

HKEC Symposium on Community Engagement V:

Family – The Key to a Healthy Community



香港復康會
The Hong Kong Society
for Rehabilitation
社區復康網絡
Community Rehabilitation Network

AN EXPERIENCE OF MUTUAL SUPPORT AMONG CHRONIC DISEASE FAMILIES

**Project: Mutual Support Platform for Families and
Caregivers of People with Chronic Illness**

「照顧者互助支援平台」服務

Presented by
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Background

- Caregiver of chronic illness patient's strain level research in 2005
 - Three main strains:
 - psychological and physical exhaustion
 - adaptation of emotional
 - adaptation of habit changes
- 根據2005年「長期病患者的照顧者壓力調查」
 - 照顧者最主要的壓力 (身心靈疲累、情緒上的適應及起居生活習慣的改變)
- Initiated by 5 SHOs and CRN
- 由5個病人自助組織(慧進會、新健社、柏金遜症會、肌健協會、柏力與確志協會)及社區復康網絡 合辦
- Funded by Social Welfare Department, Chronic Illnesses Relief Fund from Pok Oi Hospital and Partnership Fund
- 由社會福利署、博愛醫院長期病患者援助金、攜手扶弱基金津助




Aims and objectives

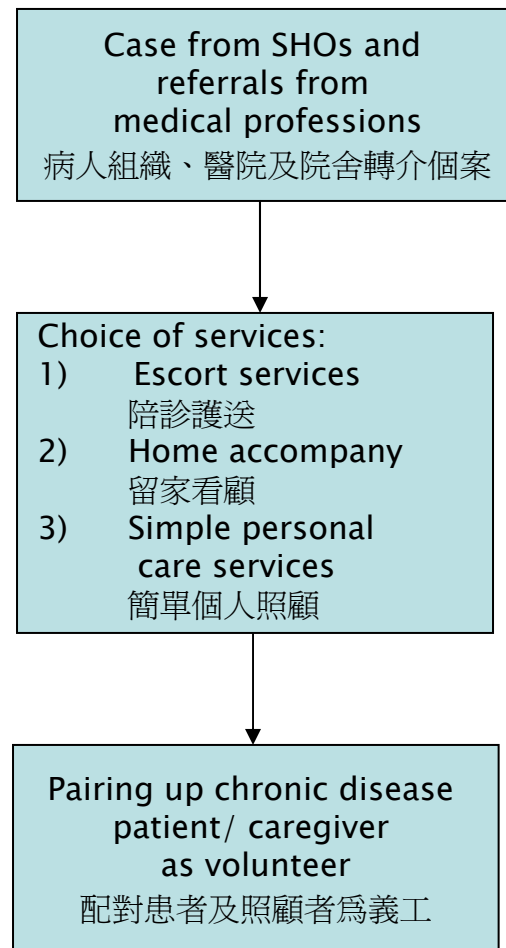
- Aims:
 - Relieve caregiver's care strain condition
 - 減輕照顧者的壓力
 - Promote mutual help among chronic disease families
 - 推動長期病患家庭自助互助的精神
- Objectives:
 - Improving chronic disease people's quality of life
 - 提升長期病患者生活質素
 - Developing self-esteem and self-efficacy
 - 提升長期病患者自尊感及自我效能感
 - Building up social support resources and network
 - 建立長期病患者及家人照顧者互助資源和網絡

Service flow and remarks

- Statistics (2007.12-2009.11) :
 - No. of chronic disease families served: 124
 - No. of volunteers involved: 52
 - Total service times/ hours: 1135 times/ 5504hrs

