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Jockey Club End-of-Life Community Care Project

Engaging Patients and Family Members in ACP Conversations: The Local Experience of End-of-Life Care for People Touched by Chronic Obstructive Pulmonary Disease

Mr Ivan FUNG *(MSW, RSW, FT)*

Expert Trainer, HKU JCECC Project

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Intended Learning Outcomes

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After this lecture, participants should be able to:

1. Understand existing barriers in engaging COPD patients and family members in ACP conversations

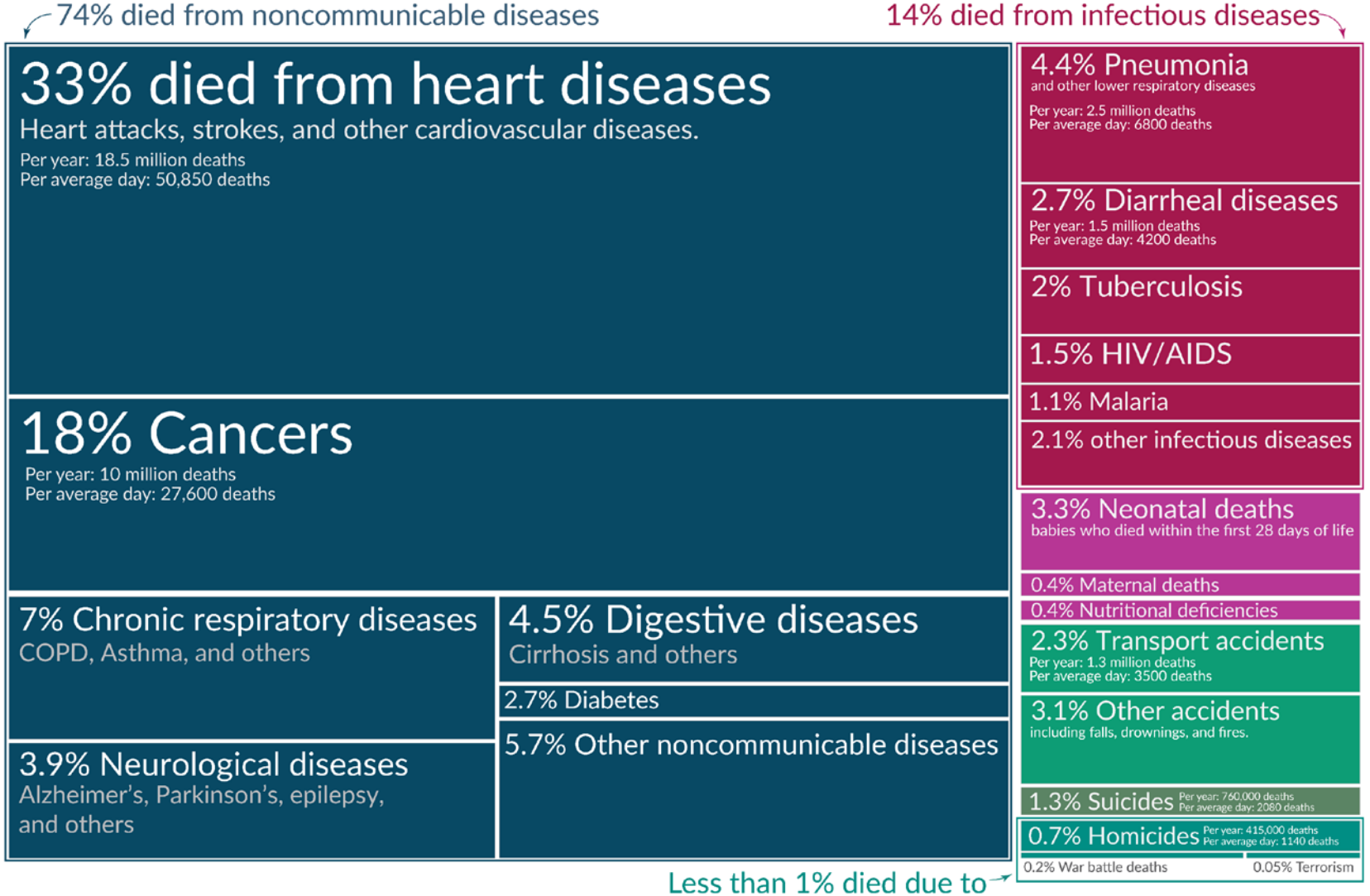
2. Understand effective communication strategies for engaging patients and family Members in ACP Conversations

