

賽馬會安寧頌



Jockey Club End-of-Life Community Care Project



“Life Rainbow” End-of-life Care Services



Volunteer as Care Partner in End-of-Life Community Care

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同心同步同進 RIDING HIGH TOGETHER

主辦機構 Organized by:



香港復康會
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策略伙伴 Strategic Partners:



HONG KONG
EAST CLUSTER
港島東醫院聯網



聯合博習 醫學士院
東區尤德夫人那打素醫院
內科部、社區及病人資源部



Community EoL Care for patients and families with late stage chronic illness

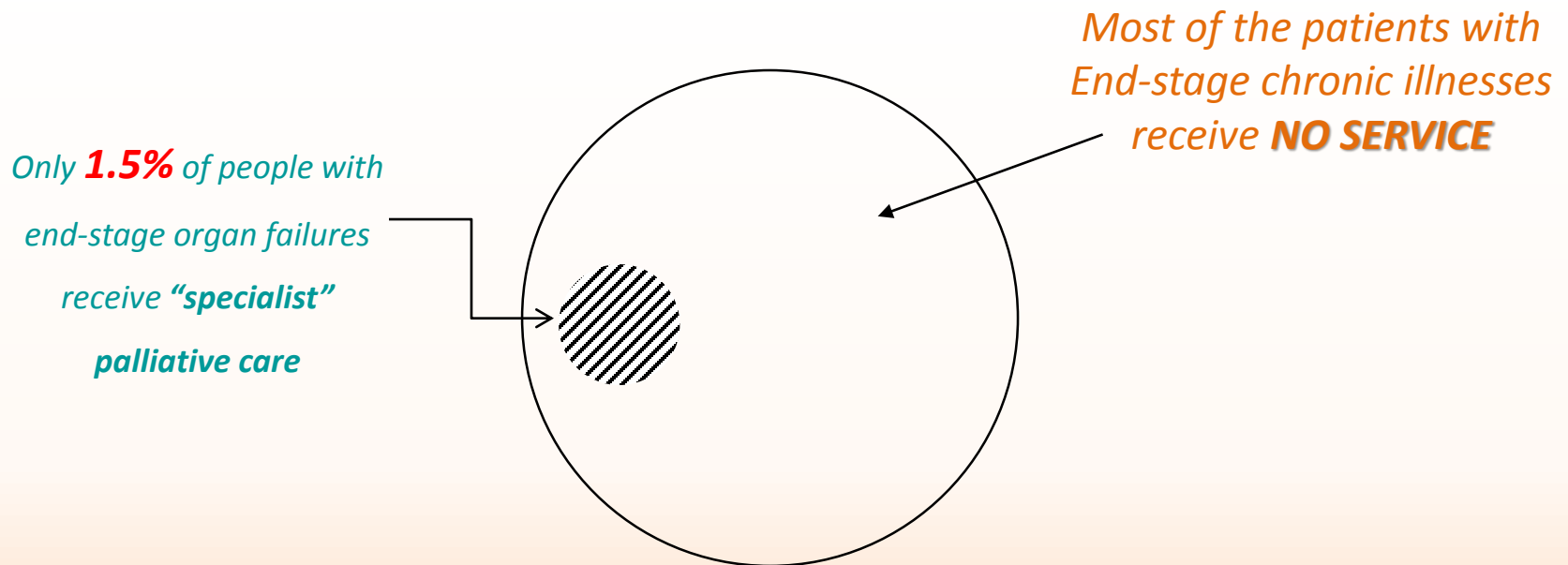


1. Chronic Obstructive Pulmonary Disease (COPD)
2. Heart Failure
3. End-Stage Renal Failure
4. Neurological Diseases (Parkinson's Disease, Motor Neuron Disease)

Unmet Service Needs

- Nearly **60%** of death in Hong Kong is from non-malignant chronic illnesses
- Only around **1.5%** of them received palliative care
(compared with that of 80% in cancer patients)

(Lau et al., 2008; Lau et al., 2010)



