P8.1 The effectiveness of initiating Advance Care Planning through Serious Illness Conversation Guide - the experience of Medical Social Worker in Hong Kong

Rachel Y H LAM
Medical Social Services (Hospital Authority)
Queen Mary Hospital
18 June 2021

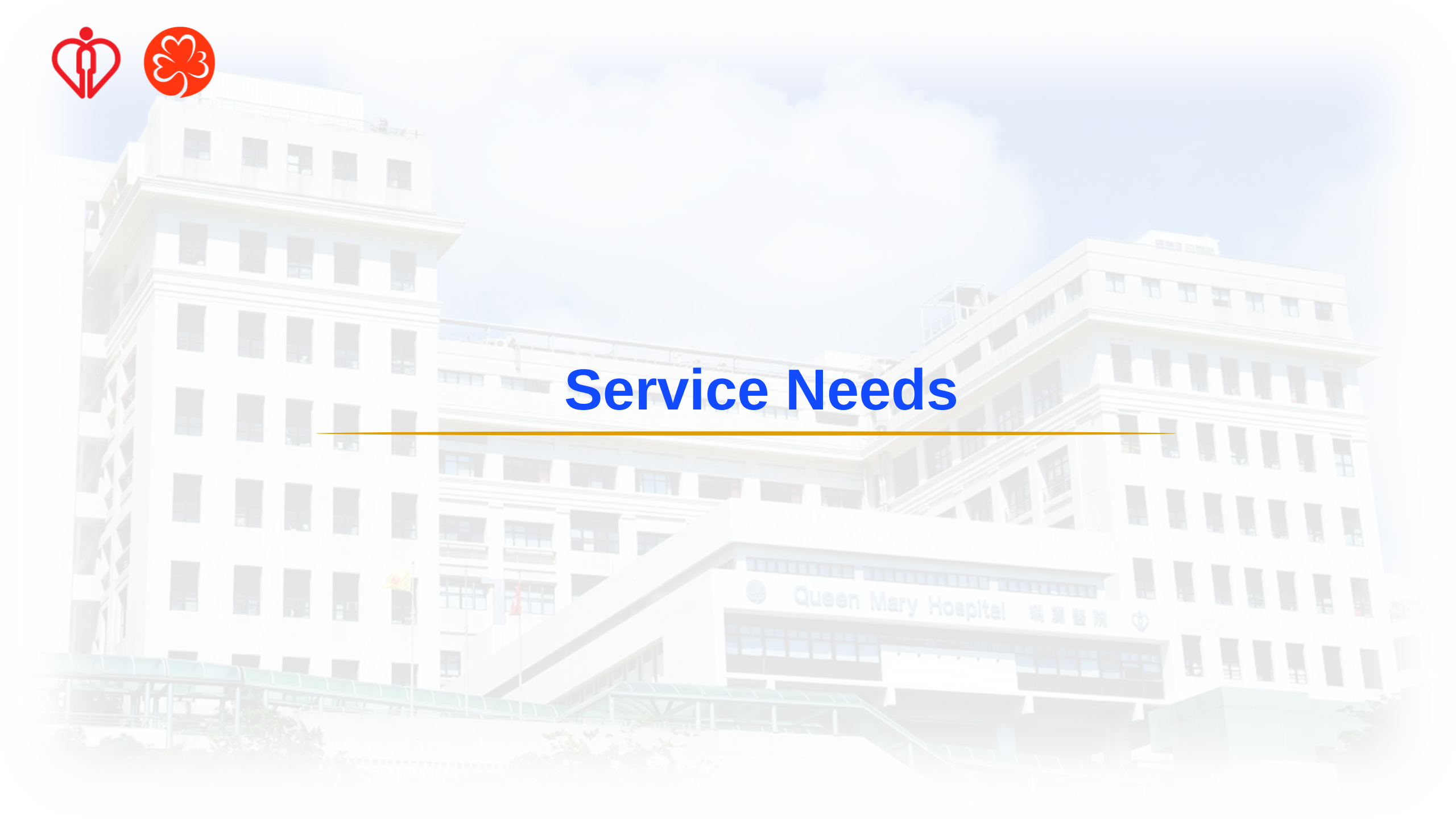
Content

1. Service Needs
2. Program design
3. Results
4. Discussion

I am not Ready to Let Go……

Respect of patient's care choice

Self autonomy on care option



Service Needs

Background

The World Health Organization (WHO 2017) defines end-of-life care is a type of palliative care for people in the final months of life and is considered when the person's condition deteriorates and active treatment does not control the disease.