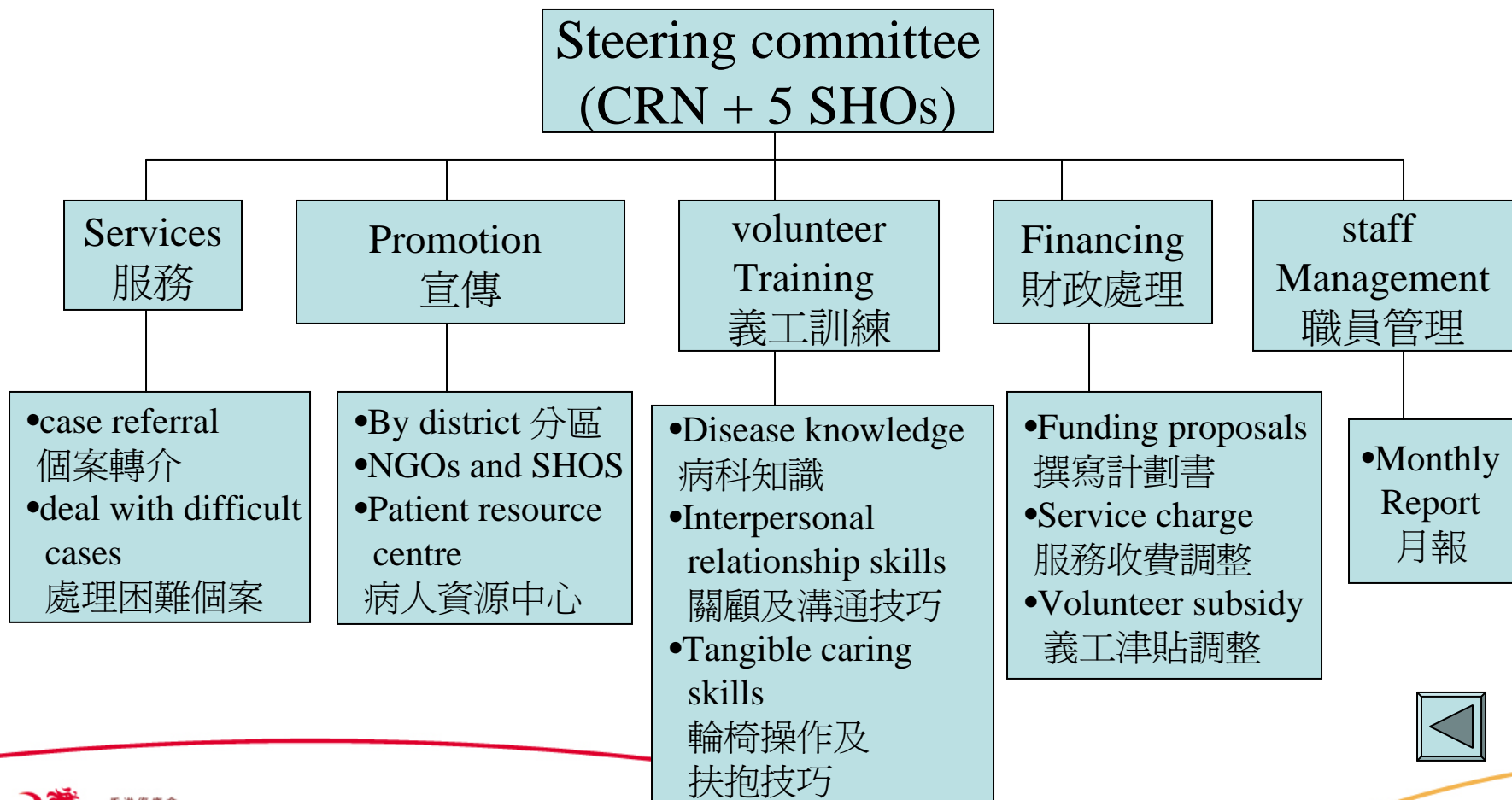
- Remarks

- Collaborations between professionals and patient groups (專業人士與病人組織的合作)
 - Project management's structure 
 - Case follow-up: network back to rehabilitation resources, eg. SHOs, CRN rehabilitation courses
- Volunteers give peer support to chronic disease families in need (義工發揮同路人角色能產生共鳴)
 - Sharing from case and carer 
- Reciprocal caring relations between volunteer and user (個案與義工間彼此接納與支持)
 - Sharing from volunteer 



Project management's structure

Role and work of steering committee 策導委員會的角色及工作



Evidence Based Practice 成效研究

- Quantitative research 量研究
 - Started from 2009.7 to 2010.6
 - Single subject multiple waves design (單一系統多項設計)
 - Four waves design (every three month for data collection)
 - Quota Convenience sampling (配額便利抽樣方法)
 - Measurement
 - General Health Questions (一般健康問卷)
 - Medical Outcomes Study Social Support Survey (社會支持問卷)
 - Caregiver Strain Index (照顧者負荷指數)
 - Self-efficacy scale (自我效能感表)
 - Rosenberg Self-esteem scale (自尊感指數)
 - Demographic factors (其他背景資料)
- Qualitative research 質性研究
 - Volunteers, service user and carer focus group 成效分享會
 - Sharing the effectiveness of the programme and successful elements

Result: User (結果: 服務使用者)

Measuring Items	Mean of W1	Mean of W2	Sig. for T-test
(I) 一般健康問卷	16.83	16.75	0.952
(II) 社會支持問卷	50.70	50.04	0.757
實務性的社會支持 Tangible Support	11.04	11.65	0.456
情感方面的社會支持 Affectionate Support	7.65	6.87	0.080
人際聯繫的社會支持 Social Interaction Support	10.39	9.57	0.275
情緒及忠告性的社會支持 Emotional Informational Support	17.74	18.65	0.420

Result: Carer (結果: 照顧者)

