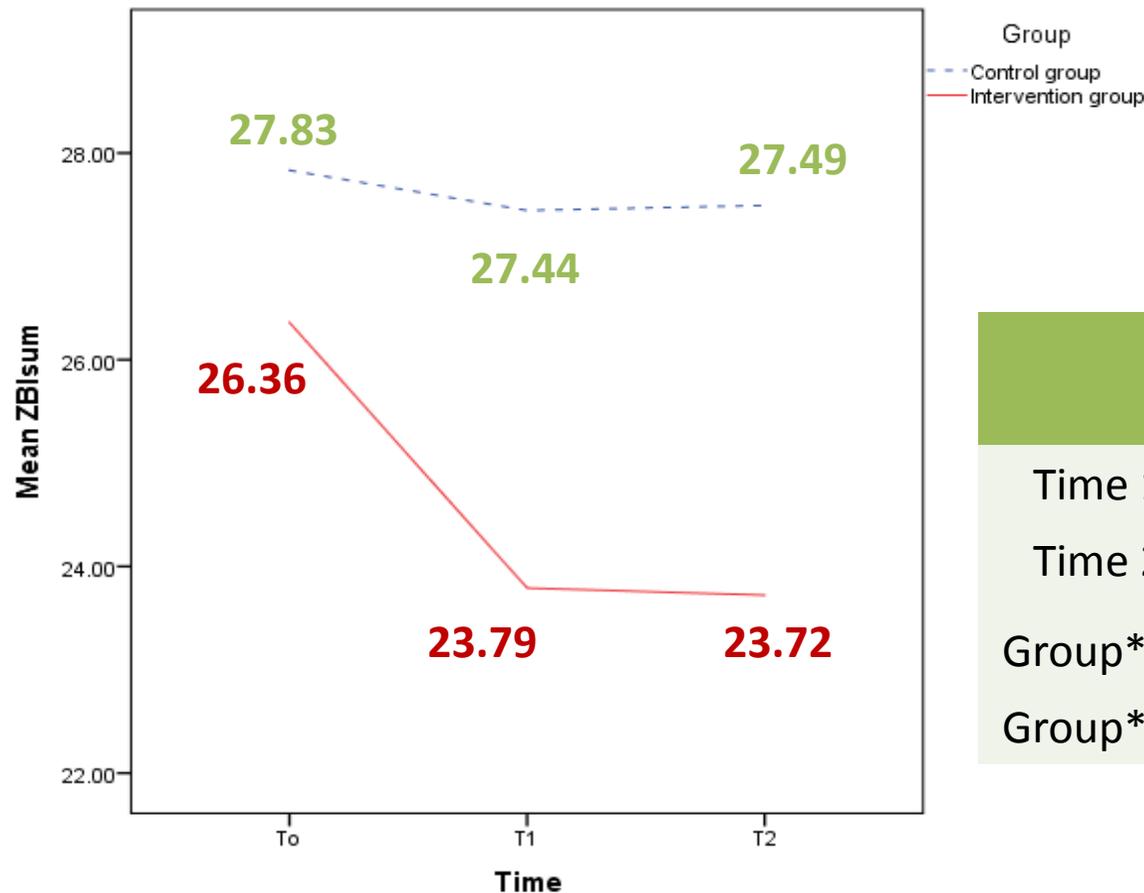
CEP effect on social support



	β (95%CI)	p
Time 1	-0.058 (-0.083, -0.032)	<0.001
Time 2	-0.071 (-0.104, -0.038)	<0.001
Group*T1	0.052 (0.022, 0.082)	0.001*
Group*T2	0.079 (0.041, 0.116)	<0.001**

Multidimensional Scale of Perceived Social Support (MSPSS)

