

賽馬會安寧頌



Jockey Club End-of-Life Community Care Project

Supporting People with Life-limiting Illness at Home – sharing of experience from JCECC Project

20th June 2018

策劃及捐助 Initiated and funded by:



香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心同步同進 RIDING HIGH TOGETHER

合作夥伴 Project Partner:



Introduction

- Home is a familiar place for all. Almost all patients wish to stay at home to spend time in their last journey as far as possible.



Introduction

- Under the support from JCECC Project, “Hospice at Home Service” commenced in Jan 2016. 安寧頌 -- 安居晚晴照顧計劃



賽馬會安寧頌 - 「安居晚晴照顧計劃」



- Patient aged 60 or above
- Suffering from advanced cancer or non-cancer illnesses
- Estimated life expectancy of 6 months
- To support patients and their family in the community

- **Service Model:** Using case management model to assist family in providing EOL care to patients with advanced disease in the community.
- **Key Features/Components of Services:**
 - Case management model -- Nurse as the case manager throughout the journey
 - Coordination of care – to facilitate access to medical, psycho-social, rehabilitation, respite care and bereavement support.

(continue)

- **Key Features/Components of Services:**
 - Seamless communication with referring medical team
 - Medical back up by specialist in palliative medicine
 - All nurses and social workers are equipped with skills to discuss Advance Care Plan (ACP). Routine engagement of clients and their family for ACP depending on the readiness of clients.

Team Members



Doctor



Nurse



Health Worker

SW,
Chaplain,
Therapist



Volun-
teer



Range of Supports



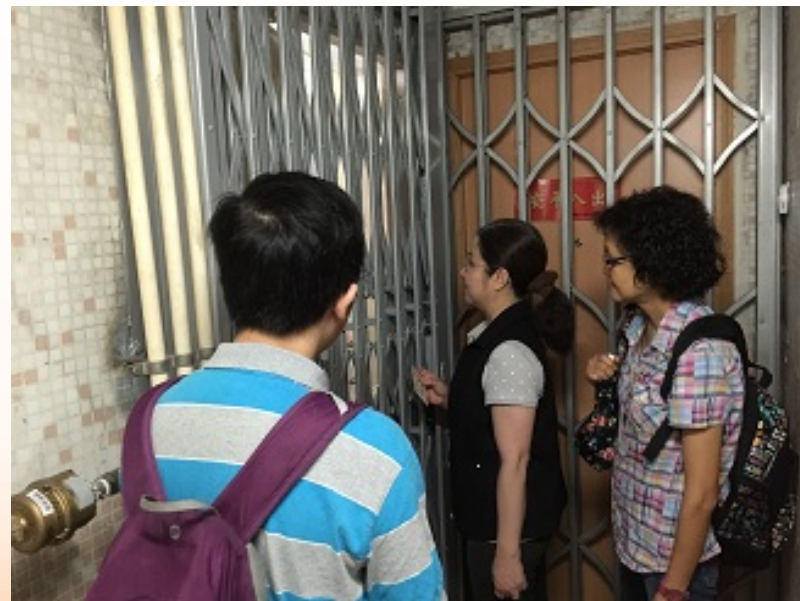
“Hospice at Home” in Action

- Case Manager: Nurse
- Social Worker (SW)
- Health Worker (HW)
- Volunteer

Physical
Psychological
Social
Spiritual



- Define needs of client/ family
- Coordinate services (e.g. doctor visit, personal care, rehab training, counselling, escort/transport service)
- Schedule visit frequency



“Hospice at Home” in Action

- Symptom management & prompt medical support



Fungal infection over flexure area



Herpes zoster over right buttock
Improved following prompt treatment

“Hospice at Home” in Action

- Personal care: bed bath, hair cutting



Volunteer providing hair cutting service for a bed-ridden patient. Health workers helped washing hair and bed bath.

“Hospice at Home” in Action

- Volunteer support



Celebrating Mid-Autumn Festival



Regular visit & shopping with patient ¹¹

“Hospice at Home” in Action

- Escort service



Patient has no family. Volunteers escorting patient for SOPC follow up.

“Hospice at Home” in Action

- Lonely terminal cancer patient expressed wish to have a dinner with volunteers.



