ACP with Seriously Ill Older Patients: Discussing Goals of Care

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Aging population and the COVID-19 pandemic

“At 89, She Fears Dying Alone More Than the Coronavirus Itself”

https://www.nytimes.com/2020/04/07/nyregion/dying-alone-coronavirus.html

The New York Times

THE NEW OLD AGE

Do You Want to Die in an I.C.U.? Pandemic Makes Question All Too Real

Sobering statistics for older patients sharpen the need to draw up advanced directives for treatment and share them with their families.

What is a good death?

Good death items	Mean score (1-10)
No physical torture　死前唔駛受病痛長時間折磨	8.78
A painless death　臨死之前能夠盡量減少身體上的痛楚	8.59
Not dependent on others　臨終前生活各方面都唔駛靠人幫	7.93
Reconcile with family　死前能夠同家人或親友和好	7.84
Financial planning for family　知道自己唔駛擔心家人以後生活	7.71
Finish family obligation　死前完成對家庭責任	7.66
Fulfill last wishes　死之前能夠完成埋未了心事	7.38
Pre-arrange funeral　能夠生前安排或決定點處理自己身後事	7.04
Psychologically prepared　心理上已預備好自己將會死去	7.01
No regrets　諗番自己一生，會覺得無咩遺憾	6.61
Body kept clean　身體能夠保持整齊清潔	6.39
Body not tampered　死後身體完整	3.63
Extravagant funeral　風光大葬	2.73
Dying at home　能夠係屋企死	2.72

Chan WCH, Chan HY 2004

End-of-Life Care Experiences in HK
(Last 6 months)

	Cancer	COPD	CHF
Hospitalization days	28	46	40
Deaths in ICU	0.3%	2.1%	2.3%
Invasive ventilation	0%	10%	14%
Non-invasive ventilation	1%	46%	13%
CPR	4%	15%	21%
Analgesic/sedatives in last 2 weeks	91%	59% analgesics 8% sedatives	

Lau KS. JPSM 2010

Can ACP fix this?

Aligning individuals' preferences and care they will receive

Evidence on ACP effectiveness

- Mixed results on effectiveness of ACP, leading to questions on whether ACP lives up to its potential

Jimenez G. J Pain Symptom Manage. 2018;56(3):436-459.e25.

- “ACP is an operator dependent process. The healthcare professionals act as facilitators of the ACP process, and should have appropriate communication skill and knowledge of the subject, in order to achieve satisfactory outcome.”

HA Guidelines on Advance Care Planning, 2019

Quality of ACP Communication

- Discussions take 6 minutes or less
- Clinicians use a checkbox-approach focused on treatments and completing forms (advance directives)
- Avoid discussion of prognosis

Benson WF et al. CDC. 2012
Sudore et al. JAMA. 2013
Tulsky JA. Ann Intern Med 1998
Janssen DJ et al. Chest. 2011

Consensus definition of ACP

"A process that supports adults at any age or stage of health in **understanding and sharing their personal values, life goals, and preferences regarding future medical care.**

Consensus definition from expert multidisciplinary Delphi panel

Sudore RL et al. JPSM 2017

How to discuss goals of care?

How would you go about understanding a patient's personal values, life goals, and preferences regarding future medical care?

Do you say:

"What are your goals or "目標" regarding your future medical care?"

How would you discuss goals of care with these 85 year olds?

Mrs. Wong

85 F with hypertension, enjoys Tai Chi daily at the park

Mr. Lau

85 M w/ history of COPD on LTO2 recently discharged for his 3rd COPD exacerbation in the past 6 months.

Context matters in ACP!