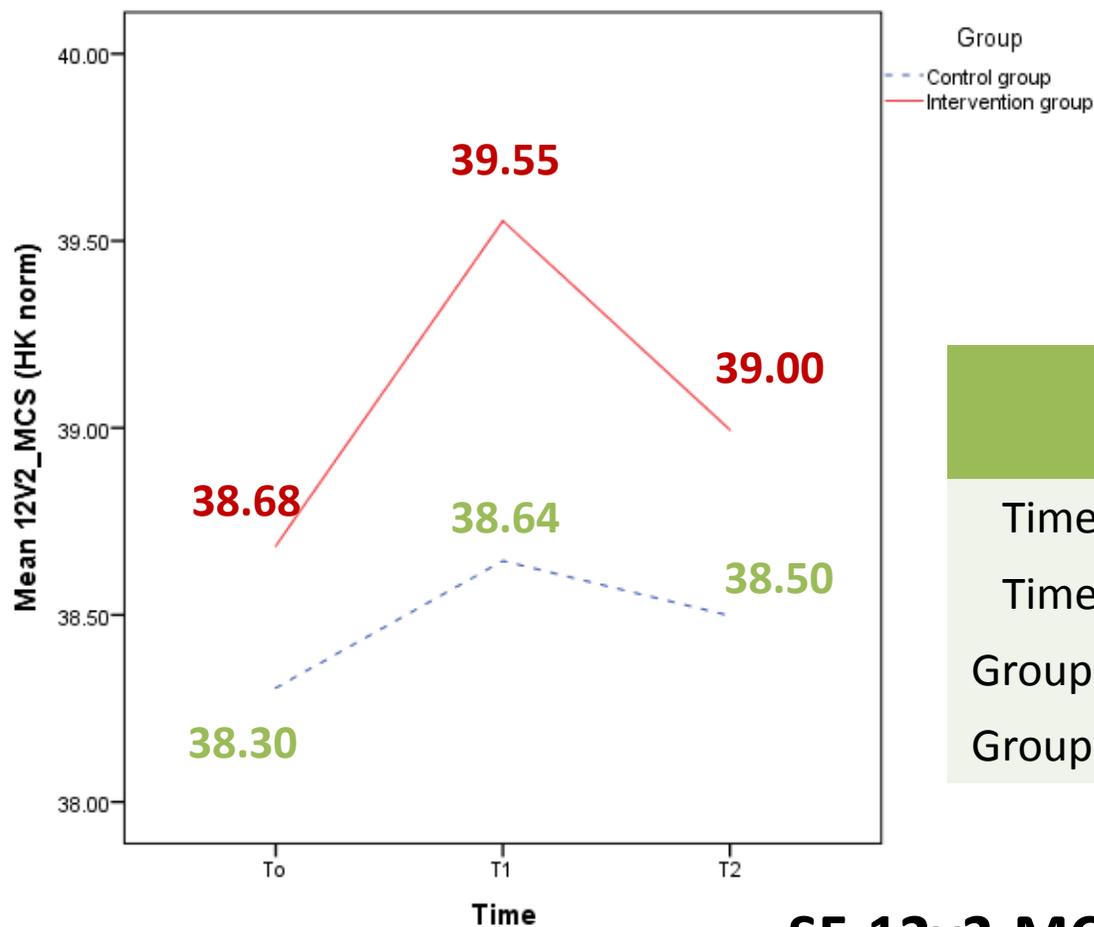
CEP effect on caregiving burden



	β (95%CI)	p
Time 1	-0.389 (-0.822, 0.044)	0.078
Time 2	-0.360 (-0.800, 0.079)	0.108
Group*T1	-2.181 (-3.340, -1.021)	<0.001**
Group*T2	-2.278 (-3.497, -1.060)	<0.001**

Zarit Burden Interview (ZBI)