3. Address the patients and family members' emotions with empathic responses

What do people die from? Causes of death globally in 2019

The size of the entire visualization represents the total number of deaths in 2019: 55 million.
Each rectangle within it is proportional to the share of deaths due to a particular cause.

Our World in Data



Data source: IHME Global Burden of Disease and Global Terrorism Database
OurWorldinData.org – Research and data to make progress against the world's largest problems.

Chronic Obstructive Pulmonary Disease

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- COPD refers to the obstruction or narrowing of respiratory tract caused by long-term damage to the respiratory system, resulting in difficulties of the lung to breathe in and out properly. This in turn causes symptoms such as hypoxia (lack of oxygen), breathlessness and coughing. COPD patients may even have difficulties in their normal daily activities.

- There is currently no cure for chronic obstructive pulmonary disease (COPD) and it will deteriorate gradually over time.

SMART PATIENT 智友站

https://www21.ha.org.hk/smartpatient/SPW/en-us/Disease-Information/Disease/?guid=fa4f5129-6dfc-4f27-a4c9-69e3b34865ba

COPD at end-of-life

- "One of the great difficulties of planning the timing of end-of-life discussions is the uncertain disease trajectory in chronic respiratory conditions. COPD has not only an insidious onset, but also, an unchartable end-stage."

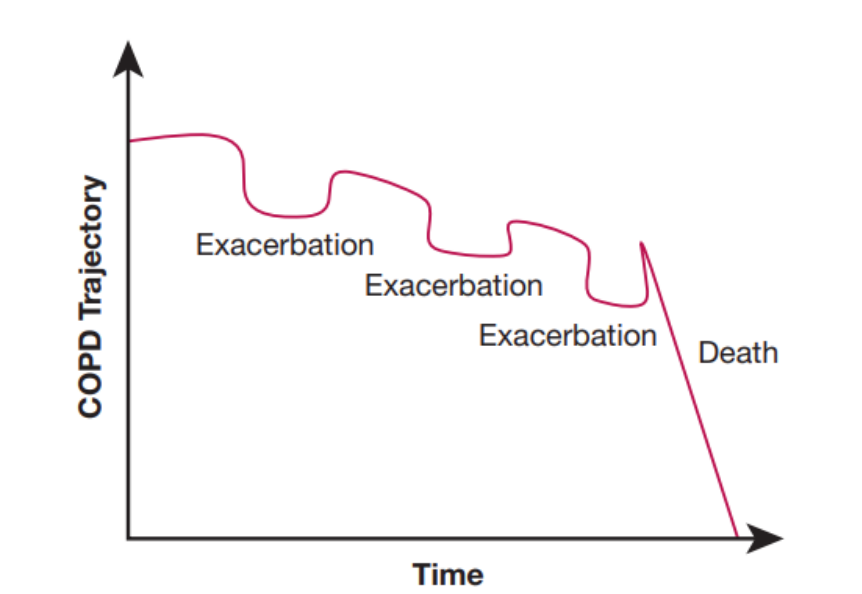

Figure 2 – *Common COPD trajectory associated with exacerbations.*

Rose, E. K., & O'Connor, J. (2022). Addressing advance care planning in patients with COPD. *Chest*, *161*(3), 676-683.

COPD at end-of-life

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- Compared to patients with lung cancer, COPD patients have more Emergency Department admissions, more anxiety & depression, and report a lower quality of life. Compared to cancer patients, financial support comes later in the disease process and patients feel in greater need of aids and appliances, and of information on services and benefits (Gore et al., 2000, Crawford, 2010).

- COPD patients are less likely to receive prognostic information, less likely to know they are dying, or know they are dying for less time and they are more likely than lung cancer patients to die in hospital. Relatives of COPD patients are less likely to be present at the time of death, although, we know most would like to be present (Edmonds et al., 2001).