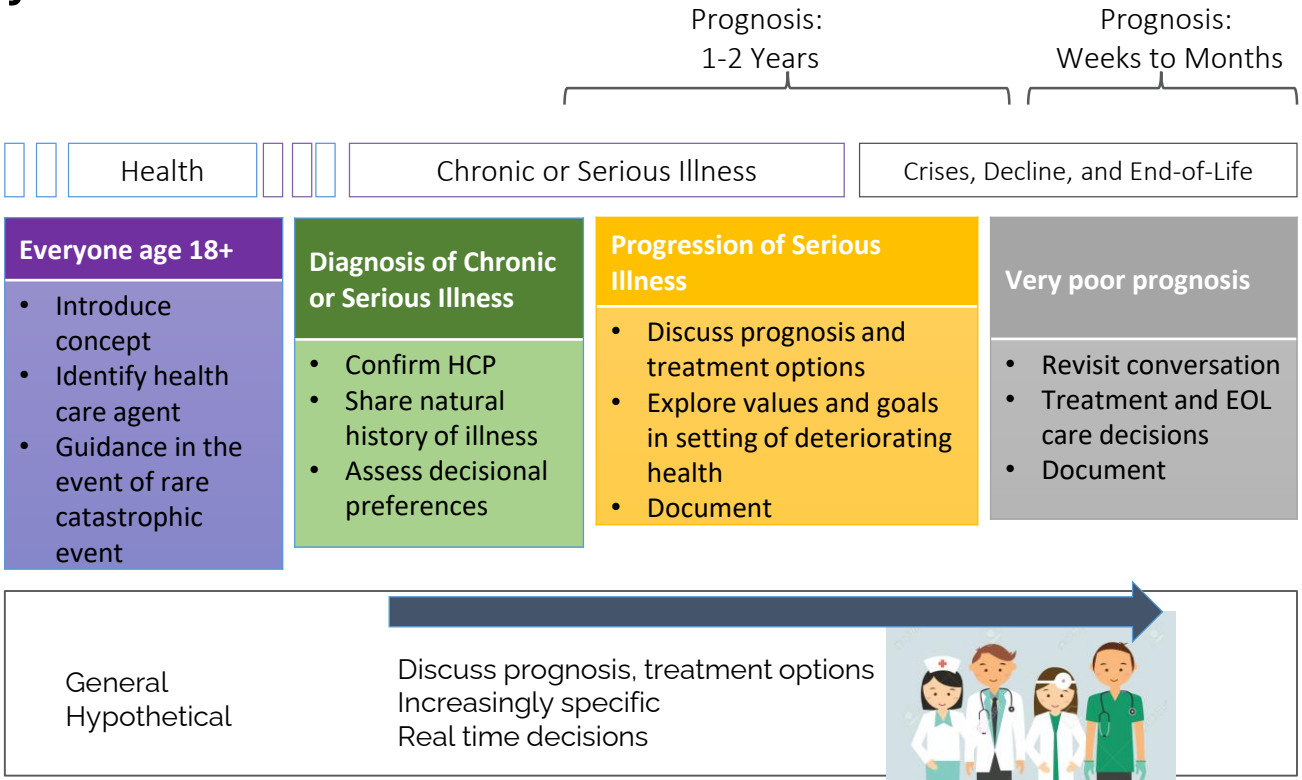
Well elderly

- Step 1: Get buy-in to discuss ACP
- Step 2: Identify & involve surrogate decision-maker
- Step 3: Explore general values/goals/preferences

Seriously ill elderly

- Pre-Step: Clarify health status/disease prognosis
- Step 1: Get buy-in to discuss ACP
- Step 2: Identify & involve surrogate decision-maker
- Step 3: Explore values/goals/preferences in context of illness
- Step 4: Match care plan to goals

Conversation and Care Planning Process: Life Cycle Model



Block SD; Institute of Medicine.2014

We examined ACP communication in HK

- Audiorecorded ACP discussions between clinicians, seriously ill patients, family members in oncology, palliative care, and renal outpatient consultations and home visits

- Interviews with patients and family members on their perceptions and experience with ACP discussions

ACP for ESRD patients – Mr. Sung's story

- 78 year old man with ESRD
- ACP discussion led by nephrologist and MSW
- Accompanied by his wife, children and sister
- Shown a video on dialysis options vs palliative care

- Doctor informed Mr. Sung that without dialysis, his prognosis is on the order of "months"

"以月數計啦，如果下年年頭仲係咁就好好彩啦"

- "Would you prefer to prolong your life with dialysis or would you prefer too choose palliative care?"