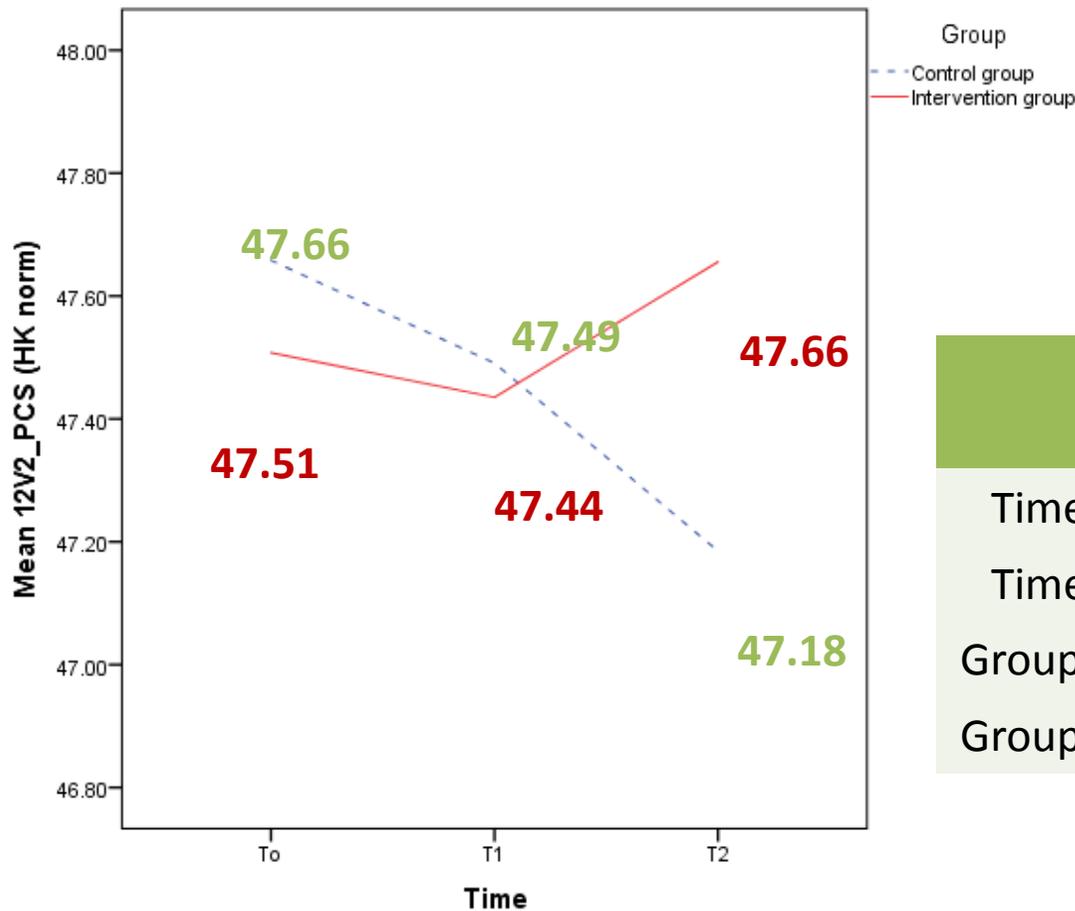
CEP effect on perceive mental health



SF-12v2-MCS

	β (95%CI)	p
Time 1	0.340 (-0.220, 0.899)	0.234
Time 2	0.193 (-0.392, 0.777)	0.518
Group*T1	0.529 (-0.665, 1.723)	0.185
Group*T2	0.117 (-0.656, 0.891)	0.266

CEP effect on perceive physical health



	β (95%CI)	p
Time 1	-0.167 (-0.555, 0.221)	0.398
Time 2	-0.473 (-1.091, 0.144)	0.133
Group*T1	0.095 (-0.928, 1.118)	0.856
Group*T2	0.621 (-0.171, 1.413)	0.124

SF-12v2-PCS

Summary of results

- The results indicated that the CEP had significant positive effects on:

	Results	
	T1	T2
Self-efficacy	↑ **	↑ **
Caregiving competence	↑ *	↑ **
Health promoting behavior	↑ **	↑ **
Adaptive coping	↑ **	↑ **
Maladaptive coping	-	-
Social support	↑ **	↑ *
Caregiving burden	↓ **	↓ **
Quality of life		
——PCS	-	-
——MCS	-	-



Limitations of the study

- Study setting and convenience sampling
 - Participants were recruited from one acute hospital with a convenience sampling method.
 - The generalization of the findings in this research should be carefully considered.
- Self-report data, a social desirability bias could not be excluded
- Short-term effect, long term effects is still unclear



