

# Between structured design and personal narrative: The report of an RCT study of a hybrid design group programme for family caregivers

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# Care for Caregivers

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Caregivers play an important role  
in patient's recovery

Treatment team collaborates  
with caregivers

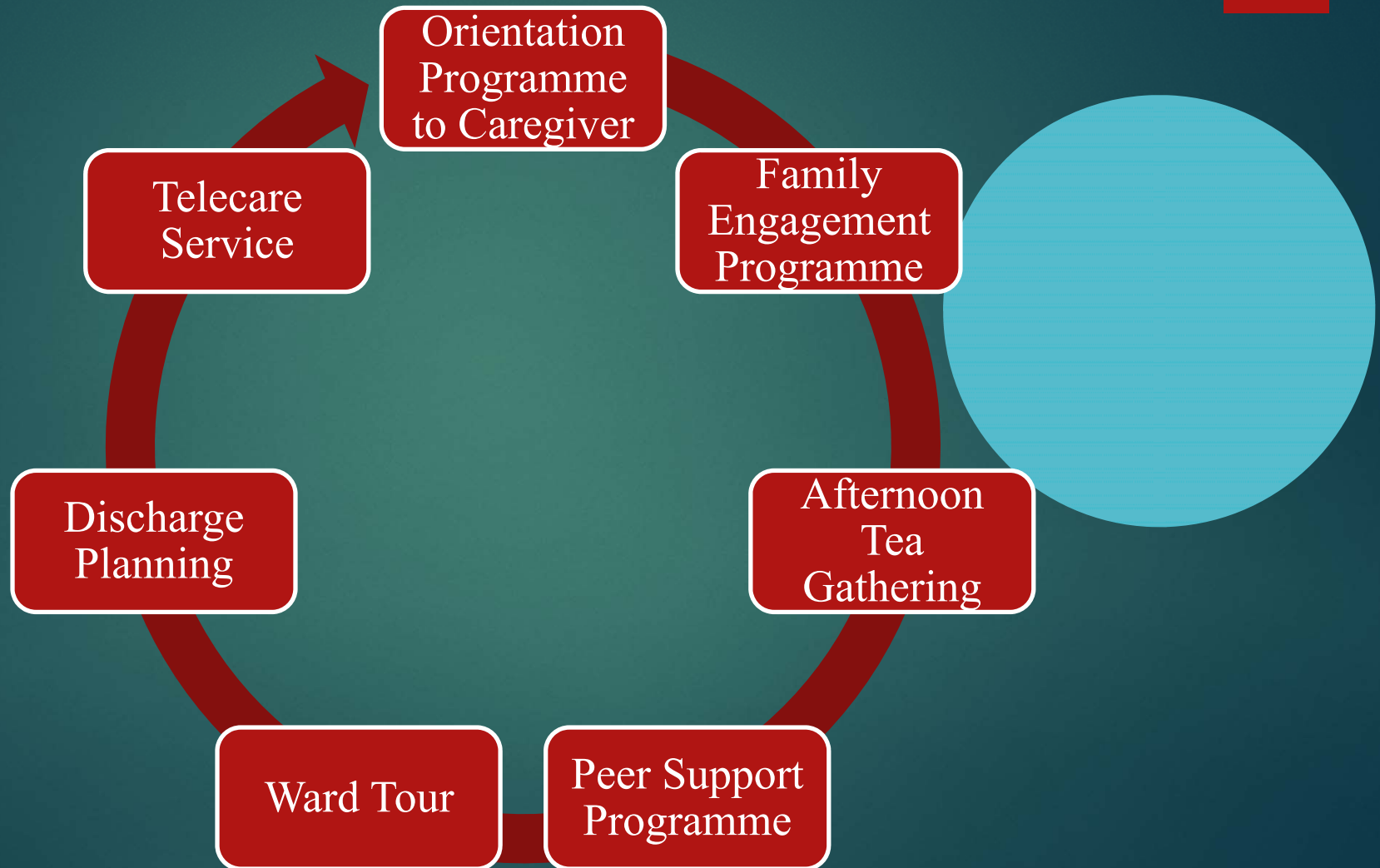
Emphasis on family participation  
and support, empowerment of  
caregivers

## Caregiver activities at service contact

- both inpatient and outpatient setting

# Caregiver Support & Involvement Programme

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# Caregiver Support & Involvement Programme

At outpatient , a caregiver's resources centre established

- Relative Forum: Bimonthly
- Mental Health First Aid Class
- Dementia Workshop
- Care For Caregiver Workshop
- CBT For Depression Workshop for Caregivers
- Mutual Support Group for Caregivers (家友站)
- Annual Mental Health Month Activity

# Caregiver Support & Involvement Programme

Collaborating with Hong Kong Shue Yan University  
on empowering caregivers of people with schizophrenia in Oct 15

Case managers joined in the groups  
and work with the investigating team

# Introduction about the Project

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- ▶ Project title: Empowering Caregivers of People with Schizophrenia: Comparing Intervention Effectiveness of Family Link Education Programme (FLEP), Narrative Practice Group (CNGP) and Integrative Peer Support Growth Group (IPSGG)
- ▶ Acknowledgement: The reported study was funded by the Research Grant Council of HKSAR (UGC/FDS15/M01/15). However, the opinions expressed do not necessarily reflect the positions of the funding agency. We want to acknowledge our great gratitude to Kwai Chung hospital for their support in multiple aspects and all caregiver participants for their active participation both in the supportive groups and research.



In 2011, Hong Kong Hospital Authority estimated that nearly 20,000 schizophrenia outpatients require community and family support in Hong Kong.

# Family Caregivers

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## Caregiving Burden (Khoshknab, Sehikhona, Rahgouy, Rahgozar, & Sodagari, 2014)

- Financial burden
- Both the mental and physical health of family members
- Disruption of routine family activities, leisure and interaction

## Profound psychological issues (Gupta, Isgerwood, Jones, & Van Lmpe, 2015)

- More experiences of insomnia
- Pain
- Heartburn
- Anxiety
- The severity of depressive symptoms





# Common Supportive Programmes for Caregivers

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## Psychoeducation

- Help the caregivers acquire and develop the knowledge and skills (Jwell, Downing, & McFarlane, 2009)
- Enhance self-efficacy, life-satisfaction, self-esteem (Chan, Yip, Tso, Cheng, & Tam, 2009; Cheng & Chan, 2005; Chiu et al., 2013)

## Peer Support Group

- Peer support groups work to untangle complicated emotions and generates social support (Bademli & Çetinkaya Duman, 2011)

# Integrative Caregiver Supportive Approach

From Outside



From Inside





# Design: A Random Control Trial

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Randomization  
Caregivers (n = 194)

Psychoeducation  
(n = 43)

Integrated  
Approach (n = 46)

Narrative  
Practice Group  
(n = 46)

Pretest

Control

Posttest

Two-months  
follow-up



# Familylink Psychoeducation Programme

(Chiu et al., 2013)

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Session 1 – Symptoms and causes of mental illness

Session 2 – Family coping and communication

Session 3 – Medicine and medical care

Session 4 – Crisis management

Session 5 – Daily life adjustment

Session 6 – Recovery pathway

Session 7 – Right of the people with severe mental illness

Session 8 - Applications

# Collective Narrative Practice Group (CNPG)

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Sessions	Therapeutic components (White, 2007)
Session 1: A day with him/her	Loitering with curiosity
Session 2: An unexpected visitor	Externalization conversation
Session 3: Sword play	Deconstruction: Situating problems in context
Session 4: Dance of life	Unique outcome
Session 5: A moment of my own	Scaffolding & therapeutic documents
Session 6: Morning tea	Re-membering conversation
Session 7: A paint of future	Re-authoring conversation
Session 8: Flow of outside witness	Outsidewitness & Definitional ceremony

# Integrative Approach

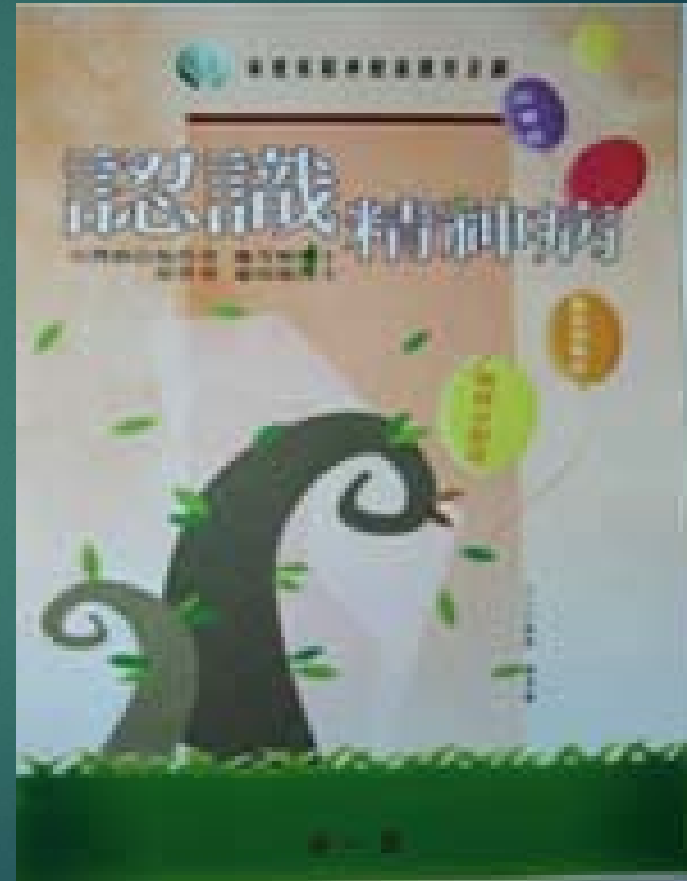
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Integrative Approach	Collective Narrative Practice Group	FamilyLink Psychoeducation Programme
S1: 不速之客	S2: 不速之客 Externalization and Deconstruction	Ch. 1 認識精神病 Psychopathology of Mental Illness Advocacy
S2: 藥的情結	S3: 見招拆招 Reauthoring Conversation	Ch3. 認識精神科藥物 and Ch.7 權益與倡導 Medications for Mental Illness
S3: 隨機應變	S3: 見招拆招 Reauthoring Conversation	Ch4. 危機處理 and Ch.7 權益與倡導 Crisis Management and Prevention
S4: 攜手共舞	S4 生命之舞 Unique Outcomes	Ch.2 誰能明白我 Two-way Communications and Coping Stance
S5: 擁抱自己	S5: 當我一個人的時候 Inner Resources	Ch.5 善待自己重整生活 Balance of Life and Care Yourself
S6: 請你飲茶	S6: 請你飲茶 Remembering Conversation	Ch.5 善待自己重整生活 Balance of Life and Care Yours Family
S7: 創造未來	S7: 待續的故事 Conversation Highlights Unique Outcomes (Art Therapy Elements )	Ch.6 康復的疑惑 Dual Process of Recovery and Remission
S8: 星星之火	S:8 流動的迴響 Outside Witness and Definitional Ceremony	Ch.8 學以致用 and Ch.7 權益與倡導 Review and Applications



# S1: Unexpected Visitor

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# Session 5: Embrace Yourself

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# Measurement Scales

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Brief Family Relationship Scale (*Fok, Allen, Henry, & People Awakening Team, 2014*)

The Chinese version of Experience of Caregiving Inventory (*Kheng, 2005*)

The Chinese version of Herth Hope Index (*Chen & Wang, 1997*)

Innerness or Inner Resources (*Howden, 1992*)

Five-item Mental Health Inventory (*Berwick et al, 1991*)



### Demographics

Family caregiver	Family Members with Schizophrenia
Mean age = 51.00 ( <i>SD</i> = 11.36)	Mean age = 39.40 ( <i>SD</i> = 13.86)
Male = 7, Female = 25	Male = 14, Female = 17

### Caregiving Relationship

Son/daughter caregivers: 9.4%,

Sibling caregivers: 37.5%

Spouse Caregivers: 18.8%

Parent caregivers: 34.4%

# Results



# Family Relationship

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Brief Family Relationship Scale	Pretest n = 19	Control n = 19	Posttest n = 19	Overall		Pretest vs Control		Pretest vs Posttest	
	<i>Mean</i> ( <i>SD</i> )	<i>Mean</i> ( <i>SD</i> )	<i>Mean</i> ( <i>SD</i> )	<i>F</i> (sig)	Partial $\eta^2$	<i>F</i> (sig)	Partial $\eta^2$	<i>F</i> (sig)	Partial $\eta^2$
Cohesion	4.68 (1.94)	4.95 (1.39)	5.95 (1.39)	9.556*** (.000)	.347	.597 (.450)	.032	16.200** (.001)	.474
Expressiveness	1.33 (1.06)	1.81 (1.21)	2.00 (1.18)	2.997 (.061)	.130	4.762 (.076)	.149	6.087* (.023)	.233
Conflict	3.23 (1.82)	3.45 (1.53)	3.91 (1.34)	2.455 (.098)	.105	.665 (.424)	.031	6.176* (.021)	.227



# Caregiving Experiences

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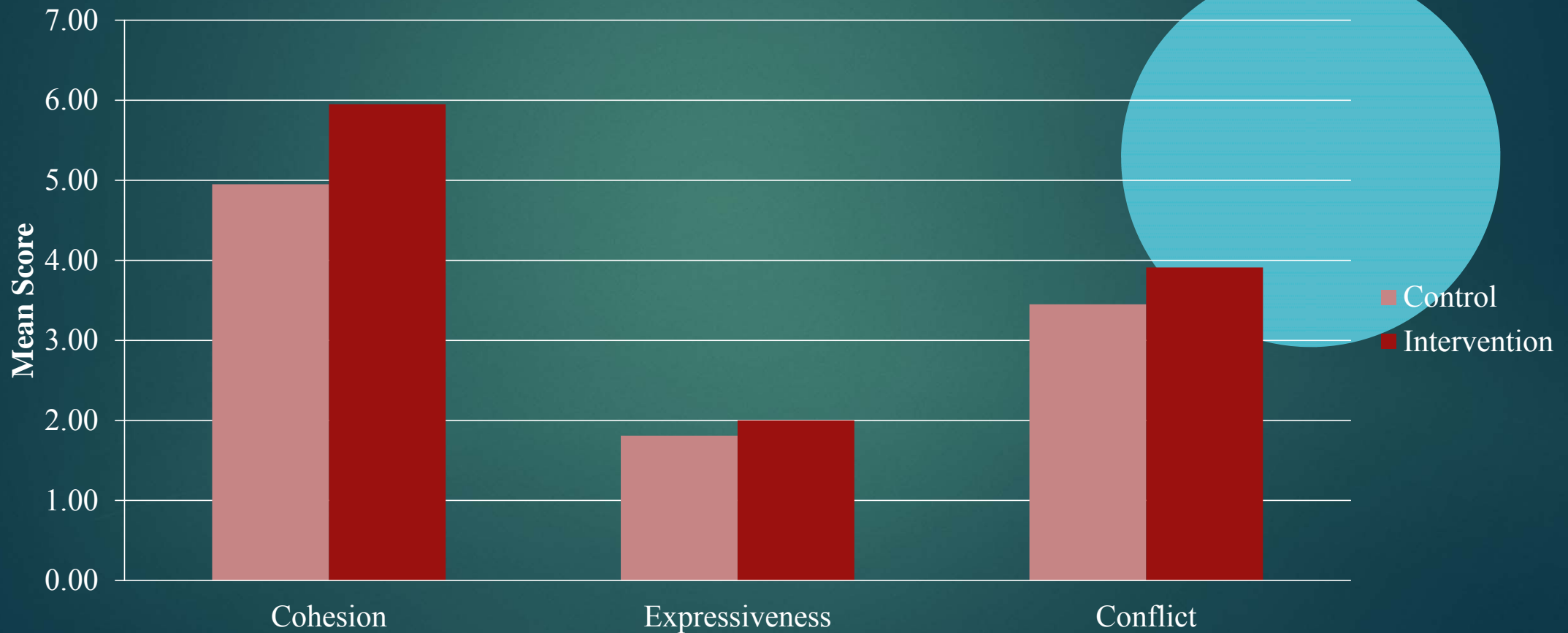
Experience of Caregiving Inventory	Pretest n = 19	Control n = 19	Posttest n = 19	Overall		Pretest vs Control		Pretest vs Posttest	
	<i>Mean</i> ( <i>SD</i> )	<i>Mean</i> ( <i>SD</i> )	<i>Mean</i> ( <i>SD</i> )	<i>F</i> (sig)	Partial $\eta^2$	<i>F</i> (sig)	Partial $\eta^2$	<i>F</i> (sig)	Partial $\eta^2$
Total positive score	22.40 (8.79)	25.35 (8.70)	28.05 (7.37)	6.058** (.005)	.242	3.552 (.075)	.158	10.452** (.004)	.355
Positive personal experiences	11.68 (5.06)	14.14 (5.64)	15.59 (4.11)	8.821** (.001)	.296	7.787* (.011)	.271	20.415*** (.000)	.493
Good aspects of Relationship	11.19 (4.76)	11.76 (4.21)	12.67 (4.07)	1.674 (.200)	.077	.484 (.494)	.024	2.591 (.123)	.115
Total negative score	73.94 (30.75)	74.31 (28.12)	65.94 (23.27)	3.155 (.057)	.174	.012 (.915)	.001	3.209 (.093)	.176
Difficult behaviors	11.55 (7.11)	12.23 (6.76)	10.41 (5.57)	1.153 (.326)	.052	.552 (.466)	.026	.768 (.391)	.035
Negative symptoms	10.22 (5.04)	10.35 (5.62)	8.91 (4.84)	1.901 (.161)	.080	.045 (.835)	.002	2.454 (.132)	.100
Stigma	5.64 (2.74)	5.55 (3.81)	4.64 (2.92)	1.233 (.302)	.055	.014 (.908)	.001	1.805 (.193)	.079
Problems with services	6.85 (3.13)	7.85 (4.25)	8.05 (3.63)	1.467 (.243)	.072	1.532 (.231)	.075	3.668 (.071)	.162
Effects on family	6.73 (4.17)	6.82 (4.20)	6.86 (3.48)	.018 (.982)	.001	.013 (.911)	.001	.030 (.864)	.001
Need to backup	12.19 (4.27)	12.24 (4.00)	11.52 (3.27)	.739 (.484)	.036	.006 (.937)	.000	.930 (.346)	.044
Dependency	9.57 (4.80)	9.70 (4.22)	7.87 (3.20)	5.936* (.013)	.212	.064 (.803)	.003	4.968* (.036)	.184
Loss	11.45 (4.88)	11.30 (4.32)	9.55 (3.65)	6.085** (.005)	.243	.041 (.841)	.002	14.319** (.001)	.430

# Inner Resources

	Pretest	Control	Posttest	Overall		Pretest vs Control		Pretest vs Posttest	
	n = 19	n = 19	n = 19	<i>F</i>	Partial $\eta^2$	<i>F</i>	Partial $\eta^2$	<i>F</i>	Partial $\eta^2$
	<i>Mean</i> ( <i>SD</i> )	<i>Mean</i> ( <i>SD</i> )	<i>Mean</i> ( <i>SD</i> )	(sig)		(sig)	$\eta^2$	(sig)	$\eta^2$
Inner Resource Scale	36.90 (9.50)	38.70 (6.59)	43.00 (6.11)	6.872** (.003)	.266	1.020 (.325)	.051	9.646** (.006)	.337

# Family Relationship Intervention Group VS. Control Group

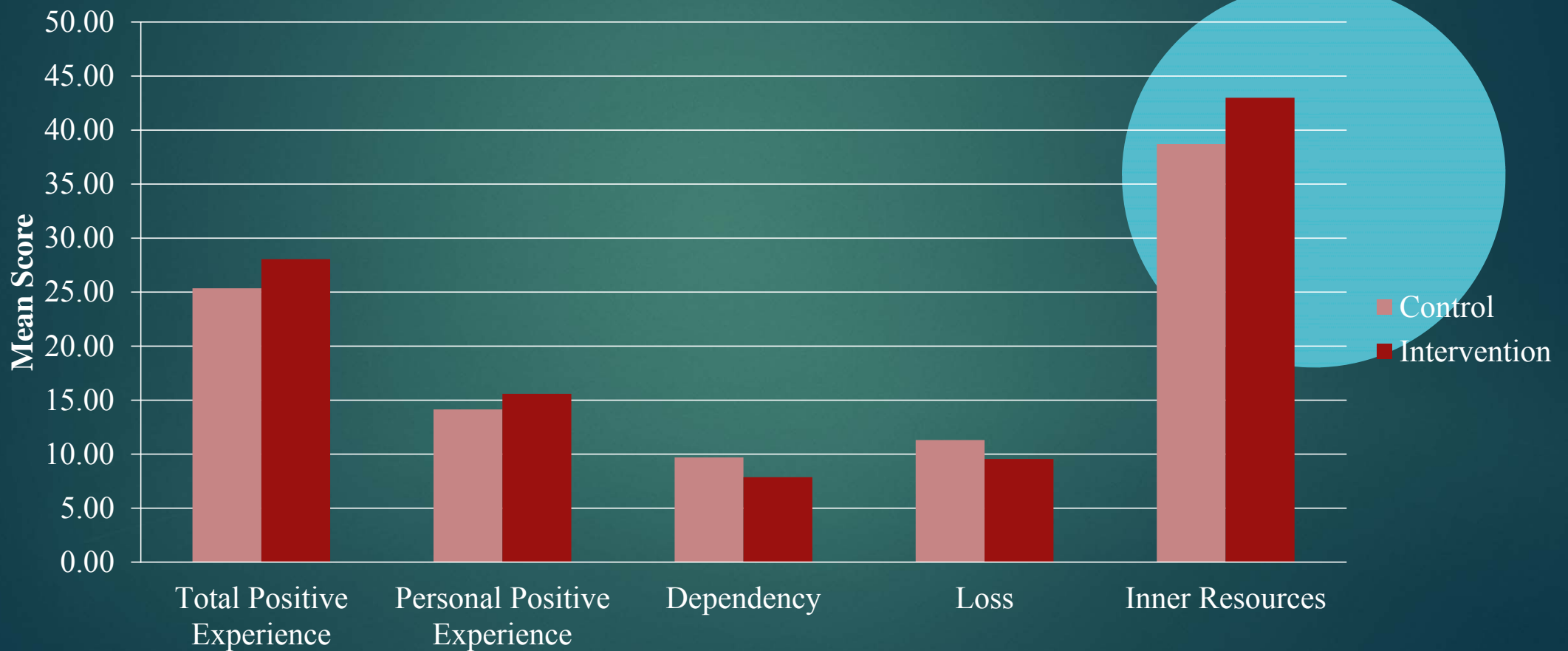
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# Caregiving Experience and Inner Resources Intervention Group VS. Control Group

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# Discussion

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An integrative approach is effective for supporting caregivers

- Improve family relationship
- Positive caregiving experience
- Strengthen the inner resources of caregivers for sustainable growth



# Caregiver Plays an Important Role in the “Recovery Journey”

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## Case Manager as a Co-therapist in the programme

- Caregivers’ s active participation & interaction
- Caregivers benefited by improved self emotional intelligence.
- Caregivers can make a change of their life
- Help self help others



# Benefits and Positive Impacts (Observed in Case's Progress)

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Clients be accepted by Family members.

Clients can build up more healthy relationship with family members.

Clients can co-work with family members in their “RECOVERY JOURNEY”

# Implications for Practices

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The need for innovative practices

Quality services by and for family caregivers

Evidence-based practice, beware of the impact of intervention (heightening the conflict).

Caregiver work should be one of the core strategies, not a supplementary/sideline work

- Family is the unit where the adverse impact of mental illness most felt and takes places; remedies are needed for both the PIR and the family caregivers.
- Family caregivers are equally perplexed by the illness.
- Rebuilding positive and functional family relationship is building long-term support for persons in recovery

Family caregivers are good partners to work with because

- They “experienced” the illness in a different way.
- Their external resources remain intact.



# Implications for Policy

Current policy of taking family caregivers as one of the self-help or mutual help groups is grossly inadequate because:

- It ignores the unique family experiences they have and they are able to shape in the coming future
- Blind to the fact that they are not the ill person yet they “suffer” from mental illness. Their suffering has been under-estimated.
- Their support assumed and resourcefulness often over-estimated.
- All these resulted in extremely poor resources implications

Putting family caregivers back as a major stake-holder and strategic partner, for consultation and collaboration



# Implications for Policy & Theory

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Working with family caregivers should be a major mental health strategy, and supported by resources

- Direct services to family caregivers
- Empowerment framework and platform
- Trained family caregivers as a “para-professional”
  - Specialist training is needed for workers
  - Family caregiver as “Family Support Worker”?

Recovery perspective/theory for family caregivers? Dual paths of recovery?

- Path of illness trajectory and coping
- Path of hope, personal growth, and recovery

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**THANK  
YOU!**



# Reference

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- Bademli, K., & Çetinkaya Duman, Z. (2011). Family to family support programs for the caregivers of schizophrenia patients: A systematic review. *Turkish Journal of Psychiatry*, 22(4), 255–265. Retrieved from <http://www.turkpsikiyatri.com/en/default.aspx?modul=summary&id=823>
- Berwick, D. M., Murphy, J. M., Goldman, P. A., Ware Jr, J. E., Barsky, A. J., & Weinstein, M. C. (1991). Performance of a five-item mental health screening test. *Medical care*, 169–176. doi: 10.1097/00005650-199102000-00008
- Chan, S. W. C., Yip, B., Tso, S., Cheng, B. S., & Tam, W. (2009). Evaluation of a psychoeducation program for Chinese clients with schizophrenia and their family caregivers. *Patient education and counseling*, 75(1), 67–76. doi: 10.1016/j.pec.2008.08.028
- Chen, H. C., & Wang, H. H. (1997). The Relationship between hope, social support and demography of hospitalized patients with hemolymph neoplasm. *The Journal of Nursing Research*, 5(6), 487–497. Retrieved from <http://journals.lww.com/jnr-twina/pages/default.aspx>
- Cheng, L. Y., & Chan, S. (2005). Psychoeducation program for Chinese family carers of members with schizophrenia. *Western journal of nursing research*, 27(5), 583–599. doi: 10.1177/0193945905275938
- Chiu, M. Y., Wei, G. F., Lee, S., Choovanichvong, S., & Wong, F. H. (2013). Empowering caregivers: impact analysis of familylink education programme (FLEP) in Hong Kong, Taipei and Bangkok. *International Journal of Social Psychiatry*, 59(1), 28–39. doi: 10.1177/0020764011423171
- Fallahi Khoshknab, M., Sheikhsa, M., Rahgouy, A., Rahgozar, M., & Sodagari, F. (2014). The effects of group psychoeducational programme on family burden in caregivers of Iranian patients with schizophrenia. *Journal of psychiatric and mental health nursing*, 21(5), 438–446. doi: 10.1111/jpm.12107
- Fok, C. C. T., Allen, J., Henry, D., & Team, P. A. (2014). The Brief Family Relationship Scale: A brief measure of the relationship dimension in family functioning. *Assessment*, 21(1), 67–72. doi: 10.1177/107319111425856
- Gupta, S., Isherwood, G., Jones, K., & Van Impe, K. (2015). Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. *BMC psychiatry*, 15(1), 162. doi: 10.1186/s12888-015-0547-1
- Hong Kong Hospital Authority (2011). Hospital authority mental health service plan for adults 2010-2015. Hong Kong: Hong Kong Hospital Authority.
- Howden, J. W. (1992). Development and psychometric characteristics of the spirituality assessment scale (Doctoral dissertation). *Dissertation Abstracts International*, 54 (1-B), 166B. (UMI No. 9312917).
- Jewell, T. C., Downing, D., & McFarlane, W. R. (2009). Partnering with families: Multiple family group psychoeducation for schizophrenia. *Journal of Clinical Psychology*, 65(8), 868–878. doi: 10.1002/jclp.20610
- Kheng, S. B. (2005). The impact of schizophrenia: The burden of care (Doctoral thesis, National University Singapore, Singapore). Retrieved from <http://scholarbank.nus.sg/bitstream/handle/10635/15000/full%20thesis%20final.pdf?sequence=1>
- White, M. (2007). *Maps of narrative practice*. New York: W.W. Norton & Co. Chicago.