Strategic Service Framework for Palliative Care (Hospital Authority 2017) indicated that all patients facing life-threatening and life-limiting conditions and their families / carers receive timely, coordinated and holistic palliative care to address their physical, psychosocial and spiritual needs, and are given the opportunities to participate in the planning of their care, so as to improve their quality of life till the end of the patients' last journey.

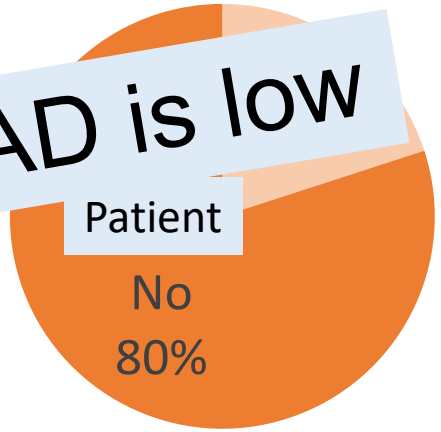
Service gap in HK

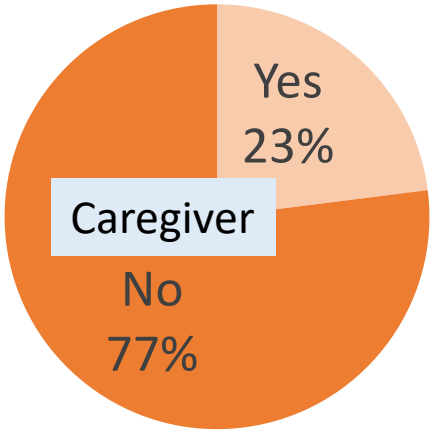
Referring to the research summary from Legislative Council, published on 6 June 2019, the public response to ADs is lukewarm, with only 5,561 ADs made with HA during 2012-2018.
(average <800 ADs made per year)

Public awareness of AD is low

According to a survey commissioned by the Government in 2016, 86% of local adults had not heard of ADs before.

Have your heard of ACP / AD in current study (2021) N=30





Source: Legislative Council (2019). Advance healthcare directives of patients. ISE07/18-19

Program Design

Methodology

Pretest posttest nonequivalent group design of quasi-experiment was adopted from Oct 2020 to Mar 2021.

Selection criteria

Patient

- Patient attended follow up consultation in Hospice Centre and agreed on treatment plan
- Aged 18 years old or above
- Mental acuity: sufficient for informed consent and questionnaire completion
- Ethnic Chinese
- With family caregiver

Caregiver

- Aged 18 years old or above
- Mental acuity: sufficient for informed consent and questionnaire completion
- Ethnic Chinese

Objective:

To facilitate quality family discussion of Advance Care Planning.

Strategy 1:
Structural Intervention Tool - HK Chinese Version of Serious Illness Conversation Guide

A structural guide to explore patient's goal, fears and worries, sources of strength, critical abilities, trade-off and readiness of family involvement.

Serious Illness Conversation Guide《嚴重病患溝通指引》
https://youtu.be/f55dlCKvH6w

Source: Dr. Lo R et al, Serious Illness Conversation Guide《嚴重病患溝通指引》 https://youtu.be/f55dlCKvH6w

Hong Kong Chinese version of Serious Illness Conversation Guide *Lo R et al*

現在希望和你談一談病情及未來進展，可以嗎？

1. 請問你此刻了解你病情狀況有幾多呢？
2. 關於你將來病情，你希望我告訴你幾多呢？
3. 病情:“我擔心時日無多”
   "有幾多得幾多？”
4. 若你健康轉差，那幾項人生目標對你是最重要？
5. 關於你將來健康，你最担心及恐懼的是甚麼？
6. 當你考慮到將來的病況，有甚麼最能給到你力量？
7. 有那方面的能力你覺得是最重要，如果沒有了你不可以想像繼續活下去？
8. 若你病得更重，你願意接受幾多來換取更長壽命？
9. 你家人知道你所着重的及所願望的有幾多？
10. 似乎這_____ 對你來說十分重要？
11. 顧及到你的目標及首要考慮，及了解到你此刻的病況，我建議 _____
12. 我們會一齊去面對.

🎯 Objective:

To facilitate quality family discussion of Advance Care Planning.

Strategy 2:
MSW conducted general education on ACP and Family Intervention through collaboration with Clinical Team

MSW provided general education on ACP and explore the family relationship in order to facilitate open communication and decision making.