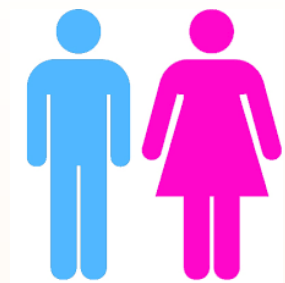
Volunteers having dinner at patient's home

Review of SASHCC Home Care Service In JCECC

Period: 1/1/2016 - 31/12/2017

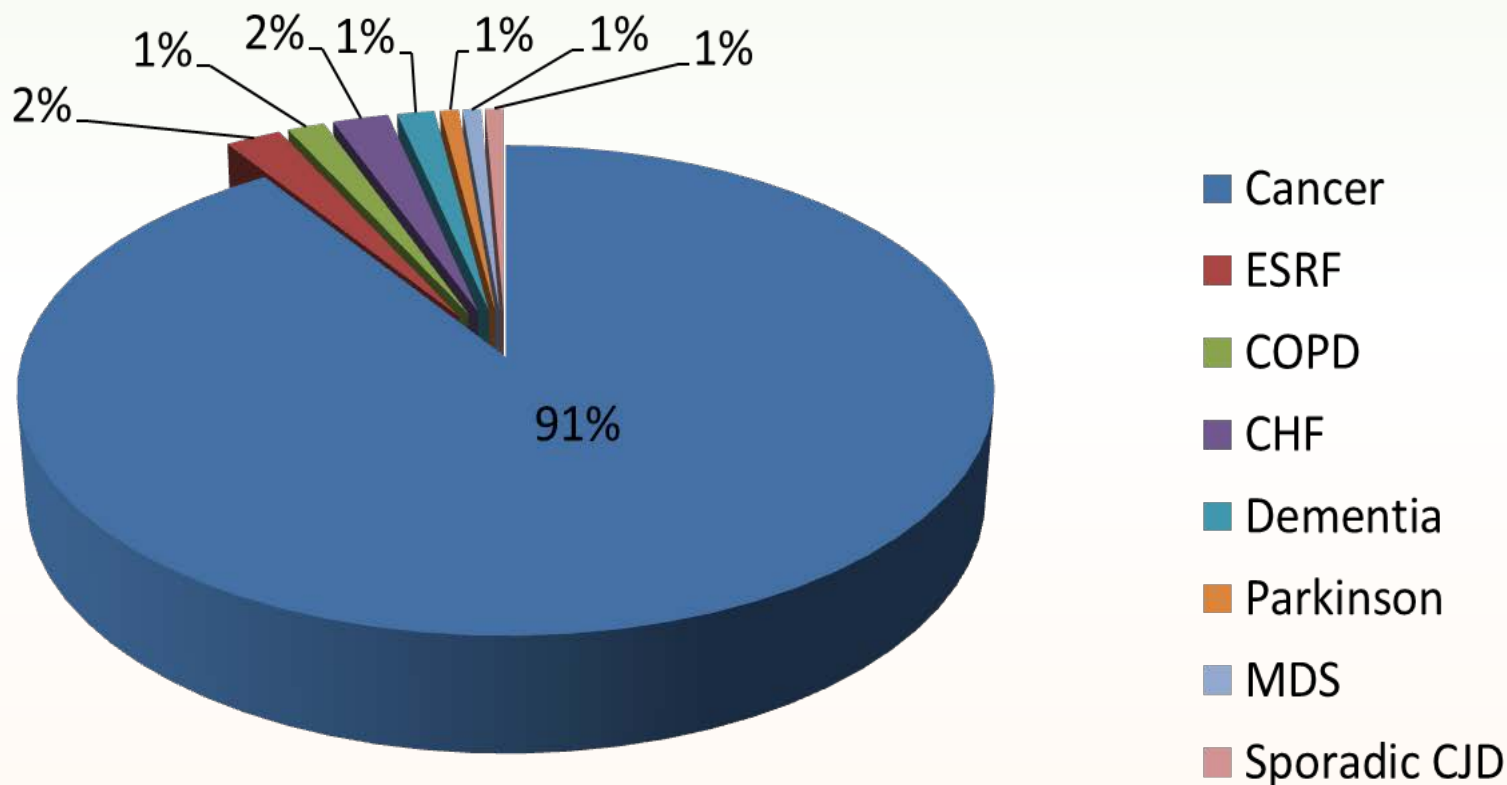


- Total patients served = 120
- Mean age (yr) = 75.74 (SD 10.442)