- Pt: Palliative care feels less torturing, dialysis will change all my quality of life
- Dr: But dialysis would prolong your life, you earn more time
- Pt: Earning time is meaningless, I have completed my responsibilities (Pt cries)
- D: I see that you are upset. It is that you don't like the treatment, or you are scared of suffering from dialysis?
- Pt: I don't want to face dialysis. Dialysis gives me a lot of pressure, and "changing water" is cumbersome
- D: You are not ready for death, right?
- Wife: No one is ready

Sharing from Mr. Sung and family

- He was scared when he learned peritoneal dialysis requires making a surgical opening in his abdomen and performing the “washing” 3-4 times a day. This was unacceptable for him.

- His main concern was being able to continue swimming, which he would not be allowed with peritoneal dialysis.

- Wife felt he was so depressed by this that he would refer choose palliative care (or choosing not to live). Family was saddened by his choice.

- Family researched more information and saw a private doctor, ultimately decided on hemodialysis. This would be more tolerable to the patient – going for treatment 2-3 times a week, leaving time for activities he enjoys.

- He still worries about financial burden on family and burdening family to take care for him.

Suggestions on ACP

- Mr. Sung was shocked to hear the news of the severity of his renal failure for the first time during the ACP consultation. He wished the doctors had alerted him earlier on his condition so that he could be more prepared. Perhaps more could have been done to treat his condition.

- They wished the doctor discussed more about the option of hemodialysis rather then focusing only on peritoneal dialysis.

Financial planning

- What do you expect from a good financial planner?

A good financial planner

- Understands your financial goals and risk-taking preferences
- Makes recommendations to help you achieve your goals that are realistic

Reflections on ACP with Mr. Sung and family

- Readiness for discussion – emotional state
  - Explore emotions
  - Ask about readiness to discuss treatment options
  - Timing – starting earlier would be better

- Understand what matters most
  - What do you hope for?
  - What worries you the most?

- Make recommendations on plan to best achieve pt's goals
  - Explain how recommendation matches pt's goals
  - Explore concerns

ACP for ESRD patients – Mr. Chau's story

56 year old man with ESRD

- First meeting with Dr. L, ACP discussion
- Single, no children

- On first meeting, Dr. L explained he had reviewed his whole medical history and summarized it for him

- Noted that Mr Chau was seen at the renal clinic last month and was told he is at risk of imminent death and advised him to be admitted the next day to start dialysis but he refused.

- Dr. L asked Mr. Chau to explain why he refused dialysis.

Pt: I told the doctor my only regret in life is not to be able to travel overseas once. The doctor told me after getting surgery for dialysis, I would never be able to travel again. But I would live longer.

Dr L: Where do you want to travel?

Pt: Singapore or maybe Malaysia

Dr: Let me explain. After dialysis, you can still travel. I have some patients who can take a short trip for 2-3 days. They get admitted for dialysis before they leave, then come back 3 days later to get dialyzed. It is possible. Don't misunderstand this.

If your goal in life is to travel to Malaysia and gamble, the first thing you need to do is first to stay alive, and the second thing is to start dialysis. This is how you can achieve your goal.

Sharing from Mr. Chau

“When I was admitted before, the doctors in the hospital used death to scare me. But I’m not afraid of death. What’s more important is to die with my body intact. I didn’t want the surgery to put a hole in my belly.

They seemed to me to be selling something for a commission. The discussion was focused on the dialysis – they sounded like a real estate salesman. I wasn’t convinced.