Objective:

To facilitate quality family discussion of Advance Care Planning.

Strategy 1:

Structural Intervention Tool -
HK Chinese Version of Serious Illness Conversation Guide

Strategy 2:

MSW conducted general education on ACP and Family Intervention through collaboration with Clinical Team

Outcomes:

- **Attitude change:** Caregiver's acceptance on ACP discussion
- **Behavioural change:** Documentation of AD

End of Life Psychosocial Support

Clinical referral

- Patient agreed to understand more about ACP
- Willing to participate in education session on end of life planning

Education session on end of life care planning by MSW

- Information of ACP and AD
- Possible care choices

ACP discussion through SICG by MSW

- Guided questions to explore patient's goals, fears, strengths, critical abilities, trade-off, family involvement, and care preference
- Facilitating family involvement and discussion

Close collaboration with clinical teams

- Multi-disciplinary collaboration to optimize patient's individual care plan
- Documentation on care plan
- Regular review
- Refer to community supportive services for comprehensive EOL care

Results

Initial Assessment

1. Fulfill selection criteria
2. Obtain Consent
3. Baseline Assessment (self designed questionnaire)

Eligible for study (N=30)

General education

Agree to ACP discussion (N=20)

Declined ACP discussion (N=10)

Intervention

Application of SICG

Follow-up by conventional services

Post assessment at the 8th week

Post assessment (self designed questionnaire)

AD documentation at the 12th week

Completed ACP discussion and AD completion (N=10)

Completed ACP discussion without AD completion (N=10)

Declined ACP discussion with AD completion (N=0)

Declined ACP discussion without AD completion (N=10)

Intention of ACP discussion with socio-demographic variables and prior knowledge on ACP

	P-value
Age	0.397
Gender	0.301
Female	
Male	
Educational level	0.827
Illiterate	
Primary	
Secondary	
Tertiary or above	
Informal education	
Living condition	0.552
Live alone	
Live with spouse	
Live with child	
Live with parent	
Live with domestic helper	
Satisfaction of family relationship	0.552
Completely satisfied	
Mostly satisfied	
Neither satisfied or dissatisfied	
Mostly dissatisfied	
Completely dissatisfied	

	P-value
Marital status	0.575
Single	
Married	
Widowed	
Divorced	
Financial status	0.545
Comprehensive Social Security Assistance	
Disability Allowance	
Old Age Living Allowance	
Family support	
Saving	
Religion	0.581
None	
Christian	
Catholic	
Buddhism	
Traditional worship	
Prior knowledge on ACP	0.333
Yes	
No	
AD documentation	**0.006**
Yes	
No	

Notes: Significant if p ≤0.05 (2 tailed) using Chi-square test

AD documentation with socio-demographic variables and prior knowledge on ACP

	P-value
Age	0.226
Gender	0.605
Female	
Male	
Educational level	0.199
Illiterate	
Primary	
Secondary	
Tertiary or above	
Informal education	
Living condition	0.820
Live alone	
Live with spouse	
Live with child	
Live with parent	
Live with domestic helper	
Satisfaction of family relationship	0.552
Completely satisfied	
Mostly satisfied	
Neither satisfied or dissatisfied	
Mostly dissatisfied	
Completely dissatisfied	

	P-value
Marital status	0.871
Single	
Married	
Widowed	
Divorced	
Financial status	0.300
Comprehensive Social Security Assistance	
Disability Allowance	
Old Age Living Allowance	
Family support	
Saving	
Religion	0.575
None	
Christian	
Catholic	
Buddhism	
Traditional worship	
Prior knowledge on ACP	0.333
Yes	
No	

Notes: Significant if $p \leq 0.05$ (2 tailed) using Chi-square test

AD documentation with socio-demographic variables and prior knowledge on ACP

	P-value
Medical follow-up frequency in Oncology Out-patient Clinic	**0.032**
Less than one month	
1-2 months	
2-3 months	
3-4 months	
4-5 months	
5-6 months	
Over 6 months	

Notes: Significant if p ≤0.05 (2 tailed) using Chi-square test

Acceptance of caregiver for patient to discuss ACP / complete AD

	Mean score (SD) 1= Totally unacceptable 2= Unacceptable 3= Slightly unacceptable 4= Neutral 5= Slightly acceptable 6= Acceptable 7= Perfectly acceptable		P-value
	Control group N=10	**Experimental group N=20**	
Caregivers' acceptance on ACP discussion by patient at **baseline**	**5.30 (SD: 1.059)**	**6.10 (SD: 0.788)**	**<0.039**
Caregivers' acceptance on ACP discussion by patient at the **8th week**	**5.00 (SD: 1.054)**	**6.60 (SD: 0.940)**	**0.000**