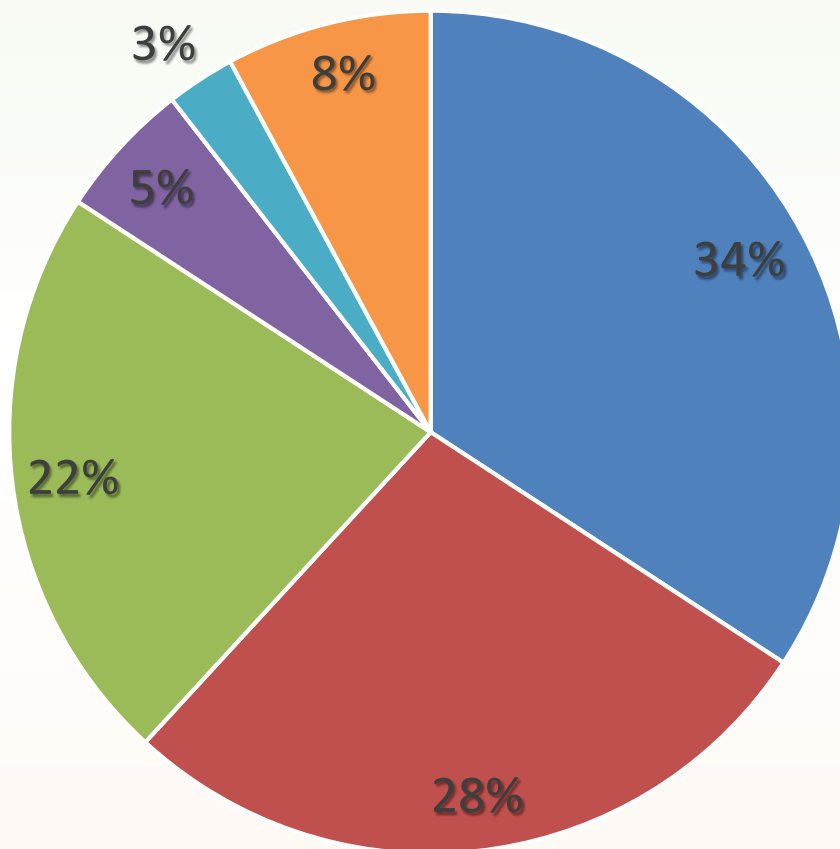


- M:F = 1 : 1.3

Disease categories

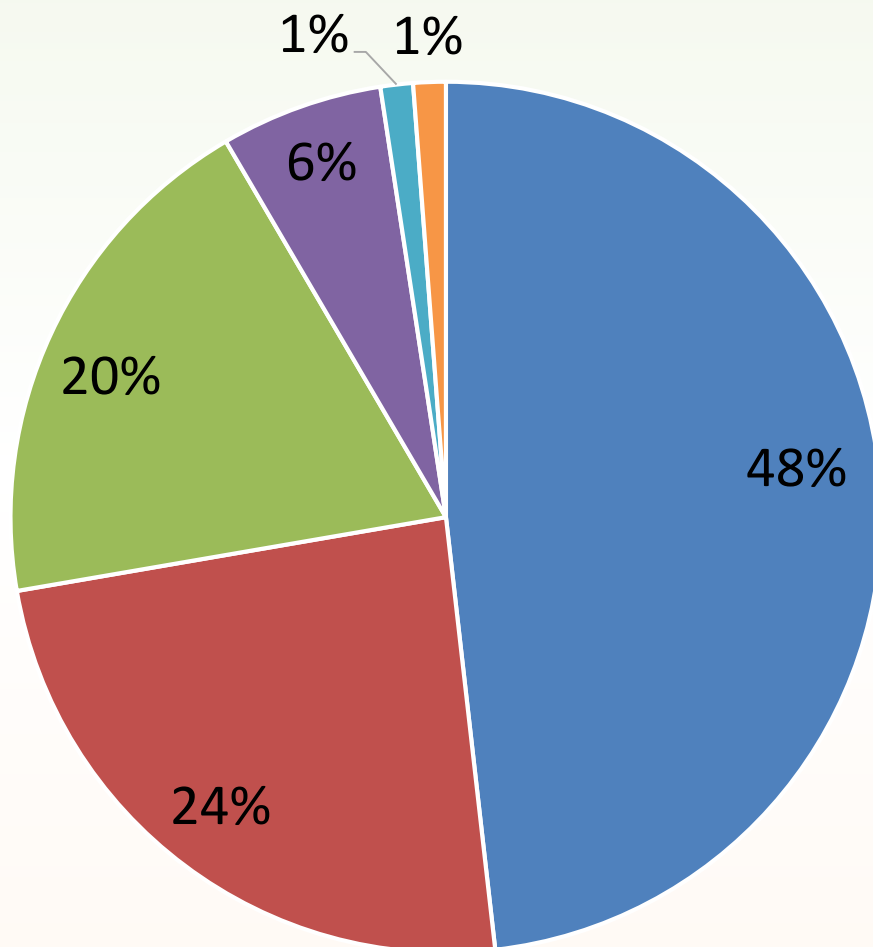


Source of Financial Support



- Personal saving
- CSSA
- Old age allowance
- Disability allowance
- Support from relative
- Others (eg Pension, medical waiver)

Living Arrangement



- Live with family only
- Live with domestic helper and family
- Live alone
- Live with domestic helper only
- Live with friend
- RCHEs

Physical Condition



- Mean PPS = 62.8/100 (30-90)
(PPS on enrolment: 60% means reduced ambulation, occasional assistance in self-care)



- 45% patients having 3 or more physical symptoms (Pain, Fatigue, Anorexia)

Duration in Program & ACP



- Mean duration in the program = 88.04 days (SD 108.838)



- 87% completed ACP
- 93% died with DNACPR (86/120)



- 35% emotionally vulnerable:
 - Mind about the negative views of other people
 - Feelings easily hurt
 - Find it hard to forgive
 - Cannot let go of many things in life



- 28% loss of meaning and hope:
 - feeling hopeless
 - Life is meaningless
 - Lost direction in life
 - Useless

Psycho-spiritual well-being



**NO
Correlation**

Age

Sex

Palliative Performance
Scale (PPS)

