Large Group Advance Care Planning: Challenges and Opportunities

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Declarations

- We have no conflicts of interest to disclose
- No funding was received for this study
- Ethics Approval was received from Laurentian University’s Research Ethics Board

Clinical Problem:

- Older adults present to hospital confused and require goals of care discussions without having completed Advance Care Planning.
- Lack of capacity within primary care to complete ACP discussions.

Solution/Study Question:

- Can Advance Care Planning documents be completed if facilitated by a Clinical Nurse Specialist in a large group setting?
- Would participants share completed ACPs with SDMs, primary providers and agencies?

What is Advance Care Planning

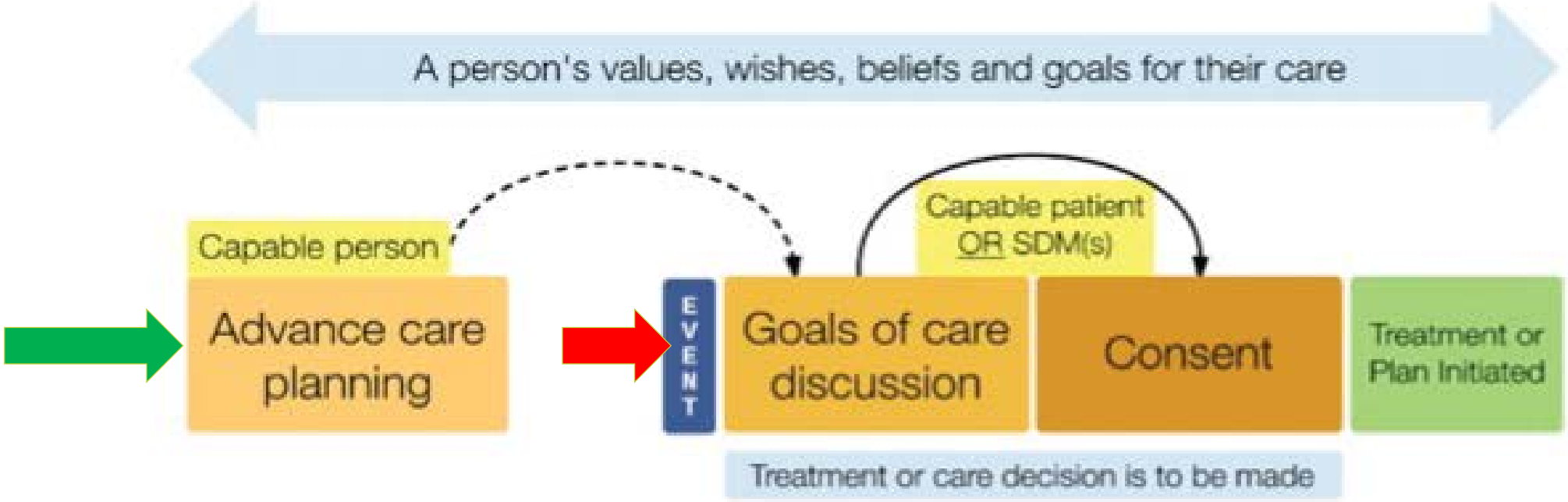
In Ontario, advance care planning (ACP) is:

1. Confirming your substitute decision maker(s) (SDMs)

2. Communicating your wishes, values and beliefs about care to help your SDM(s) make health and personal care decisions for you if you become incapable of doing so for yourself.

Speak up Ontario. Retrieved from https://www.makingmywishesknown.ca/what-is-advance-care-planning/#skip on October 10, 2021

Person-Centred Health Decision-making



ACP Conversation Guide Questions

- **Understanding:** Based on previous discussions with your health care providers, what is your understanding of your illness? What do you expect to happen in the future?
- **Information:** Do you think that you need to know more about your condition? Is there any information about your illness that you don't want to know?
- **Values, Beliefs & Quality of Life:** What brings quality to your life? What do you value, or what is important in your life that gives it meaning?
- **Worries and Fears:** Think about the care you might need if you have a critical illness or if you are near the end of your life. What worries or fears come to mind?
- **Trade Offs:** If you have a critical illness, life support or life extending treatments might be offered to you with the chance of gaining more time. Think about what brings quality to your life and what you value.
- **Near the End:** If you were at the end of your life, what might make the end more meaningful or peaceful for you?

Methods

Two workshops offered 6 weeks apart:

Workshop One Goals

- to learn language and tools to help complete ACP
- assistance identifying current SDM or alternative
- self-assessment of current state of health using clinical frailty scale as guide

Workshop Two Goals

- Engage both SDMs and participants
- Facilitated group Advance Care Planning using standardized ACP tool
- Encourage participants to share completed ACP document
- Offer anonymous, voluntary survey at the end of the second session

Participant Characteristics

- Over age 65
- All female
- Living in Northern Ontario
- Capable and well

- All participants belong to the same community group
- Total participants 47 (confidentiality forms to participate in the workshop collected)
- Total surveys collected: 38 (81% response rate)

Results:

Questions 1-14 asked participants about their understanding of the terms and concepts (palliative care, end of life, Power of Attorney, Substitute Decision Maker, Medical Assistance in Dying…)

- Over 90% of respondents indicated that they could describe terms above
- Approximately 25% of respondents did not understand how to change their ACP once it was completed
- There was some confusion about the term ‘goals of care’ 28% of respondents did not understand this term
- How frailty relates to ACP was confusing with 24% of respondents indicating difficultly understanding.

Results

Questions 15-28 related to the SDM and Completion of the ACP tool.

Before the workshops:

- 75% could identify their SDM
- **13%** percent of respondents had completed a written ACP document.

After the workshops:

- 90% of participants could identify their SDM
- **46% indicated that they had completed a written ACP**
- **52% indicated that they had partially completed a written ACP**

Results

Questions 29-38 related to sharing the documented ACP with SDMs, health care providers and health care agencies

- 87% of respondents indicated that they intend to discuss the content of their plans with their SDM.
- **Only 42% indicated an intention to discuss their completed ACP document with their primary care provider!**
- Only 18% had an intention to discuss it with their specialist or surgeon.
- Only 8% have an intention to share their ACP document with their hospital

Challenges

- Participants were observed experiencing emotional reactions during both workshops.
- Workshops were overwhelming for one clinician to run!
- Developing tailored teaching materials vs. HPCO resources.
- Confusion by some SDMs at second workshop
- Provide ACP tools before coming to the second workshop
- Pandemic may necessitate virtual platforms in the future

Opportunities

- Promising results overall: ACP **can be** completed in a large group by a nurse with ACP training.
- Church groups, apartment complexes, senior's centers, legions…
- Primary health care providers may need to take the lead in asking about previously completed advance care planning
- Primary health care providers may be best positioned to offer ACP to their patients in a facilitated group setting
- Specialists, community agencies and hospitals can invite patients to share completed ACP documents but must have mechanisms/pathways in place to store and retrieve ACP documents when required.

Discussion/Questions

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