Challenges for end-stage chronic patients

loneliness

anxiety

POOR MOBILITY

depression

DIFFICULTY IN SLEEPING

CONSTIPATION

POOR APPETITE

EDEMA

PAIN

grief

DYSNEA

FATIGUE



Four Intervention Focus

*Symptom
Management
Education & Optimize
Health Functioning*

*Psychosocial Spiritual
Support*

*Positive Death
Preparation*

*Connecting to
Community Resources*

Multi-disciplinary Team

Social Workers

Nurse

Therapists



*Professional
Volunteers*

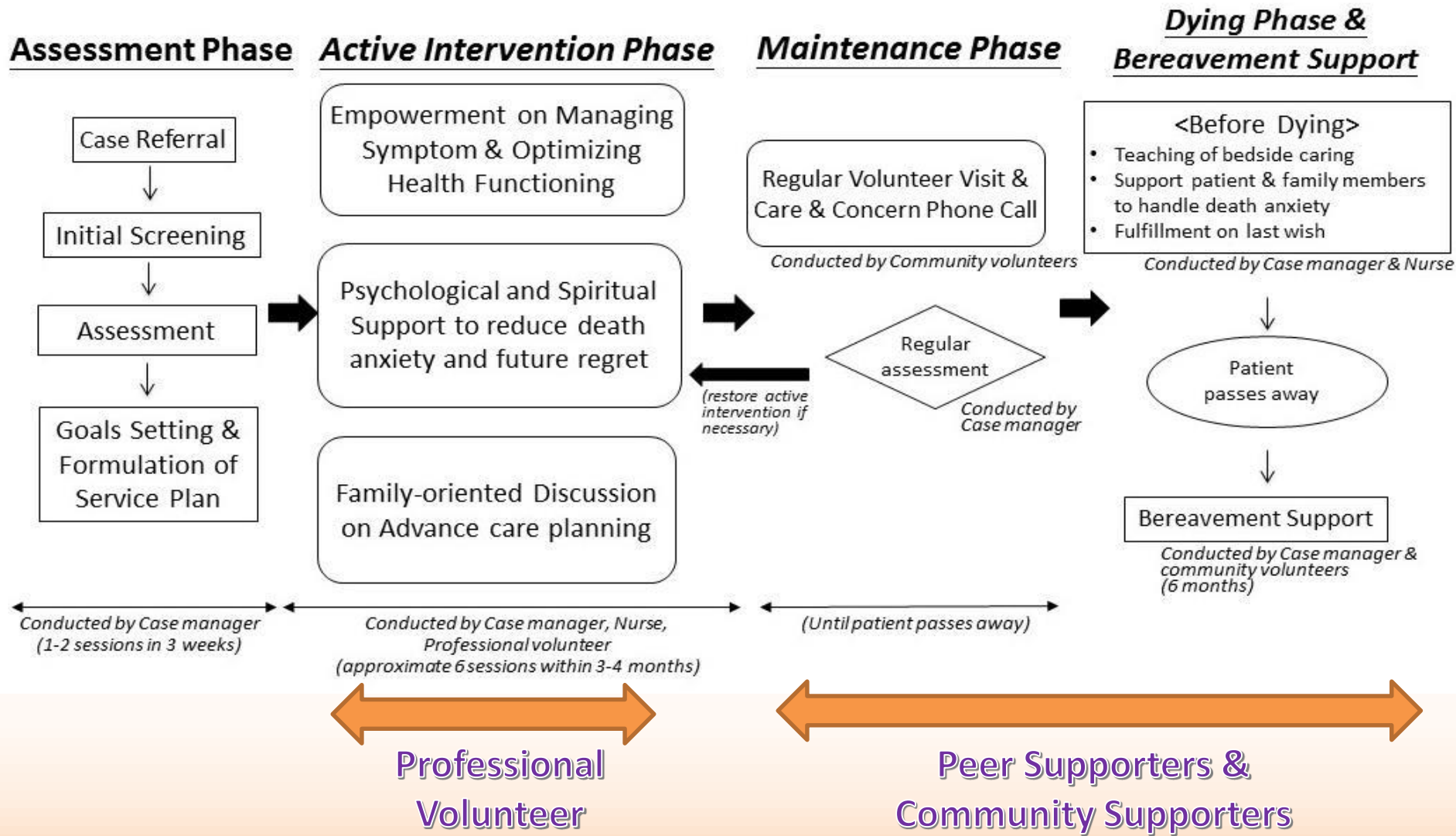
Peer Supporters

*Community
Supporters*

Professional Team

Volunteer Team

Service Protocol



Professional Volunteers

- Retired medical & healthcare practitioners (*e.g. nurses, physiotherapists, occupational therapists, social workers*)
- Roles: **symptom management education, caregiver empowerment, prescribe plan related to symptom management in maintenance phase** (for volunteers to follow-up)

Conduct Assessment

**Symptom
Management
Education**

**Caregiver
Empowerment**

Peer Supporters

- Ex-family caregivers or patients with chronic illness with stable conditions
- Support in **maintenance** and **bereavement** phases
- Roles: Sharing of **experience & practice wisdom** in daily caring, **monitoring of the health care action plan**, **emotional support**, **role model**

Sharing tips in meal preparation to improve patient's appetite

Sharing tips in mindfulness practice for caregivers

Exercise practice with patients

Community Supporters

- Volunteers with passion in end-of-life care and recruited in the community
- Support in **maintenance** and **bereavement** phases
- Roles: Assisting in **wish fulfillment**, **joyful activities**, **practical supports in daily life**

Outings with patients and families

Joyful Activities

Practical Support



Project Outcome