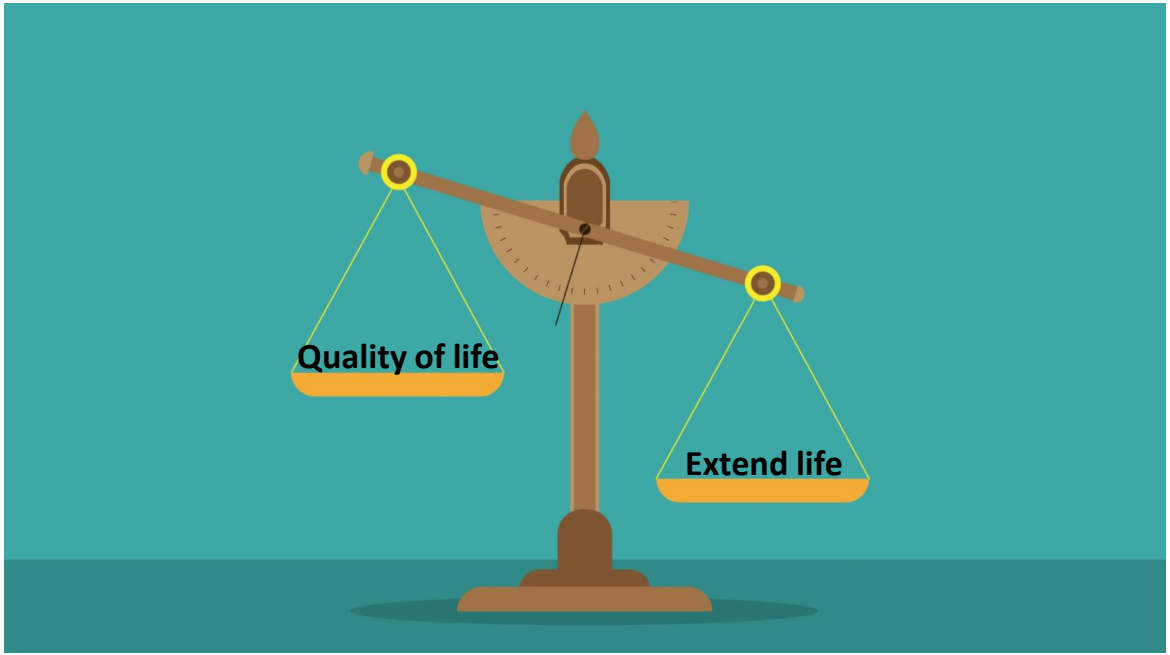
But Dr. L was different. He seemed experienced and was caring. He understood my goal. He even understood how important gambling is to me.”

REMAP: Framework for Discussing Goals of Care in Serious Illness

- **Reframe**
- **Expect emotion**
- **Map the goals**
- **Align**
- **Plan**

VITALtalk

Understanding tradeoffs: Mapping the goals



- What do you hope for?
- What activities do you enjoy most?
- What worries you most?
- What can't you live without?

Discussing CPR preference

- Not helpful to ask about every component of CPR
  - Uncomfortable for pt/family
  - Feeling of abandonment
- When goal is comfort-focused, can make recommendation for DNACPR along with other plans to align with this goal
- Frame in positive terms: "*Allow natural death*"

Conversation is about goals rather than treatments

Mapping the goals: Place of care

- Prior experiences with hospitalization
- Caring concerns/Caregiver burden
- Pain control vs. Staying alert
- Prepare for when hospitalization is needed