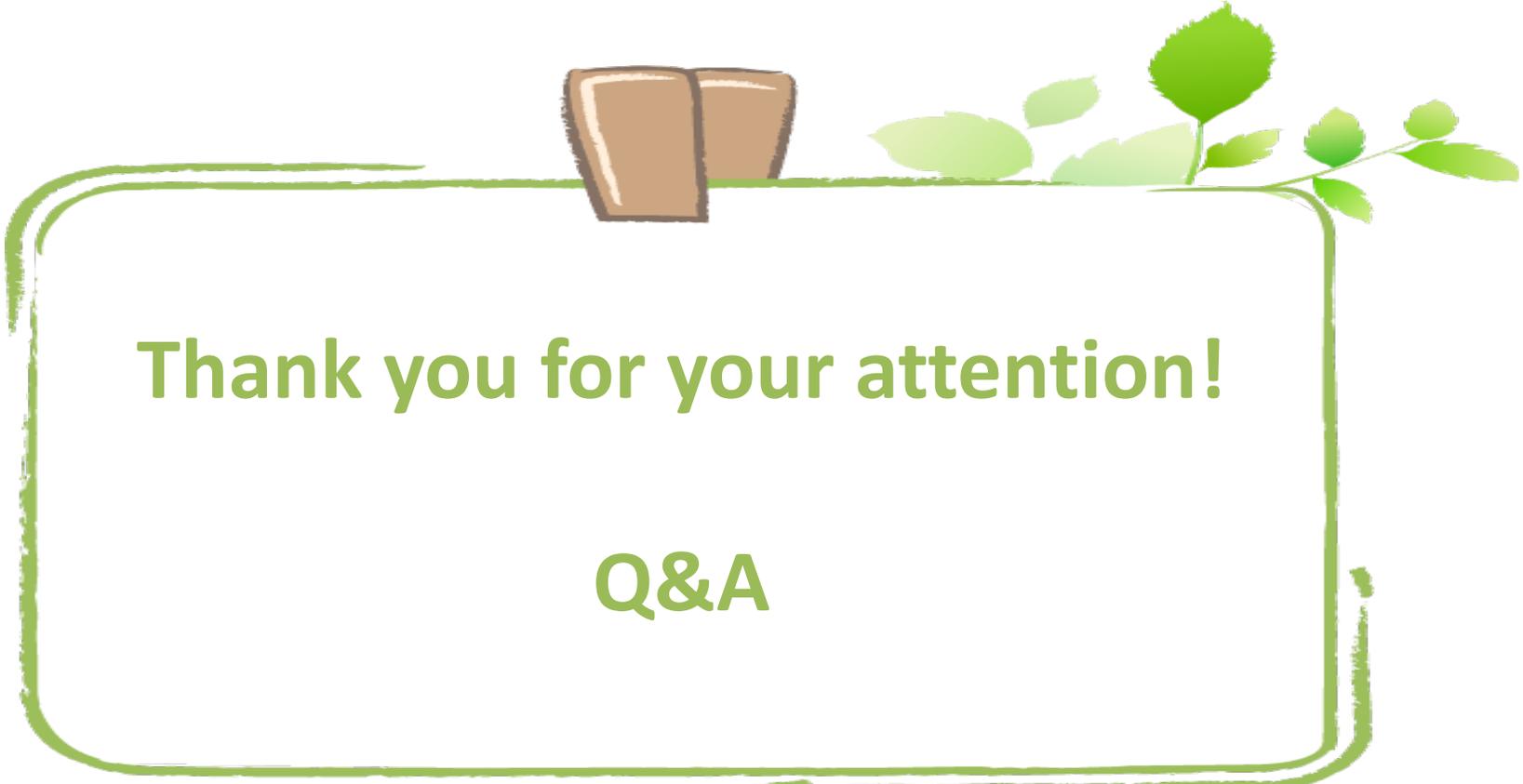
Implications for practice

- Empowerment-based interventions with bolster sessions for family caregivers could be adopted as a component into the stroke rehabilitation program to improve the support for the vulnerable groups
- The incorporation of the face-to-face sessions and telephone sessions into routine practice allowed for structured intervention, and acknowledging the preferences and values of individuals.



Conclusion

- The current study developed a caregiver-centered empowerment-based interventions for Chinese stroke family caregivers and the effects of the intervention were examined by the use of RCT.
- The study presents an encouraging picture of the CEP and demonstrating the value of such a program in Chinese stroke family caregivers.

A decorative frame with a green border, a brown book icon at the top, and a green plant with leaves on the right side.

Thank you for your attention!

Q&A