	N	T ₀ service intake Mean (SD)	T ₁ 1 st month Mean (SD)	T ₂ 3 rd month Mean (SD)	t	Sig. (2-tailed)
T₁-T₀ (1st month of service)						
IPOS Total (0-68) ↓	32	18.63 (7.197)	12.91 (4.848)		-4.931	.000
IPOS Physical Symptoms (0-40) ^a ↓	72	7.26 (4.409)	5.29 (4.001)		-4.477	.000
IPOS Renal Failure Symptoms (0-20) ↓	32	1.53 (2.286)	.97 (1.576)		-2.509	.018
Patient Depression (0-4)** ↓	74	.99 (.836)	.43 (.575)		-6.416	.000
Patient's Anxiety (0-4) ↓	73	1.32 (.743)	.85 (.758)		-4.97	.000
Patient not at Peace (0-4) ^a ↓	73	1.27 (.886)	.77 (.717)		-4.989	.000
Family Anxiety (0-4) ↓	73	1.42 (.912)	1.07 (.733)		-3.49	.001
Patient Unable to Share Feelings with Family/Friends (0-4) ↓	72	2.13 (.978)	1.58 (1.071)		-4.389	.000
Practical Problems (0-4)** ↓	75	1.51 (.95)	.83 (.812)		-7.288	.000
Unmet Information Needs (0-4) ↓	34	1.94 (.952)	1.24 (1.017)		-5.416	.000
Time Wasted on HealthCare Appointments (0-4) ^a	75	1.76 (1.944)	1.63 (1.964)		-1.217	.228
	N	T ₀ service intake Mean (SD)	T ₁ 1 st month Mean (SD)	T ₂ 3 rd month Mean (SD)	t	Sig. (2-tailed)
T₂-T₀ (3rd month of service)						
IPOS Total (0-68) ↓	16	16.5 (6.89)		9.63 (5.702)	-3.375	.004
IPOS Physical Symptoms (0-40)* ↓	46	6.96 (4.839)		4.93 (4.008)	-3.494	.001
IPOS Renal Failure Symptoms (0-20)	19	1.37 (2.499)		.79 (1.182)	-1.207	.243
Patient Depression (0-4)* ↓	47	.94 (.87)		.28 (.452)	-5.217	.000
Patient's Anxiety (0-4) ↓	45	1.18 (.684)		.58 (.69)	-5.157	.000
Patient not at Peace (0-4) ↓	46	1.09 (.812)		.37 (.532)	-5.654	.000
Family Anxiety (0-4) ↓	47	1.23 (.865)		.77 (.633)	-3.643	.001
Patient Unable to Share Feelings with Family/Friends (0-4) ↓	45	1.93 (1.053)		1.24 (1.19)	-4.266	.000
Practical Problems (0-4) ^a ↓	48	1.27 (.869)		.58 (.7096)	-5.575	.000
Unmet Information Needs (0-4) ↓	18	1.56 (.856)		.61 (.85)	-4.994	.000
Time Wasted on HealthCare Appointments (0-4)**	48	1.54 (1.901)		1.5 (1.913)	-.275	.785

