Advance Care Planning for End Stage Chronic Illness – How to go into the topic with clients?
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It was a difficult, distressing, and lonely journey.

“From the doctor's summing up, Ivan Ilych deduced the conclusion that things looked bad, and that he, the doctor, and most likely everyone else, did not care, but that things looked bad for him. And this conclusion impressed Ivan Ilych morbidly, arousing in him a great deal of pity for himself, of greater anger against this doctor who could be unconcerned about a matter of such importance.”
**What is Advance Care Planning (ACP)?**

1. **Definition**
   
   Advance care planning (ACP) usually refers to the process of communication among a patient with advanced progressive diseases, his/her health care providers, and his/her family members and caregivers regarding the kind of care that will be considered appropriate when the patient can no longer make those decisions (Teno, Nelson HL, and Lynn 1994). Some organizations include planning for future care of incompetent adults and minors with advanced progressive diseases in the scope of ACP (Australian Health Ministers' Advisory Council 2011; 10; Canadian Paed Society 2008). In the Hospital Authority, the term ACP extends beyond communication with mentally competent adult patients to include that with family members of the mentally incompetent and minor patients (Hospital Authority 2014, section 8.1).

2. **Purpose of ACP**
   
   2.1 The Hospital Authority promotes ACP as an integral part of clinical care for patients with advanced progressive diseases. ACP is an overarching and preceding process for expressing preferences for medical and personal care, which in turn will shape the care for the patients thereafter and at the end-of-life.

   2.2 Through the ACP process:

   a) A mentally competent and properly informed patient may express preferences for future medical or personal care, or make an advance directive refusing life sustaining treatments, including DNACPR. The patient may also assign a family member to be the key person for future consultation.

   b) The family members of a mentally incompetent adult or a minor together

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Proactive, anticipatory, iterative approach

https://youtu.be/mPtu-FpY1Kw
维生治疗是指任何有可能延長病人生命的治療，但部分治療方式卻可能極具侵入性，對病人帶來痛苦與身體之損傷，若病人一旦脫離這些維生儀器，往往就無法繼續生存。 (HA, 2016)
Efficacy of LST

Hospital Authority Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR), 2016

- Survival rate: 23.8 – 44%
- Survived to discharge: 7.6 – 17%
- 6 months situation: persistent vegetative state (66%), aware but with cognitive impairment (9%), conscious (23%)
True / False

- ACP is only for people who are terminally ill.
- Forgoing life-sustaining treatment is different from euthanasia.
- In a serious traffic accident, CPR will NOT be conducted if the victim has signed an advance directive / DNACPR form.
- Avoiding ACP can protect people from emotionally sensitive topic.
- It’s the doctors’ duty to talk about end-of-life care.
Leading causes of death

- Terminal cancer
- Organ failure
- Senility / Decline

- Cancer
- Heart disease
- Stroke
- Chronic lower respiratory disease
- Kidney disease, Kidney disease
- Cognitive disorder
- Septicemia
- Diabetes

More than 50% of the world lives with chronic disease.
Development of Micro-Movies to Empower Senior Citizens in Advance Care Planning (ref. no.: 29150504). Health Care and Promotion Fund, Food and Health Bureau
When there is no way to share my view...
WHEN is the appropriate time for ACP?

There may be goals and priorities besides living longer
Driving Miss Norma

Norma Bauerschmidt, the Michigan woman who declined cancer treatment to spend her final days traveling, died Friday morning at 91.

(3 Oct 2016)
Readiness towards ACP


Not only for those who are well prepared!!
Shared decision making

Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial

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Impacts on wellbeing

Existing evidence does not support the claim that ACP would increase anxiety, stress, sense of hopelessness, or depressive symptoms among patients

(Bernacki & Block, 2014; Brickman-Stoppelenburg et al., 2014)

Dyadic agreement on EOL care preferences

**DNACPR**

\[ p = 0.024^* \]

**Not for tube feeding**

\[ p = 0.034^* \]

**Not for intubation**

\[ p = 0.018^* \]

**Goal of care**

\[ P < 0.001^{***} \]

Chan HYL. A Community-based Advance Care Planning Programme to Improve End-Of-Life Care in Patients with Advanced Disease: A Mixed-Method Approach (ref no.:11120861). Health and Medical Research Fund, Food and Health Bureau
Qualitative comments from patients & family carers

Better understanding of end-of-life care planning
- Increased knowledge regarding care options
- Increased knowledge regarding individual rights in care planning

Engaging in end-of-life care planning
- Expressing personal end-of-life care wishes
- Communicating personal wishes with family members

Being relieved from concerns over a burdensome death
- Reducing concerns over lingering death
- Reducing concerns over becoming family conflicts

Chan, HYL. A Community-based Advance Care Planning Programme to Improve End-Of-Life Care in Patients with Advanced Disease: A Mixed-Method Approach (ref no.:11120861). Health and Medical Research Fund, Food and Health Bureau
Serious Illness
Conversation Guide
Communication in Serious Illness

Serious Illness Care Program
Reference Guide for Clinicians

Key Ideas for Outpatient, No Time

Principles
- Set up the conversation
- Introduce the idea and reassess
- Ask permission

Practices
- Talk through options
- Give advice
- Presume competence
- Acknowledge
- Ask
- Acknowledge
- Focus
- Help

6. Close the conversation
Summarize what you’ve heard
Make a recommendation
Adjust your commitments to the patient

1. Set up the conversation
- Ask permission

2. Assess illness understanding and information preferences
- Ask, “What did you understand about what you’re going to do?”
- “How did you think about your illness?”