Note: Significant if p≤0.05 using Mann-Whitney U Test (2-tailed)

Facilitating factors for AD completion after ACP discussion

Reason	N	
	Patient (N=10)	Core family member (N=10)
Acceptance of prognosis	10	7
Improvement on ACP / AD knowledge	8	7
Improved family communication and decision making after ACP discussion	8	5

Reasons of declining AD completion after ACP discussion

Reason	N	
	Patient (N=10)	Core family member (N=10)
Stable physical condition	5	5
Patient attended medical f/u alone	3	0
Not fully accept the prognosis	1	1
Inadequate information of ACP / AD	0	2
Need further discussion with other family members	0	2
Respect family's decision	1	0

Discussion

Effectiveness

- **Chinese version of Serious Illness Conversation Guide is an effective and structural tool to facilitate ACP discussion.**

Synergy

- **MSW's close collaboration with clinical team not only enhance the completion of AD, but also facilitate the implementation of ACP & AD.**

Strategy on service provision

- **General education on ACP and AD enhances the awareness & readiness;**
- **Individual follow-up on ACP discussion through SICG enhances patients and their families' acceptance for completion of AD in HA;**
- **Holistic ACP with Social & Medical components.**

Further research evidence on

- **The appropriate timing to initiate ACP discussion.**

Conclusion

Chinese version of SICG is an effective tool for MSW to initiate ACP discussion with patients and their families and explore patients' care preference in end of life care issues.

By respecting patient's personal core value and optimizing patient's self-autonomy in care plan, patient centered care is ensured.

Acknowledgements

*This project is under **Master of Science in Clinical Gerontology and End-of-Life Care in The Chinese University of Hong Kong***

I would like to express my heartfelt gratitude and sincere thanks to:

Dr. Raymond LO	Clinical Professor (Hon), Department of Medicine and Therapeutics, The Chines University of Hong Kong
Dr. K K YUEN	Chief Of Service of Clinical Oncology Department, Queen Mary Hospital, Hospital Authority
Dr. James LUK	Service Director (Primary & Community Health Care), Hong Kong West Cluster, Hospital Authority
Ms. Gigi LAM	Advanced Practice Nurse of Clinical Oncology Department, Queen Mary Hospital, Hospital Authority
Ms. Sharon MO	Social Work Officer of Medical Social Services (Hospital Authority), Queen Mary Hospital, Hospital Authority
Ms. Mei Ling HO	Assistant Social Work Officer of Medical Social Services (Hospital Authority), Queen Mary Hospital, Hospital Authority

References

1. The world health organization. WHO Definition of Palliative Care. [Online]. Available from: https://www.who.int/cancer/palliative/definition/en/ [Accessed 20 March 2021].
2. Hospital Authority. Strategic Service Framework for Palliative Care. 2017.
   Hospital Authority. HA Strategic Service Framework [Internet]. Ha.org.hk.2020 [cited 20 March 2021]. Available from: https://www.ha.org.hk/haho/ho/ap/PCSSF_2.pdf.
3. Chu D, Yen Y, Hu H, Lai Y, Sun W, Ko M et al. Factors associated with advance directives completion among patients with advance care planning communication in Taipei, Taiwan.PLOS ONE.2018;13(7);e0197552.
4. Dalal S, Bruera E. End-of-Life Care Matters: Palliative Cancer Care Results in Better Care and Lower Costs. Europe PMC. 17 Mar 2017; 22(4):361-368
5. Bernacki R, Hutchings M, Vick J, et al. Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. BMJ Open 2015; 5:e009032.
6. Hall A, Rowland C, Grande G. How Should End-of-Life Advance Care Planning Discussions Be Implemented According to Patients and Informal Carers? A Qualitative Review of Reviews. J Pain Symptom Manage. 2019; 58(2):311-335.
7. Kavikondala,S., Stewart, S.M., Ni, M. Y., Cha, B.H.Y., Lee, P.H., Li, K-K., McDowell, I., Johnston, J. M., Chan, S. S., Lam, T. H., Lam, W. W. T., Fielding, R., & Leung, G. M. Structure and Validity of Family Harmony Scale: An Instrument for Measuring Harmony. Psychological Assessment. Advance online publication. 2015.
8. Geerse OP, Lamas DJ, Sanders JJ, Paladino J, Kavanagh J, Henrich NJ, Berendsen AJ, Hiltermann TJN, Fromme EK, Bernacki RE, Block SD. A Qualitative Study of Serious Illness Conversations in Patients with Advanced Cancer. J Palliat Med. Jul 2019; 22(7):773-781
9. HA Guideline of life sustaining treatment in the terminally ill (2015), HA clinical ethics committee [Internet]. Ha.org.hk. 2015 [cited 20 March 2021]. Available from: https://www.ha.org.hk/haho/ho/psrm/LSTEng.pdf
10. Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. JAMA Intern Med. 2014;174(12):1994-2003.