Notes. * $p < .05$; ** $p < .01$; ^a $p < .1$; ^b Positively worded items have been changed to negative, so that high scores indicate more severe problems in all items. A negative t -value indicates an improvement.



Project Outcome

	N	T ₀	T ₁	T ₂	t	Sig. (2-tailed)
T₁-T₀ (1st month of service)						
		Mean (SD)	Mean (SD)	Mean (SD)		
Pain	73	.79 (.865)	.68 (.926)		-.970	.335
Shortness of breathe ** ↓	74	1.49 (1.208)	1.14 (1.064)		-3.206	.002
Weakness or lack of energy *** ↓	74	1.30 (1.179)	.85 (.902)		-3.803	.000
Nausea	74	.09 (.411)	.07 (.416)		-.815	.418
Vomiting	74	.08 (.361)	.05 (.366)		-2.382	.418
Poor appetite * ↓	73	.60 (.829)	.38 (.757)		.705	.02
Constipation	74	.04 (.199)	.07 (.253)		-1.932	.483
Sore or dry mouth ^a	74	.09 (.376)	.01 (.116)		-3.053	.057
Drowsiness** ↓	44	.89 (1.211)	.53 (.815)		-3.257	.003
Poor mobility ** ↓	74	1.73 (1.296)	1.38 (1.107)		-1.438	.002
Itching	32	.50 (.984)	.44 (.914)		-1.854	.161
Difficulty sleeping ^a	33	.42 (.792)	.18 (.465)		-1.438	.073
Restless legs or difficulty keeping legs still	32	.25 (.762)	.125 (.421)		-1.438	.161
Changes in skin	32	.31 (.354)	.19 (.535)		-1.438	.161
Diarrhea	32	.063 (.354)	.063 (.354)		.000	1.000
T₂-T₀ (3rd month of service)						
	N	T ₀	T ₁	T ₂	t	Sig. (2-tailed)
		Mean (SD)	Mean (SD)	Mean (SD)		
Pain** ↓	47	.89 (.914)		.53 (.718)	-3.131	.003
Shortness of breath* ↓	48	1.46 (1.071)		1.13 (.959)	-2.369	.022
Weakness or lack of energy** ↓	48	1.10 (1.115)		.71 (.988)	-2.992	.004
Nausea	48	.15 (.505)		.06 (.245)	-1.430	.159
Vomiting ^a	48	.13 (.444)		0 (0)	-1.952	.057
Poor appetite	47	.49 (.777)		.36 (.673)	-1.231	.224
Constipation	48	.02 (.144)		.10 (.309)	1.663	.103
Sore or dry mouth	48	.15 (.461)		.06 (.320)	-1.071	.290
Drowsiness ^a	48	.75 (1.246)		.5 (.923)	-1.811	.077
Poor mobility	48	1.60 (1.364)		1.38 (1.347)	-1.532	.132
Itching ^a	19	.58 (1.071)		.26 (.562)	-2.051	.055
Difficulty sleeping	20	.35 (.813)		.25 (.786)	-.438	.666
Restless legs or difficulty keeping legs still	20	.35 (.933)		.2 (.410)	-.900	.379
Changes in skin ^a	20	.25 (.639)		.1 (.308)	-1.831	.083

Notes. * $p < .05$; ^a $p < .1$; ^b High scores indicate more severe problems in all items. A negative t-value indicates an improvement.