- Some ways to approach these difficult conversations include beginning discussions early in the disease course, using the uncertain disease trajectory to ease discussions and building a caring and respectful relationship with patients. It is useful to have a team approach with recognition of the collective responsibility of GPs, respiratory nurses and physicians to proactively identify and use opportunities to talk about prognosis (Halliwell et al., 2004).

Gullick, J. (2012). Psychosocial dimensions of COPD for the patient and family. Chronic obstructive pulmonary disease current concepts and practice. Rijeka: InTech Publishers, 153-178.

What is Advance Care Planning (ACP) ?

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- ACP is a process of communication among a patient with advanced progressive diseases, the healthcare providers, and the patient's families/carers regarding the kind of care that will be considered appropriate when the patient cannot make those decisions.

- It is an overarching and preceding process for expressing preference and values for medical and personal care, which in turn will shape the care for the patients thereafter and at the end of life. Through the ACP process, a mentally competent and properly informed patient may express preferences for future medical or personal care, or make an advance directive (AD) refusing futile life-sustaining treatment.

HA Guidelines on Life-Sustaining Treatment in the Terminally Ill (2015)

Why is ACP Important?

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- Improvement of the Patient/Physician Relationship
  - helps HCPs truly understand patient goals.
  - help patients prepare to make informed choices (aligned with their overall goals
- Reduction of Burden
  - When a patient cannot make his or her own decisions, that stress is amplified because families have to make the decisions, potentially leading to family uncertainty or conflict

COPD at end-of-life & ACP

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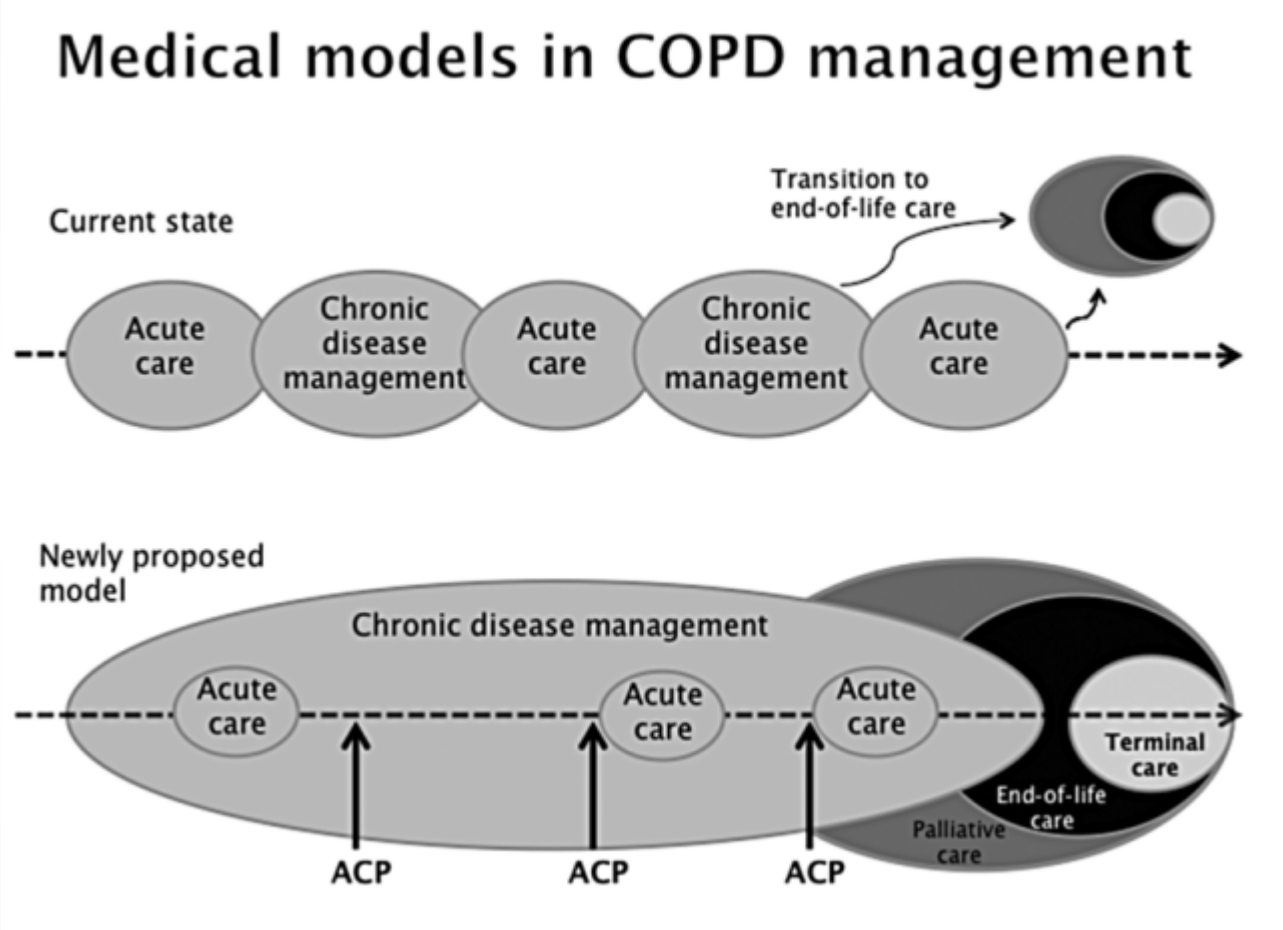
- The aim of good end-of-life discussions is to inform without removing hope, and to bring to the forefront the wishes of the patient and family
- Physicians can foster hope by giving a 'commitment to non-abandonment', by addressing people's fears, such as fear of pain at end-of-life, and by having a management plan that addresses their changing situation (Curtis et al., 2008)
- Helping people to identify realistic goals and discussing their concerns about day-to-day living can also be useful (Clayton et al., 2005).
- trying to understand and be true to the patient's core values whilst remaining flexible around practical details such as where they would prefer to die.
- what is 'good' or 'safe' for patients at different stages of their illness experience ?