Benefits of ACP beyond autonomy

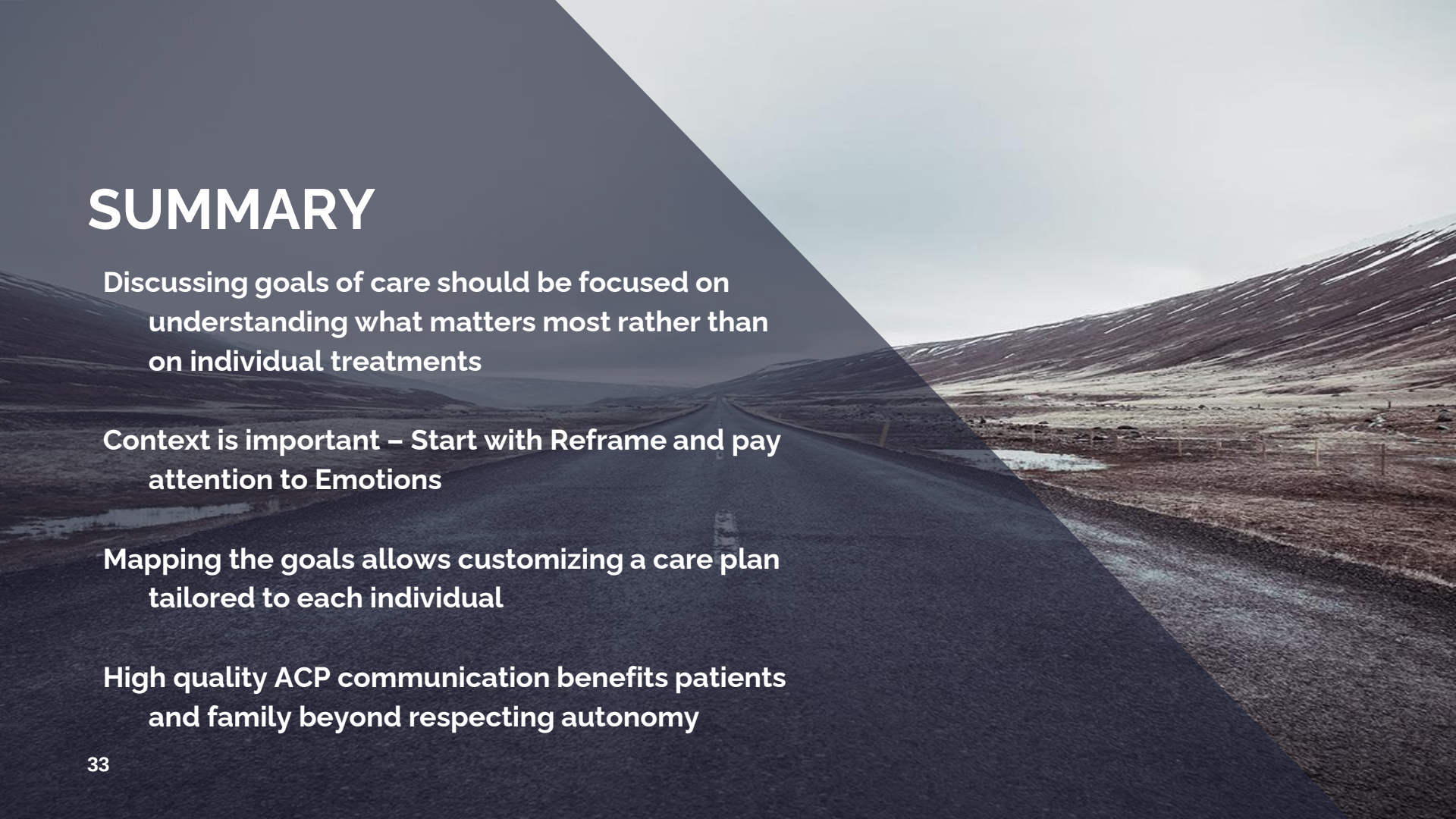
Patient

- Prepare for one's death
- Fulfill last wishes
- Decrease burden on family
- Increase communication with loved ones

Family

- Be prepared to make decisions for loved ones
- Avoid conflict with family members
- Prepare for loved one's death, avoid uncertainties
- Improve bereavement outcomes

Kolarik RC. J Pall Med 2002.



SUMMARY

Discussing goals of care should be focused on understanding what matters most rather than on individual treatments

Context is important – Start with Reframe and pay attention to Emotions

Mapping the goals allows customizing a care plan tailored to each individual

High quality ACP communication benefits patients and family beyond respecting autonomy

To learn more on Map the Goals

- Asking the important questions

  V-values that are important to the patient

  A-activities that they enjoy the most

  L-living well and unacceptable ways of living

  U-uncertainties, fears and worries

  E-experiences with illness

  S-source of strength or support

Berns S, Camargo M, Meier DE, Yuen JK. Goals of Care Ambulatory Resident Education (GOCARE): Training Residents in Advance Care Planning Conversations in the Outpatient Setting. *Journal of Palliative Medicine* 2017;20(12):1345-1351. doi: 10.1089/jpm.2016.0273.

Thank you!

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