Learning Insight (1): It's a "Mutual Help" Process!



- Patients and families receives **emotional support, companionship,** and **practical assistance** from volunteers
- Meanwhile, volunteers often say they **receive more than they give** from the patients and families and it is a **privilege** to work with them

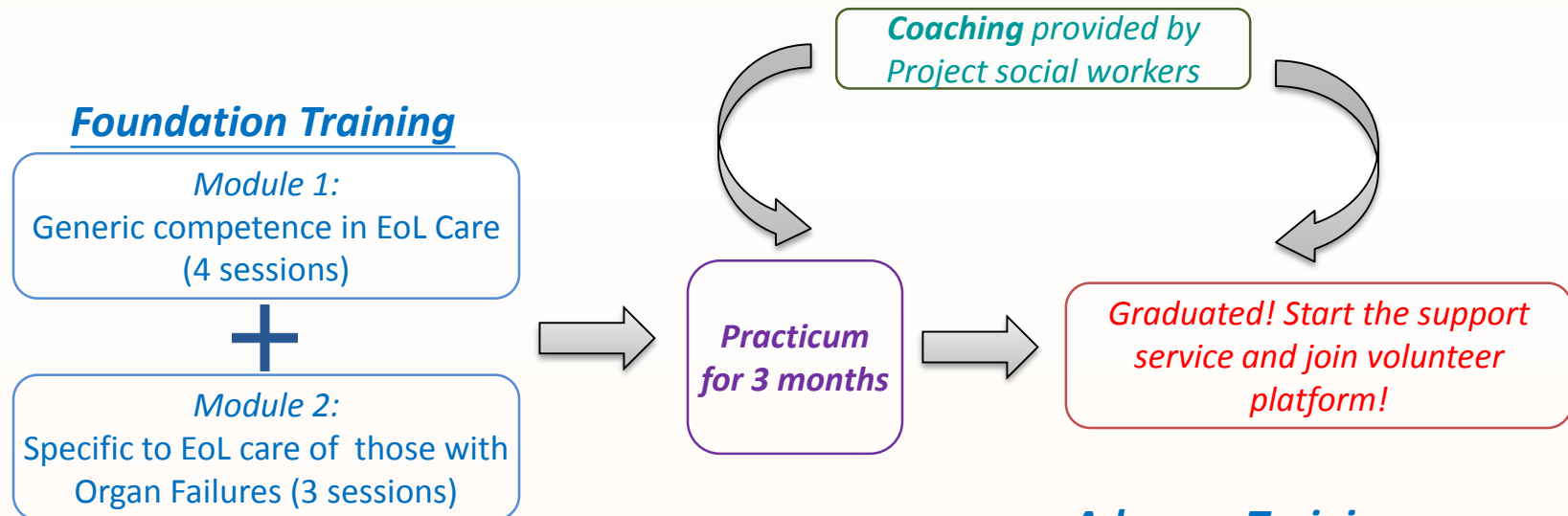
- ✓ Personal growth
- ✓ Greater appreciation to life
- ✓ Obtain new insights in life
- ✓ Increases self-confidence
- ✓ Improve communication skills
- ...etc



Continuous Support to Volunteers is Crucial



- Systematic and continuous **training system** (Knowledge x Skills x Attitude)
- Provide **close mentorship** (debriefing and evaluation with volunteers after each visit)
- **Regular meeting** to share service experience and feelings



Advance Training

Training topics:
Life review, horticultural activity, music activity, traditional games, photography

The use of IBMS techniques to relieve patients' symptoms.



Learning Insight (3): Communication between volunteers



Case Manager



Users' Guidebooks



WhatsApp



Conclusion

- Project shows effectiveness in relieving symptoms and improving psychosocial-spiritual wellbeing for late-stage chronic patients.
- **Community Care End-of-Life Care** approach has a promising prospect in the future local palliative care to meet the huge service demand.
- Volunteers are important **social capital** in the community care model of end-of-life care.



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