Measuring Items	Mean of W1	Mean of W2	Sig. for T-test
(I) 一般健康問卷	15.11	17.11	0.160
(II) 社會支持問卷	54.11	58.22	0.439
實務性的社會支持 Tangible Support	8.56	9.89	0.459
情感方面的社會支持 Affectionate Support	7.78	7.89	0.892
人際聯繫的社會支持 Social Interaction Support	10.11	11.67	0.202
情緒及忠告性的社會支持 Emotional Informational Support	27.44	22.56	0.613
(III) 照顧者負荷指數	14.11	14.00	0.912

Result: Volunteer (結果: 義工)

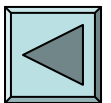
Measuring Items	Mean of W1	Mean of W2	Sig. for T-test
(I) 一般健康問卷	12.96	13.83	0.164
(II) 社會支持問卷	66.70	75.35	0.113
實務性的社會支持 Tangible Support	11.78	12.43	0.305
情感方面的社會支持 Affectionate Support	9.17	9.83	0.126
人際聯繫的社會支持 Social Interaction Support	12.39	14.91	0.172
情緒及忠告性的社會支持 Emotional Informational Support	<u>23.48</u>	<u>25.22</u>	<u>*0.037</u>
(III) 自我效能感量表	26.29	24.54	0.067
(IV) 自尊感指數	21.09	20.17	0.136

Focus group result (成效分享會分析)

- To measure how each of the core services achieve the goals
- 量度主要服務種類達致各項目標的調查
 - Service type (主要服務種類)
 - 陪診、外出、留家看顧
 - Goals (目標)
 - 減壓、生活開心d、有人陪伴
 - Targets (對象)
 - 服務使用者及義工
 - Scale (評分): 1-5分 (Highest 最高為5分, Lowest 最低為1分)
- Result (結果)
 - 整體計算：
 - 外出令生活開心d 得分最高 (3.92)
 - 各服務種類最能達致的目標
 - 陪診: 助減壓 (3.89)
 - 外出: 令生活開心d (3.92)
 - 留家看顧: 助減壓 (3.39)
 - 服務使用者的看法:
 - 陪診助減壓 (4.09)
 - 義工的看法:
 - 外出令生活開心d (4.00)

Sharing from carer, patient and volunteer

- Wheelchair patient's carer
 - “「平台義工」除了受過專業培訓外，更是細心；對個案關心之餘又明白其處境，我欲在此向義工們表達我的敬意及謝意。”
- Patient with neuro-muscular disease living in care & attention home
 - “感謝平台義工，為我找到一所我可以進出的酒樓，雖然受到四週茶客的著目，還很細心地把食物剪碎件，續一端到我口裏。那種與正常人一樣的自由選擇及大快朵頤的感覺，到如今，都是我那枯燥生活中最窩心的一刻。”
- Epilepsy volunteer
 - “他致電關心我，問我身體是否安好。我感到很開心及感動，我沒有想過我去服務及關心別人，別人也會反來關心我，我的自信心慢慢開始增強。”



Sharing from a carer of stroke patient



Key message

Chronic disease persons may not be a burden of society, when knowledge, experience, strength gain from disease can be a social capital to families with chronic disease persons and the society

長期病患者及其照顧者的知識、經驗及能力
本可成爲社會資本, 能減省社會的重擔

Difficulties

- Lack of volunteers in certain districts
部份地區義工不足
- Challenge to maintain volunteer's commitment
維持義工參與服務
- **Challenge of great demands, but not enough resources**
服務需求眾多, 但資源不足
- Balance of service fee and volunteer subsidy
調整服務收費及義工津貼, 求取平衡
 - Low rated service fee = more subsidy needed to pay for volunteer subsidy
 - Eg. \$10/hr service fee + \$10/hr subsidy
= \$20/hr volunteer subsidy
 - How about the volunteers providing cross-district services?
 - 設立跨區服務津貼?

***Ample funding is needed ! 充足資源是不可或缺的!**

Conclusion

- **Opportunity: service gap 服務縫隙**
 - Compare with main stream service
 - Flexibility in human resource and less boundary restriction
 - Peer support between chronic disease persons and families
 - 比較主流服務，此服務能彈性地處理人手安排，且沒有地區性規範，更重要是提供「同路人」支持和鼓勵
- **Strength:**
 - Training up chronic disease persons and families to serve each other, by making use of their unique disease and emotion management experience
 - 鼓勵患者及照顧者分享寶貴的復康經驗，包括疾病及情緒管理，推動自助互助
 - User's participation: collaborations with SHOs
 - Steering committee to manage project
 - Patients to deliver service
 - 以「同路人」提供服務及病人組織策劃整個服務能體現用者參與精神

柏力與確志協會



Thank you 謝謝!

小腦萎縮症協會



新健社



肌健協會



慧進會



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