Presentation Matters in Advance Care Planning and Goals of Care Conversations

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TVN Improving care for the frail elderly

Background

- Alberta Advance Care Planning (ACP) and Goals of Care Designation (GCD) patient and HCP materials were developed using anecdotal evidence
- Needed to test usability, user-friendliness, & functionality of resources with patients, family, and HCPs during medical encounters

Functionality

Dysfunctional communication is evidenced by:

- Several disruptions to the talk with people asking for clarification and repetition of points,
- People appear distracted, have a furrowed brow while listening, and provide answers and/or information that deviates from that which was requested
- HCP need to do more discursive work to keep the conversation going and get the necessary information

Functional communication is evidenced by:

- smooth flow to the talk with minimal interruptions from misunderstandings or misinterpretations
- People make eye contact, ask pertinent questions, write notes, display interest in the discussion, provide relevant information
- HCP's discursive work is minimized while still obtaining necessary information

Study Objectives

Phase 1: Establish a baseline understanding of the process by which ACP/GCD conversation are conducted in different medical contexts

Phase 2: Develop and test senior friendly patient information materials and discussion strategies for HCPs that better reflect the needs of patients

Phase 3: Solicit HCP feedback on refinements to further tailor new materials

Phase 1: Method

- Recruited from 4 clinical areas: renal care, cancer care, palliative care and geriatric care (Edmonton/Calgary – 7 clinical sites)
- HCP conduct discussion as usual
- Data was analyzed within and across sites using conversation analysis to pull out those elements of ACP/GCD discussions that were empirically shown to be working well

Phase 1: Participants

- Patients: N=25 (Men=15; Women=10)
  - Age range: 39-89 years (>60 years= 88%)
  - Range of illness - all with at least one serious illness
- Family: N=15
- HCPs: N=11
  - Physicians (N=3)
  - Nurse Practitioners (N=2)
  - RNs (N=4)
  - Social Workers (N=2)

Phase 1: Key Findings

- Patients displayed more engagement in the ACP process when it was a conversation rather than enacted as an interview or an information session
- Patients displayed greater understanding of the elements of ACP/GCD and more engagement in the process when they had resource materials to follow along with during the consultation
- Patients appreciated paper info materials – but want something more suitable – 'senior-friendly'
- Patients/families found the terms ACP, GCD and the Green Sleeve to be technical/medical jargon

Phase 2: Method

- Recruited from 5 clinical areas: renal, heart, cancer, palliative care, & geriatric care (10 clinical sites – Edmonton/Calgary)
- HCPs asked to incorporate at least 3 evidence-based conversation strategies in each consultation
- HCPs asked to '***use***' one of the new senior-friendly patient information resources during the patient consultations
- Patients (family) were given the new resource(s) to take home
- Data was analyzed using conversation analysis within and across sites to determine if the new evidence-based resources improved consultation functionality

Phase 2: Participants

- Patients: N=31 (Men=18; Women=13)
  - Age range: 40-90 years (M=70; >60 years= 84%)
  - Range of illness - all with at least one serious illness
- Family: N=20
- HCPs: N=15
  - Physicians (N=6)
  - Medical Fellow (N=1)
  - Senior Medical Resident (N=1)
  - Nurse Practitioners (N=1)
  - RNs (N=4)
  - Social Workers (N=2)

Phase 2: Key Findings

- Patients/family displayed engagement in and understanding of ACP, GCD & GS when the new materials were used
- After the consultations, 29/31 patients & 17/20 family expressed appreciation for having the materials during the consult
- Requests for a copy of each resource – Personal Journal for patient (or family) to record wishes; Info Booklet to explain process to other important people in patient's life

Phase 3: Method

- Recruited from 5 clinical areas: renal, heart, cancer, palliative care, & geriatric care (10 clinical sites – Edmonton/ Calgary)
- HCPs interviewed after 'using' new patient and HCP resources ('What worked?, What didn't work?, What would you change?)
- Thematic analysis was performed

Phase 3: Participants

HCPs = 13

- Physicians (N=6)
- Nurse Practitioners (N=1)
- RNs (N=4)
- Social Workers (N=2)

Phase 3: Main Findings

Very positive feedback

HCP Recommendations:

- Some minor word changes
- Create an ACP/GCD Discussion App for HCPs
- Have PDF versions of the patient resources available online

Phase 3: Testimonials

Palliative Care Physician:

"I was just really surprised. After I had had that discussion and I'd left and I was just—it just struck me as to how effective it was to have that tool [Personal Journal] in front of me. I know that I was able to address those aspects of Advance Care Planning much more effectively than I would have without that tool… I consider myself to be more advanced in practice with regards to Advance Care Planning and if I can get value out of that tool, then I think it's a pretty good tool. I think it's a very reliable thing and if it was available, I would be using it much more in my practice."