References

11. Field A, Miles J. Discovering statistics using SAS. Los Angeles: SAGE; 2010.

12. Boerner K, Carr D, Moorman S. Family relationships and advance care planning: do supportive and critical relations encourage or hinder planning? J Gerontol B Psychol Sci Soc Sci. 2013 Mar;68(2):246-56.
13. Kumar P, Wixon-Genack J, Kavanagh J, Sanders J, Paladino J, and O'Connor N. Serious Illness Conversations With Outpatient Oncology Clinicians: Understanding the Patient Experience. JCO Oncology Practice. August 2020; PMID: 32749931.
14. Cheung, J.T.K., Au, D., Ip, A.H.F. et al. Barriers to advance care planning: a qualitative study of seriously ill Chinese patients and their families. BMC Palliat Care 19, 80 (2020).
15. Aua D, Lee J, Chan HY, Wong MW, Cheung NL, Ng K.Woo J. An exploratory investigation into advance care planning, end-of-life communication and decision-making in an acute hospital setting. CUHK Jockey Club Institute of Ageing [Internet]. [cited 30 Mar 2021]. Available from: http://www.ioa.cuhk.edu.hk/images/ content/others/nawa_em17_4/CU_12357_Poster_Prof_Doreen_Au_et_al.pdf.
16. David D, Barnes D, McMahan R, Shi Y, Katen M, Sudore R. Patient Activation: A Key Component of Successful Advance Care Planning. Journal of Palliative Medicine. 2018;21(12):1778-1782.
17. Spelten E, Geerse O, Vuuren J, Timmis J, Blanch B, Duijts S et al. Factors influencing the engagement of cancer patients with advance care planning: A scoping review. European Journal of Cancer Care. 2019;28(3).
18. Toguri JT, Grant-Nunn L and Urquhart R. Views of advanced cancer patients, families, and oncologists on initiating and engaging in advance care planning: a qualitative study. BMC Palliative Care. 2020; 19:150.

19. Zwakman M, Jabbarian LJ, van Delden J, et al. Advance care planning: a systematic review about experiences of patients with a life-threatening or life-limiting illness. Palliat Med 2018;32:1305e1321. 69. Adams JA, Bailey DE J.
20. UpToDate[Internet]. Uptodate.com. 2021 [cited 30 March 2021]. Available from: https://www.uptodate.com/contents/advance-care-planning-and-advance-directives.

References

21. Keeley MP. Family Communication at the End of Life. Behav Sci (Basel). Jul 2017; 7(3):45.

22. Chan H, Kwok A, Yuen K, Au D, Yuen J. Association between training experience and readiness for advance care planning among healthcare professionals: a cross-sectional study. BMC Medical Education. 2020;20(1).
23. Wang C, Chan C, Chow A. Social workers' involvement in advance care planning: a systematic narrative review. BMC Palliative Care. 2017;17(1).
24. Louangrath P, Sutanapong, Chanoknath. Minimum Sample Size Calculation Using Cumulative Distribution Function. International Journal of Research & Methodology in Social Science. 2019; Vol., 5, No. 1: pp. 100-113.
25. Background and Objectives | JCECC [Internet]. Foss.hku.hk. 2020 [cited 14 April 2021]. Available from: http://foss.hku.hk/jcecc/en/about-us/background-and-objectives/
26. Wong EL, Kiang N, Chung RY, Lau J, Chau PY, Wong SY, Woo J, Chan EY, Yeoh EK. Quality of Palliative and End-Of-Life Care in Hong Kong: Perspectives of Healthcare Providers. Int J Environ Res Public Health. Jul 2020;17(14):5130.
27. Hospital Authority : HA Guidelines on Advance Care Planning (2019) [Internet]. Ha.org.hk. 2021 [cited 14 April 2021]. Available from: https://www.ha.org.hk/visitor/ha_visitor_ index.asp?Content_ID=252688&Lang=ENG&Dimension=100
28. Hebert R, Schulz R, Copeland V, Arnold R. Preparing Family Caregivers for Death and Bereavement. Insights from Caregivers of Terminally Ill Patients. Journal of Pain and Symptom Management. 2009;37(1):3-12.
29. Yip K, Wong T, Alhamid S, Nadkarni N, Tan C, Pang A et al. Integrating advance care planning as part of comprehensive geriatric assessment for hospitalised frail elderly patients: findings of a cross-sectional study. Singapore Medical Journal. 2020;61(5):254-259.
30. Advance Care Planning (ACP)? Advance Directives (AD)? Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR)? Patients and families should know more! [Internet]. Ha.org.hk. 2019 [cited 18 April 2021]. Available from: http://www.ha.org.hk/haho/ho/psrm/Public_education2.pdf.
31. Legislative Council of the Hong Kong Special Administrative Region - Advance healthcare directives of patients [Internet]. Legco.gov.hk. 2021 [cited 21 May 2021]. Available from: https://www.legco.gov.hk/research-publications/english/essentials-1819ise07-advance-healthcare-directives-of-patients.htm