Number of symptoms

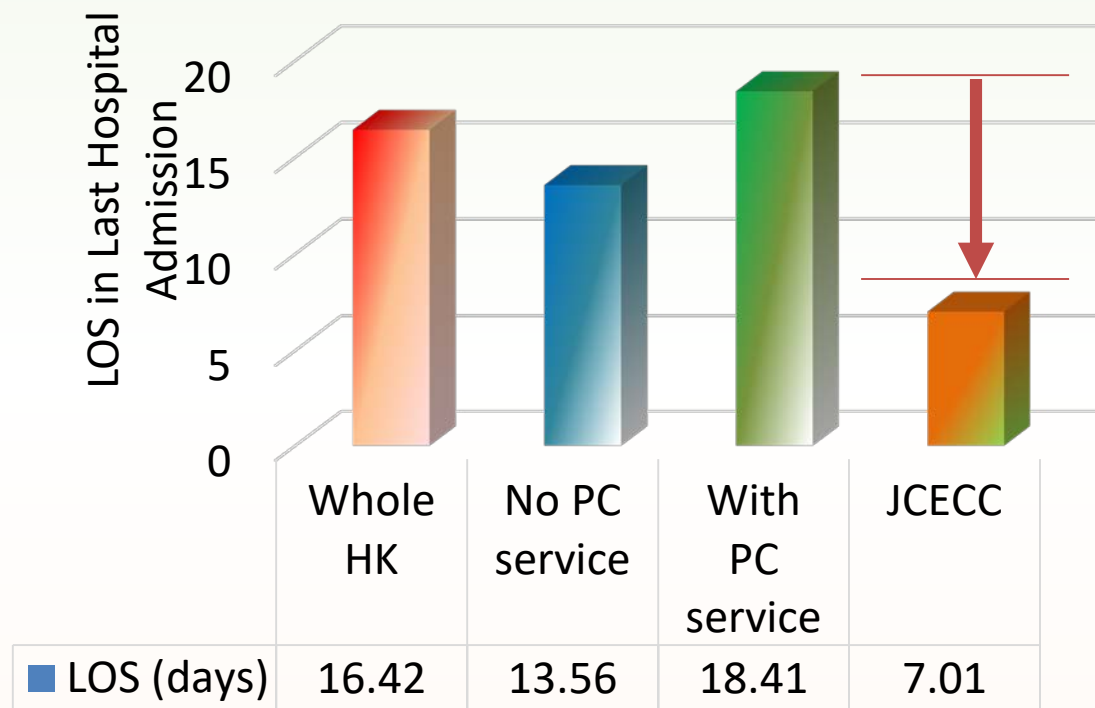
Place of care

Social support

Marital status

LOS in Last Hospital Admission

Length of Stay (LOS) in last hospital admission among cancer patients



Patients in this program has 62% reduction in LOS compared with cancer death under PC service in HK (P<0.05)

whole HK overall cancer death in 2015 (N = 675)

Cancer death under JCECC Hospice at Home program 1/2016-12/2017 (N = 81)

Satisfaction Survey

Rating: 1-10		N	Mean (SD)
Overall Mean		19	8.75 (1.126)
5	Enabled you to help patient live a dignified life till the last moment of life.	19	9.16 (0.958)
3	The service team respected your wishes.	18	9.06 (1.11)
4	Empowered patient to live a life consistent with his/her wishes.	18	9 (1.188)
16	Enabled you to effectively take care of patient's daily life at home.	16	9 (1.095)
10	Provided you with information that you needed, e.g. information and knowledge about medical services and social support services.	18	8.83 (1.465)
8	Helped alleviate your negative emotions and psychological stresses.	18	8.83 (1.295)
12	The social work service of the service team met your needs.	16	8.81 (1.167)
17	The cooperation between the hospital and the service team facilitated a stable and satisfactory care for the patient.	14	8.79 (1.528)
6	Facilitated effective communication between you and the patient.	16	8.75 (1.483)
13	The volunteer service of the service team met your needs.	12	8.75 (1.357)
11	In regards of care plan, Service team had communicated sufficiently with you and patient.	19	8.74 (1.368)
2	Overall, you are satisfied with the service.	19	8.74 (1.368)
9	Helped alleviate negative emotions and psychological stresses of the patient.	18	8.67 (1.188)
18	You are satisfied with the available choices of EoLC, and those choices meet my expectations for EoLC.	14	8.64 (1.499)
1	Overall, the service met your needs.	19	8.63 (1.257)
15	Help alleviate your caregiving stress.	17	8.59 (1.326)
14	Help prepared you to face the death of the patient.	18	8.5 (1.618)
7	Helped improve distressing symptoms of the patient.	18	8.44 (1.504)

Case Sharing

- Advanced hepatocellular carcinoma
- Want to stay at home to enjoy the time with family and grandson. Supportive daughters.
- Felt being supported by health care team.
- Passed away 2 days after admission to SASHCC.



Patient reviewing her life with social worker

Possible Factors Enabling Staying in the Community

- Case management approach with comprehensive home assessment by a trained nurse supported by a holistic care
- Readily accessible in-patient palliative/ respite care
- Trained volunteers are very helpful in practical and psychosocial support to the patients and their families.

Conclusion

- Home Care service is an essential component of palliative care.
- The JCECC program enables patients with advanced illness to stay in the community until very end. The LOS in last admission is significantly reduced by 62% compared with those receiving PC service in existing HK health care system.
- Advance Care Planning is successfully performed by home care nurses with the completion rate of 87%. Majority of them (93%) died with DNACPR.

Conclusion

- Psycho-spiritual distress is a distinct entity regardless of the physical condition and social status of patients. Care of the psycho-spiritual needs should be incorporated in the routine palliative home care service.
- volunteering is a relational activity and volunteers plays an important role in the palliative care provision in the community.

Acknowledgement

- HK Jockey Club
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