Patel, K., Janssen, D. J., & Curtis, J. R. (2012). Advance care planning in COPD. *Respirology*, *17*(1), 72-78.

Engaging Patients and Family Members in ACP Conversations

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- (1) preparation of the discussion;
- (2)content; style; and family-related aspects of the discussion;
- (3) follow-up / documentation

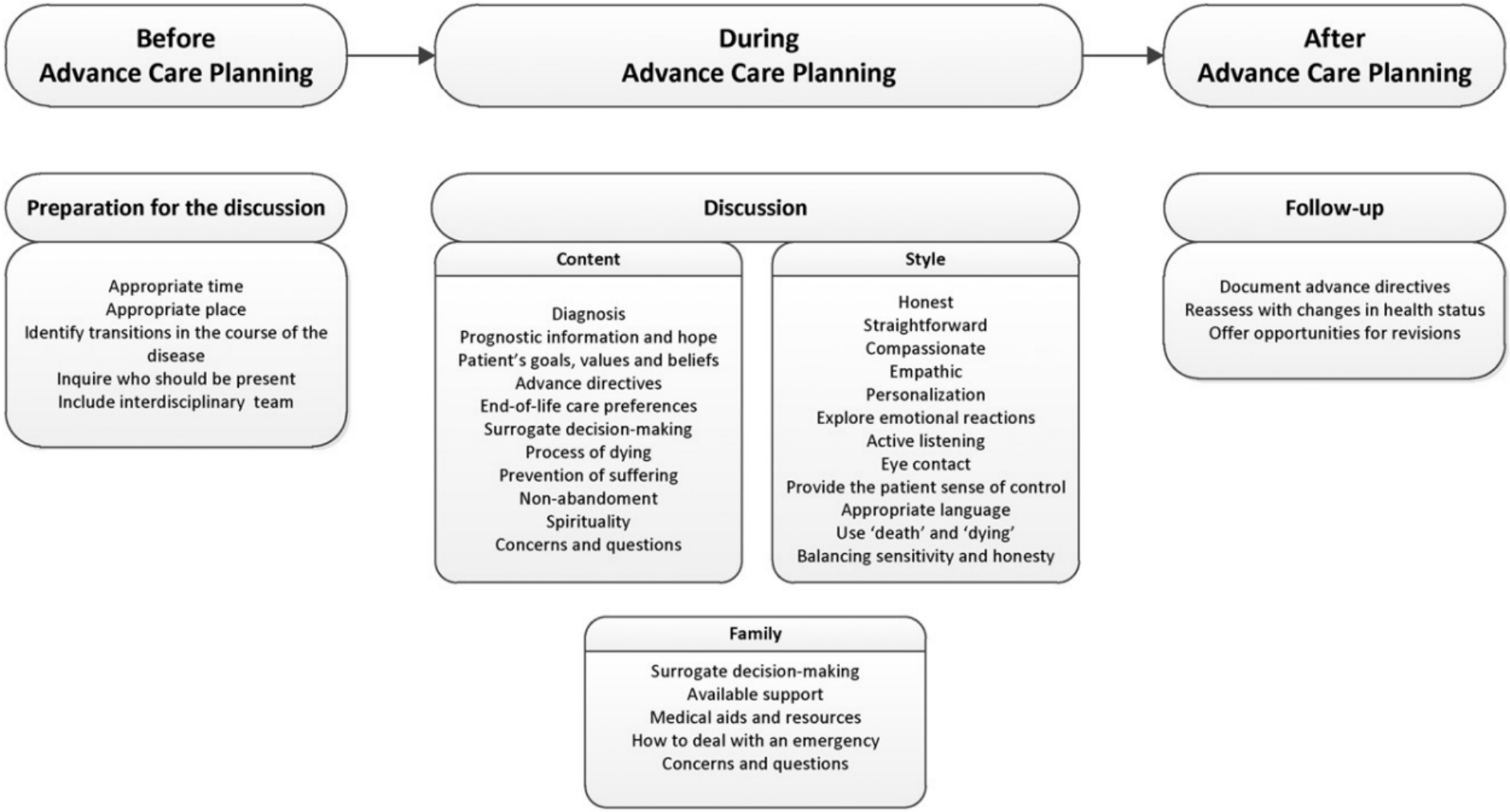

Fig. 1. Conceptual approach to advance care planning.

Janssen, D. J., Engelberg, R. A., Wouters, E. F., & Curtis, J. R. (2012). Advance care planning for patients with COPD: past, present and future. *Patient education and counseling*, 86(1), 19-24.

Goals of Care Options

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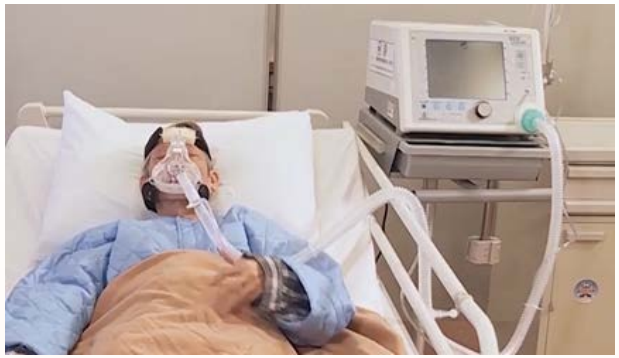
- Invasive treatment

- Non-Invasive treatment



- Comfort Care

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From triggers to ACP discussion

- Initiate the Serious illness Conversation

  The skill of SPIKES

- Present our empathic concern

  NURSE Statement

SPIKES

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- STEP 1: SETTING UP the Interview
- STEP 2: Assessing the Patient's PERCEPTION
- STEP 3: Obtaining the Patient's INVITATION
- STEP 4: Giving KNOWLEDGE and Information to the Patient
- STEP 5: Addressing the Patient's emotions with EMPATHIC responses
- STEP 6: Strategy and Summary

(Rosenzweig , 2012)

1. Preparation - Setting up the Interview

triggers

- Prepare yourself (WHAT)
  - Familiarise yourself with the patient's background, medical history and test results. You will also need to have some knowledge of the choices in the future management of the patient's condition.
  - It is helpful to mentally rehearse the interview, the likely questions you will be asked, the patient's emotional and potential responses.