3. Share information
- Tailor information to patient preference
- Allow silence, explore emotion

4. Explore key topics
- Goals
- Fear and worries
- Sources of strength
- Critical abilities
- Truths
- Family

5. Close the conversation
Summarize what you’ve heard
- “What did you think about your illness?”
- “What did you think about your illness?”
- “What did you think about your illness?”

6. Document your conversation
- “What did you think about your illness?”
- “What did you think about your illness?”
- “What did you think about your illness?”

* HarvMed Press, A Journal of Palliative Care at Harvard Medical School, June 2013

Harvard Medical School Center for Palliative Care

Nethersole School of Nursing
The Chinese University of Hong Kong

Atul Gawande
Being Mortal

那 打 素 維 理 學 院

The Nethersole School of Nursing
“REMAP”

- Reframe why the status quo isn’t working
- Expect emotion and empathize
- Map the future
- Align with the patient’s values
- Plan medical treatments that match patient’s values
1. Set up the conversation

• Introduce the idea and benefits
• To orient the patient
• Emphasize the need to plan
• **Asking permission

「我想趁早與你討論有關你現在健康的情況 (病情) 及進展，及預早計劃一下將來會面對的情況。這是我們為患有長期病者所提供的照顧服務中的一部分。可以嗎？」

「我們都知道這種病是會令病者的健康逐步衰退，你有沒有想過這方面？」
2. Assessing illness understanding & readiness

- 你可以說一下你對自己健康情況的了解嗎？
- 可否告訴我你最近的數星期 / 月 / 年的健康情況如何？
- 你可否說一下呢個病對你有怎樣的影響？
- 關於你的健康接下去的情況，你想要哪方面的資訊？
3. Prognostication

- Tailor information to patient preference
- Allow silence
- Explore emotion

「雖然現在你的情況穩定，但都可能會有突然轉變。先了解你的需要會對跟住下去的醫護照顧很有幫助。」

(Present prognostic information as a range)

Avoid giving premature reassurance
4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

如果你的健康情況轉差，你覺得最重要的目標是什麼？

對於將來的健康，你最怕或擔心什麼？

當你想到關於將來的健康時，有什麼方面給予你力量/支持？

有什麼能力對於你來說是非常重要，即你覺得不可以失去？

萬一你的健康情況轉差，你願意以什麼去換取多一些時間

你的家人了解你的這些意願嗎？
5. Closing the conversation

- Summarize what you’ve heard
- Make a recommendation
- Affirm your commitment to the patient

聽你剛才的分享，似乎 ... 對你來說是很重要。

就著你剛才分享的意願及目標，我會建議 ...

我們會陪你一起面對...
Evaluating an Intervention to Improve Communication Between Oncology Clinicians and Patients With Life-Limiting Cancer
A Cluster Randomized Clinical Trial of the Serious Illness Care Program

Joanna Paladino, MD; Rachelle Bernacki, MD, MS; Bridget A. Neville, MPH; Jane Kavanagh, BA; Stephen P. Miranda, MD; Marissa Palmor, BS, MBE; Joshua Lakin, MD; Meghna Desai, MPH; Daniela Laman, MD; Justin J. Sanders, MD, MSc; Jonathon Gass, MPH; Natalie Henrich, PhD, MPH; Stuart Lipsitz, ScD; Erik Fromme, MD; Abd A. Gwande, MD, MPH; Susan D. Block, MD

JAMA Oncol. doi:10.1001/jamaoncol.2019.0292
ROLE PLAY
Debriefing

• How is the role play?

• What helps?

• What can be improved?
Communication skills

O - Open questions
A - Affirmations
R - Reflections
S - Summaries
Open-ended questions

不要討論這些，
我會支持下去。

我不會放棄。

一定有辦法！

有什麼事讓你擔心/恐懼？

有什麼事讓你擔心/恐懼？

可以說一下你最在乎的是什麼？

可以說一下當中最大的掙扎是什麼？
Affirmation

- P: 我有諗清楚架啦，我將來去到最後階段最緊要係去得舒服。
- A:
Reflection

• Double-Sided Reflection
  – P: 阿囡話會幫我做決定，叫我唔好唸埋一邊，我都無辦法啦。
  – R:

• Reframing
  – P: 我屋企人次次都有佢講冇我講，我冇辦法說服佢地。
  – R:
Blocking behaviours

Blocking occurs when a patient raises a concern, but the care provider either fails to respond or redirects the conversation

1. Leading / Closed questions
2. Premature reassurance
3. Lecturing (Uninvited advice)
4. Defensive behaviours
5. Jollying along / Irrelevant chit chat
6. Shifting the focus to relatives
7. Passing the buck… etc
奶奶，我就當為我而做，好不好？
奶奶，我不是要逼你，但不能拖了
你捨不得我，更加要堅強
True / False

- ACP is only for people who are terminally ill.
- Forgoing life-sustaining treatment is different from euthanasia.
- In a serious traffic accident, CPR will NOT be conducted if the victim has signed an advance directive / DNACPR form.
- Avoiding ACP can protect people from emotionally sensitive topic.
- It’s the doctors’ duty to talk about end-of-life care.
Take home message

1. Don’t talk too much
   - Patients have goals and priorities besides living longer
     → Giving patients an opportunity to express fears and worries is therapeutic

2. Need multiple encounters

3. Interdisciplinary collaboration
Thank you!

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