NARP ACP Discussion Guide

Method:

- Recruited from 7 renal clinics in Edmonton
- ACP-Fs used the Discussion Guide to assist them in facilitating ACP
  - Tool to assist with the development of own discussion style
  - Questions give structure and effective ways of soliciting info
  - Goal of Guide is to reduce ACP-F's discursive work, yet ensure all information needed is collected in a timely manner
- Feedback from ACP-Fs collected after each use of the Guide
- Constant comparison method used to revise tool during testing (analysis + feedback)
- Patients/Agents completed a survey

ACP Discussion Guide Participants

- Patients: N=11 (Men=3; Women=8)
  - Age range: 59-85 years (M=73)
  - Varying degrees of kidney disease
- Family: N=13
- ACP-Fs: N=5

ACP Discussion Guide: Key Findings

- Patients/Agents displayed engagement in and understanding of ACP/GCD/GS
- ACP-Fs stated Guide significantly improved the facilitation experience
- Patient/Agent Survey – very positive feedback
- NARP team has continued evidence-based modifications to the Guide - currently in use in NARP and used to train new NARP ACP-Fs

How addressed the problem of Advance Care Planning, Goals of Care Designation and Green Sleeve being technical/medical jargon

ACP/GCD/GS Icon Study: Objective

- Developed evidenced-based meaningful icons/symbols to assist seriously ill and/or older adults to recognize and understand ACP/GCD/GS

Icon Study: Procedure

- 2 rounds of data collection:
  - 1st to determine presentation preference
  - 2nd to validate new designs
- Participants: inpatient/outpatient renal and geriatric patients and some family members in Edmonton
- Researcher-administered survey
- Icons empirically tested for preference, appealingness, perceived understanding, and functionality

Demographics – Round 1

- N=268
  - (ACP: N=90; GCD: N=88; GS: N=90)
- Patients=225; Family=43
- Men=133; Women=135
- Age range: 18-94 years (mean=61 years; >60 years = 58%)
- Broad range of ethnicity
  - predominantly white (77%)

Demographics – Round 2

- Total surveys completed=95*
  - (ACP=32; GCD=32; GS=31)
- Patients=33
- Men=18; Women=15
- Age range 40-94 years (mean= 70 years; >60 years = 26 (79%)

* Collected until saturation

Main Findings

- Unanimous preference for revised version of ACP/GCD/GC icons
- Respondents believed that the picture, simple slogans and information explaining the AHS' slogan *Conversations Matter* is important

New *Patient/Family* Resources to Enhance Advance Care Planning & Goals of Care Conversations

Personal Journal for Advance Care Planning & Goals of Care

- Encourages people to actively participate in the ACP process
- Everything inside 'evidence-based'
- Can be independently filled in or with the help of loved ones and/or healthcare providers
- Tabbed sections: ACP, Agent, Personal Directive, Goals of Care, Green Sleeve

Advance Care Planning & Goals of Care Patient Information Booklet

- Brief informational resource intended to introduce people to the concepts
- Same basic information as Personal Journal without areas for active involvement
- Note page at the back

New *Healthcare Provider* Conversation Resources to Enhance Advance Care Planning & Goals of Care Conversations

ACP/GCD Discussion Guide for HCPs

- Contains guide on how to introduce the topic, what to talk about, examples of talk from other HCPs, questions to ask, tips on asking questions and designing your talk
- Focus groups in Edmonton/Calgary for key stakeholders/end users
  - Resource more suited to novice/student
  - Some info applicable to HCPs skilled at ACP but difficult to easily find

HCP Conversation Strategies Feedback Mechanism Grid

Do More Of	Start Doing
- Asking open-ended telling questions such as What do you think makes your life worth living?; What concerns do you have about your health?; Is there some health information you would find helpful; What life experiences make you think about the type of healthcare you'd want? - Asking the patient "What are some of your questions?" and/or if what you said makes sense (especially after explaining a component of the process) - Saying the terms 'advance care planning' and 'goals of care' during your conversation. These terms are often unfamiliar and repetition will help patients become more familiar with the terminology. - Praising the patient for ACP/GCD tasks completed	- Pausing after every few statements for a count of four to yourself (especially when explaining about the ACP process) - Asking one question at a time, with a pause after each question to allow the patient to answer - Associating the term "Advance Care Planning" with the slogan "Plan your healthcare together;" "Goals of Care" with the slogan "Talk about your medical wishes;" and "The Green Sleeve" with "Document medical plans together" - Acknowledging and supporting patients' hopes whenever possible – avoid dismissing hopes
Do Less Of	**Stop Doing**
- Asking questions that 'test' the patient's knowledge such as "What do you know about CPR?" - Asking questions for which you have a predetermined answer in mind – rather, keep an open mind for a response - Focusing on what you cannot do for them – rather focus more on what can be done to meet their goals for care and to make their life worth living - Overburdening the patient with too much information at one time – rather, tailor information-giving to patient's goals of care	- Asking questions that include the word "any" ("Do you have any questions?") – rather ask "Do you have some questions? - Merging a question into your previous talk – count to four to yourself between your talk and the question

Availability of Materials

- Personal Journal
- Patient Information Booklet
- HCP Conversation Strategies Feedback Mechanism Grid
- Discussion Guide for HCPs

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Available through Canadian Virtual Hospice website

- The content is posted under the titled "*Advance Care Planning and Goals of Care Discussion Toolkit.*"
- More specifically it can be found within 'Books, Links and More' or the 'Tools for Practice' sections filed under *advance care planning* or *communication*.

- NARP ACP-F Discussion Guide
  - Contact Sara Davison for more information (sara.davision@ualberta.ca)

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Thank you ☺

Questions, Comment, