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Empowering Primary Family Caregivers of People with Schizophrenia in Hong Kong

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Good morning. I am very glad to share our work in empowering family caregivers for people with schizophrenia in Hong Kong. In this project, we were very much touched by the caregivers and witnessed their tender care to their family members. They shared many precious experiences that support the recovery of their family members. For example, it is very insightful to know how they deal with the anxiety and fear of their family members in taking regular medications and working together with the medical team to deal with their side effect.

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Family Caregivers

As estimated by Hong Kong Hospital Authority (2011), there are nearly 20,000 schizophrenia outpatients in need of community and family support in Hong Kong. This figure is still rising. The caregivers of family members with schizophrenia were reported to experience mental burdens, experiences of insomnia and symptoms of anxiety and depression (Fallahi Khoshknab, et al., 2014; Gupta et al., 2015). Family caregivers show strong intention to know more about mental health knowledge and build up better communication and relationship with their family members who are battling with schizophrenia and other mental health issues. Psychoeducation is a prevalent supportive approach for family caregivers of people with schizophrenia in Asia, including Hong Kong, with the aim to equip caregivers with knowledge and skills in caregiving (Chiu et al., 2013). Psychoeducational programme holds the premise that supporting caregivers by providing external resources, such as caregiving skills and mental health knowledge, can help them address the perceived stress due to contextual influence (Jewell et al., 2009). In addition to this approach, our family work experiences informed us that family caregivers have their own inner strength and agency in facing adversities and their experiences developed from living together with people of schizophrenia need to be acknowledged in working with family caregivers (Zhou et al., 2020a). However, this aspect was less addressed by previous caregiver empowerment work and researchers. Our research aims at exploring the effectiveness of strengthening the inner strength of caregivers and encouraging them to make meaning of their caregiving experiences in empowering caregivers and integrating it with psycho-educational approach. (Zhou et al., 2020a; 2020b).

The Intervention Study

The whole project involves a randomized controlled trail to compare three intervention groups. FamilyLink Psychoeducational Group provided

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training to equip family caregivers with mental health knowledge and caregiving skills. Collective Narrative Practice Group focused on strengthening caregivers' inner strength by facilitating their self-exploration and their reflection of the caregiving experiences. Integrative Peer Support Growth group combined the strength of the two approaches, which valued the experiences and wisdom of the caregivers and at same time provided them mental health knowledge and caregiving skills. In this study, 194 caregivers participated screening test. 132 participants have been randomized to take in one of the three caregiver supporting groups. Two effectiveness studies about the psycho-educational group and the narrative group have been published in international peer reviewed academic journals (Zhou et al., 2020a; 2020b). For this sharing, we focuses more on the comparison of Integrative Peer Support Growth group and the control group. For this integrative group, 36 participants joined groups, among them 26 participants have completed all eight group interventions. The average age is 51 (SD=11.36). Among them 7 are males and 25 females. 37.5% of them are sibling caregivers. 34.4% of them are parent caregivers. Spousal caregivers are 18.8% and children caregivers are 9.4%.

The FamilyLink Psychoeducational group is a very well-established approach based on the work of Chiu et al. (2013), which was found to be effective in Taipei and Hankou (Chiu et al., 2013; Zhou et al., 2020b). The Collective Narrative Practice Group externalized schizophrenia from people diagnosed with schizophrenia. Caregivers named schizophrenia as "an unexpected visitor". This externalization (White, 2007) made such a difference and provided more space for family caregivers to contemplate their relationship with "schizophrenia". Some family caregivers chose to use an attack-and-defence metaphor, "How can we drive away this unexpected visitor?" Other family members chose to live together with this unexpected visitor, "We welcome you and won't push you out, but let's see how we can live together?" This is different from the psychoeducational approach. The group was not held to teach caregivers what they need to know. In contrast, family carers were invited to speak out what their experiences were with the unexpected visitor of schizophrenia and contributed their views to this community of people who wanted to support their family members in their recovery journey. Thanks to precious sharing of the caregivers, we were privileged to gain a phenomenological perspective of schizophrenia. Based on their input, we developed a new protocol, which we combined professional mental health knowledge, caregiving skills with the knowledge and skills that we obtained from primary family caregivers of schizophrenia in the integrated approach. The Integrative Peer Support Growth group has eight sessions, entitled as Unexpected Vistor: What is Schizophrenia, Complex of Medication: How to Maintain Regular Medication, Flow with Changes: Crisis Management, Dances in Pairs: Family Communication, Self-Embracement: Self Compassion and self-Care, Teatime: Re-membering Life Significant Others, Reconstructed Future: Preferred Identity, Passing on the Torch: Community Work and Social Support.

In order to test effectiveness of the Integrative Peer Support group, standardized scales such as Family Relationship Scale (Fok, Allen, Henry, & People Awakening Team, 2014), The Chinese Version of Experience of Caregiving Inventory (Kheng, 2005), Inner Resource Scale (Howden, 1992), The Chinese version of Herth Hope Index (Chen & Wang, 1997) have been used to do the pre and post-test and the follow up test. In the pre-test, there were no statistically significant differences between the Integrative Peer Support Growth Group and the control group. After the eight integrative peer support growth group sessions, caregiver participants in the integrative peer support group outperformed the participants in the control group in their scoring of many aspects. As Table 1 shows, scoring of most scales or subscales have improved. Some improvement has reached statistically significant level. Family cohesion of the integrative peer support growth group improved significantly in comparison with the control group. Regarding caregiving experiences, the total negative score, dependency and loss significantly improved. The inner resources of participants also improved significantly.

This study shows us that the Integrative Approach is effective for supporting caregivers. It helped improve family relationships, mitigate negative caregiving experience and strengthen

Table 1
Dependent t-test between Integrative Peer Support Growth Group and Control group in the post-test

All measures	Control n = 26		IPSGG n = 26		*t*	Sig.	Cohen's *d*
	Mean	*SD*	*Mean*	*SD*			
Brief Family Relationship Scale							
Cohesion	4.90	1.34	5.95	1.32	-4.481***	.000	.79
Expressiveness	1.83	1.15	2.09	1.16	0.901	.377	-
Conflict	1.38	1.50	3.92	1.32	-1.544	.136	-
Experience of Caregiving Inventory							
Total positive score	25.24	8.49	28.38	7.34	-2.040	.055	-
Positive personal experiences	14.09	5.52	15.87	4.24	-1.668	.109	-
Good aspects of relationship	11.68	4.12	12.68	3.97	-1.512	.145	-
Total negative score	77.85	27.12	66.60	22.50	3.534**	.002	.45
Difficult behaviors	12.74	7.05	10.87	5.87	1.430	.167	-
Negative symptoms	10.54	5.58	8.96	4.74	1.709	.101	-
Stigma	5.65	3.76	4.65	2.85	1.790	.087	-
Problems with services	7.91	4.07	8.09	3.46	-.249	.806	-
Effects on family	7.09	4.31	6.96	3.43	.222	.826	-
Need to backup	12.78	4.28	11.52	3.85	1.599	.124	-
Dependency	9.88	4.22	7.92	3.13	4.329***	.000	.53
Loss	11.27	4.15	9.45	3.88	3.288**	.004	.45
Inner Resource Scale	38.19	6.84	43.44	6.15	-3.544**	.002	.81
Herth Hope Index	30.33	3.29	31.33	2.94	-1.149	.264	-

Note. $*p < 0.05$, $** p < 0.01$, $*** p < 0.001$

the inner resources of caregivers for sustainable growth.

During the integrative peer support growth group, a father chose a card of a treasure box to symbolize his experiences as a caregiver. He recalled his past experiences with his son who suffered from schizophrenia and said that all past experience, no matter positive or negative, were precious treasure of life that enriched their life experiences and enhance the understanding between a father and his son. He chose a running train to symbolize presence. He said that he took his son for travelling to see a bigger world. At first, his son was afraid of going out. He started to take him from near to far places. They have travelled to Lamma Island and several cities in Mainland China. Now they planned together where to spend their leisure time. The father chose a card of flying doves to show his hope of embracing a future of freedom. A young man who took care of her mother with schizophrenia, drew a picture of a sailboat with four sails. The four sails symbolized four people in their family. He said that his family has passed through life challenges. He used waves and darkness to symbolize the life adversities. In front of the sailboat, is a sea that is more calm and colorful because he firmly believed that the future would be better for the whole family when they all support each other. (Zhou & Wong, 2019)

The Continuity of the Recovery Journey

Primary family caregivers stand firmly beside their family members with schizophrenia outpatients in Hong Kong. They co-work with them

in their journey of recovery. Their experiential knowledge and skills should be acknowledged and valued. In our research, we have got in touch with around 190 family caregivers and their narration is not all focused on burden. Most stories are about love, appreciation and mutual growth. Growth surpasses burden in their reflection of the caregiving experiences. The group intervention of practice and our research findings suggest the following implications for future practices in the field:

First, putting family caregivers back as a major stakeholder and strategic partner for consultation and collaboration. Family caregivers are good partners to work with because they experience mental illness in a different way. For example, psychiatrists know schizophrenia and medications the best. Caregivers know the persons with schizophrenia better as they have lived together with them in their daily life. They know how to support their family members to maintain their regular medication. It is important that medical team, family members and social welfare agencies can work closely together to support the recovery journey of people with mental illness.

Second, caregiver work should be one of the core strategies, not a supplementary or side-line work. Working with family caregivers should be a major mental health strategy and supported by resources. Family is the unit where the adverse impact of mental illness most felt and takes places. Sometimes, family caregivers are equally perplexed by the illness. Remedies are needed for both the mental health outpatients and the family caregivers. The focus of family caregiver programmes should not be solely focused on helping their family members with mental illness. One can only help others if they first help themselves or receive necessary help. Family caregivers should not be the next patients. Health and wellbeing of family caregivers are equally important. Self-nurturing and self-compassion should be encouraged in the caregiving progammes. It is important for caregivers also to have their own future and life. Caregiver should not be their only identity. In addition to their caregiving roles, their own preferred life should also be brought to the foreground. We call for direct services to family caregivers and a new empowerment framework that values their experiences and wisdom and put their inner strength, emotion regulation and personal growth. After equipping them with psychoeducational knowledge and skill, we make a step further to ask how we can empower them from inside.

Third, we call for a recovery perspective for family caregivers. Rebuilding positive and functional family relationship is important for long-term support for persons in recovery. There is a path of illness trajectory and coping and also a path of hope, personal growth and recovery. The latter is worth exploring and investigating. We are hoping that trained family caregivers can be involved in the mental health field as "para-professionals". Family caregivers can receive trainings and becomes "Family Support Workers". They can become the ambassadors to share message of hope, personal growth and recovery.

Thanks for your attention!

References

Bademli, K., & Çetınkaya, D. 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/defau lt.aspx?modul=summary&id=823

Chen, H. C., & Wang, H. H. (1997). The relationship between hope, social support and demography of hospitalized patients with hemolymph neoplasm. *Journal of Nursing Research, 5(6)*, 487-497. Retrieved from http://journals.lww.com/jnr-twna/pages/default.aspx.

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. https://doi.org/10.1177/0020764011423171

Fallahi Khoshknab, M., Sheikhona, 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: doi.org/10.1177/1073191111425856.

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. https://doi.org/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. https://doi.org/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, NY: W.W. Norton & Co.

Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., Kuipers, E. & Kendall, T. (2015). Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. *The British Journal of Psychiatry, 206(4)*, 268–274. https://doi.org/10.1192/bjp.bp.114.147561

Zhou, D.H. R., Chiu, Y. L. M., Lo T. L. W., Lo, W. F. A., Wong, S. S., Luk, K. L., Leung, C. H.T., Yu C. K., & Chang, Y.S. G. (2020). An unexpected visitor and a sword play: A randomized controlled trial of collective narrative therapy groups for primary carers of people with schizophrenia. *Journal of Mental Health*. Doi: 10.1080/09638237.2020.1793123

Zhou, D.H. R., Chiu, Y. L. M., Lo T. L. W., Lo, W. F. A., Wong, S. S., Luk, K. L., Leung, C. H.T., Yu C. K., & Chang, Y.S. G. (2020). Outside-in or inside-out? A randomized controlled trial of two empowerment approaches for family caregivers of people with schizophrenia. *Issues in Mental Health Nursing. 41 (9)*, 761-772. doi: 10.1080/01612840.2020.1734992

Zhou, D. H. R. & Wong, S. S. (2019). Stories of family caregivers: Theatre of life. In D. H. R. Zhou, T.L. W. Lo, Y. L. M. Chiu, & W. F. A. Lo. (Eds). *Convoy of recovery: Healing of Psychosis* (pp. 207-229). Hong Kong: City University of Hong Kong Press. (In Chinese) 周德慧、黃兆星(2019)。〈家屬的故事：精分劇場〉。周德慧、盧德臨、趙雨龍、盧慧芬（編）。護航復元—思覺失調的療癒（頁207–229）。香港：香港城市大學出版社。