助病友規劃最後一段路

醫家友「情」照顧服務

醫家講你知

人生要面對不同階段的選擇及規劃，你會計劃自己的事業、家庭，甚至退休生活，但你又會好好規劃自己生命晚期的生活及照顧模式嗎？瑪麗醫院去年底展開為期半年的醫家友「情」照顧服務試驗計劃，讓病友未雨綢繆，與家人討論病情末期的照顧安排。有病友向家人坦誠表達了「不作入侵性治療」的意願後，不但促進了家庭和諧，更避免了生命的遺憾。

本報記者報道

■瑪麗醫院去年底展開為期半年的醫家友「情」照顧服務試驗計劃，讓病友與家人討論病情末期的照顧安排。（資料圖片）

年近70的楊女士於2017年被診斷患有肺癌，癌細胞已擴散到其他器官。她害怕痛楚，但深知女兒希望嘗試不同方法去延長她的生命，爭取多點相處時間，所以她寧願收藏自己的想法，變得沉默寡言。瑪麗醫院的醫務社工（醫院管理局）了解到楊女士的情況，邀請她參加試驗計劃，幫助她與家人商討晚期照顧規劃。

坦誠分享隨遇而安價值觀

楊女士坦言自己不害怕死亡，但怕離世前的痛楚；她覺得人生已經圓滿，又擔心病情會影響家人。在醫務社工的引導下，楊女士鼓起勇氣，向女兒敞開心扉，表明不希望在生命晚期時作沒意義的入侵性治療，女兒恍然大悟，亦百份百支持及尊重媽媽的決定。楊女士年初在女兒陪同下簽署「預設醫療指示」，決定當病情到了末期、處於持續植物人狀況或陷入不可逆轉的昏迷時，不作入侵性治療，例如心肺復甦法。「隨遇而安」是楊女士的價值觀，向家人坦誠分享自己的意願，避免了生命的遺憾。

當疾病到了不能逆轉階段，延長生命，其實只是延長離世過程，對病人可能沒有意義，甚至增加痛楚。瑪麗醫院醫務社會工作部（醫院管理局）指出，在適當的時候與病人及家人商討晚期生活照顧，可讓家人思考如何配合病人的想法，避免在醫療決定上需要猜測病人的意願，或因家人間意見分歧造成兩難。

晚期照顧系列網上講座

瑪麗醫院臨床腫瘤科及醫務社會工作部（醫院管理局）一直積極進行公眾教育、職員培訓、義工訓練及相關研究工作，致力支援病人和家屬的晚期照顧規劃。港島西醫院聯網「醫家友支援計劃」將於3 月及4 月舉行「晚期照顧系列」Facebook 講座。瑪麗醫院內科醫生會分享何為「預設照顧計劃」。醫務社工（醫院管理局）及社區合作伙伴亦會分享地區服務如何配合病人的晚期照顧和照顧者支援。

■透過「預設照顧計劃」，讓病友有機會向醫護人員及家人表達對晚期照顧的期望及治療意願。

講座一：3 月25 日(四) 下午2 時 — 預設照顧計劃及「智」享生活
講座二：4 月24 日(六) 上午10 時— 吾生好死的規劃
Facebook Page ：醫家友支援計劃
Facebook 連結： https://www.facebook.com/CaregiverSupportNetwork.HKWC
照顧者熱線：2255 4343

Thank you

We walk with patients and their families along the care journey

Sources of online graphics: google, freepik