- Prepare your setting (WHERE) –
  - Arrange for quiet and private location
  - Sit down
  - Make connection with the patient: maintain eye contact and/or touch the patient (if he/she is comfortable with you doing so)
  - Manage time constraints and interruptions
- Involve important family members as per the patient's choice (WHO)

* Starting off? Introductions and appropriate opening

2. Assess the patient's perception

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- What the patient knows already ?
- "Tell me what you understand about your illness?"
- "Did anyone discuss with you about your illness?"

- Listen to the patient's level of comprehension
- Determine if the patient is engaging in illness denial

3. Obtain the patient's invitation

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- Are you ready to share the views on your illness ?
- "Would it be okay for me to discuss the results with you now?"
- "Do you want your family to participate the discussion of your illness?"

- Accept the patient's right not to know
- Offer to answer questions later if he (she) wishes

4. Give knowledge and information

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- The four crucial headings are: Diagnosis, Treatment Plan, Prognosis and Support

- "I have something serious … May I discuss with you now?"
- Warn the patient that bad news is coming; this may lessen the shock that can follow the disclosure of bad news
  - "Well, the situation does appear to be more serious than that"
  - " For COPD patient, the lung function will only be getting worse, and it is almost irreversible…"

- Use simple way to deliver the message. (Use non-technical words , Use their words if possible)
- Pause and let the news sink in

- Give information in small chunks, and periodically check the patient's understanding
  - "Am I making sense?"
  - "This might be a bit bewildering, do you follow roughly what I'm saying?"
  - Could you just tell me the general drift of what I have been saying, to check I've explained it clearly?"
- Repeat Important Points – patients who are upset or shocked don't hear or remember well.
- Use diagrams, written messages as an aide memoir, audiotapes or leaflets.

Avoid !!!

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- Avoid excessive bluntness
- Avoid using phrases such as “There is nothing more we can do for you”

→ goals in care will change to good pain control and symptom relief, all of which are possible

- Encourage questions and allow time
- Offer to speak to family members or carers should the patient wish.

Address the patient's emotions with empathic responses

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- "I know this is not what you expected hear"
- " This news might be very difficult to you"

- Observation
- Identification
- Connection
- making a connecting statement

NURSE Statement

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Responding to Emotion: Articulating empathy using NURSE statements

- Naming
- Understanding
- Respecting
- Supporting
- Exploring

VITALtalk

https://www.vitaltalk.org/resources/quick-guides/

Address the patient's emotions with empathic responses

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- Providing support to the patient begins with responding to the patient's emotions, which can range from silence to disbelief, crying, denial or anger.

- An empathetic response consists of five steps:

a) Observe for emotions such as tearfulness, silence or shock.

b) Acknowledge and identify with the emotion experienced by the patient.

When a patient is silent use open questions, asking them how they are feeling or thinking. This will help them articulate what their emotions are. Allow time for silence and tears.

Address the patient's emotions with empathic responses

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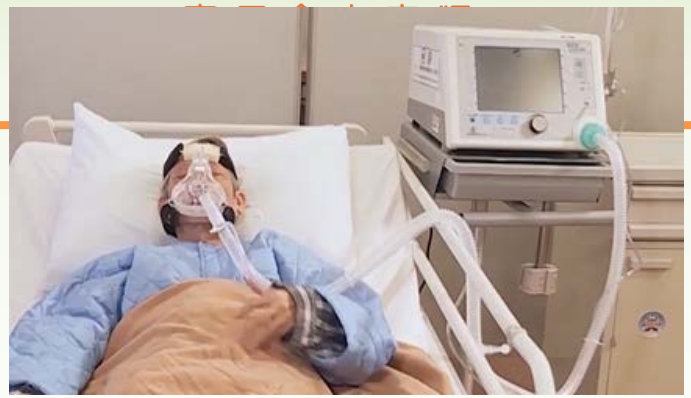
c) Do not say "I know how you feel". Even if you have had personal experience of the disease or condition, you cannot know how an individual feels. Empathy can be shown by using terms such as "I think I understand how you must be feeling".

d) Check the reason for the response. This will usually be related to the news you have just given them or the impact the news will have on their family or children.

e) Encourage and allow the patient time to express their emotions and let the patient know you understand and acknowledge their emotions. This reduces the patient's isolation, expresses solidarity and validates their feelings or thoughts as normal and to be expected. Unless the emotions of the patient are adequately addressed it is difficult for the doctor/other professional and patient to move on to discuss other relevant issues.

Explore the patient's feeling



- E.g. using the breathing machine
- Mr. Chan has used BiPAP before to help with breathing. Did he talk about his attitude towards using BiPAP with you ?
- Are there any specific reasons that he doesn't want to wear the mask ?
- Some times we may not fully understand patients' thoughts….
- Has he ever expressed his wishes or plan before ? Would he prefer being comfortable or opt for a longer life ?

Strategy and Summary

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- Summarize the information
- Discuss the next steps and follow up plan
- Sharing responsibility for decision making

- "We have talked about a lot of things today, you may need sometime to understand the information or discuss with others. How about we stop for today and discuss next time after your full consideration?

What do patients want?

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- Doctors and professionals now increasingly share information it was believed to be in the best interests of the patient.

- The evidence indicates that patients increasingly want additional information regarding their diagnosis, their chances of cure, the side effects of therapy and a realistic estimate of how long they have to live.

- Patients want their doctor to be honest, compassionate, caring, hopeful and informative.

- They want to be told in person, in a private setting, at their pace, with time for discussion and if they wish, with a supportive person present

What is the impact on you as a health care professional?

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- Uncertainty about the patient's expectations
- Fear of destroying the patient's hope.
- Fear of their own inadequacy in the face of uncontrollable disease.
- Not feeling prepared to manage the patients anticipated emotional reactions.
- Embarrassment at having previously painted too optimistic a picture for the patient

Beyond Engaging Patients and Family Members : Helping patients who suffer

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- (1) Finding strength
- "When bad thing have happened to you before, how have you coped?"
- "Whom will you turn to for support?"
- Prescribe resources available to the patient:
  - Regular physician follow up
  - Psychologist, social worker, chaplain, home care referral
  - Reading material, videos
  - Support groups

Rabow, M. W., & McPhee, S. J. (2000).

- (2) Enhancing growth
- "Even though there are some things you can no longer do, what activities can you still enjoy?"
- "Are there things about you this disease does not affect?"

Prescribe steps toward growth:

- Identify times when patient has grown in the past
- Research what has been possible for others

- (3) Embracing the moment
- "What do you feel like doing right now?"
- "Is there something you've always wished you could do? What is stopping you from doing it?"

- Prescribe a redirection toward current reality:
  - Coordinate disease treatment with personal goals
  - Help set priorities
  - Teach or encourage meditation

- (4) Searching for meaning in suffering
- "What does this news mean to you?"
- "Does this news scare you in any way?"
- "What do you think caused your illness?"

- Prescribe life examination exercises:
  - Journal writing,
  - autobiography,
  - life review
  - Revisiting the past through photos, people, travel

- (5) Seeking acceptance and reconciliation
- "Do you have any regrets in life?"
- "Is there anyone you really want to talk to before you die?"
- "Is there someone you've never been able to forgive?"

- Prescribe steps toward self-acceptance and reconciliation:
  - Distribution of personal possessions
  - Communication by letter, telephone, e-mail
  - Meetings, goodbyes

- (6) Achieving transformation
- Inquire about spiritual and religious beliefs:
  - "Are you a spiritual or religious person?"
  - "Has illness ever changed you in a fundamental way in the past? If so, how?"
  - "Do you know anyone who was transformed in a positive way by illness?"
  - "Where do you think things are headed?"

- Prescribe movement toward transcendence:
  - Spiritual mentor
  - Prayer
  - Letters to loved ones

Take home message

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- Understanding patients and family members' uncertainty and concerns
- Engaging patients and family members in early ACP Conversations
- Addressing the patients and family members' emotions with empathic responses

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ivanfkw@hku.hk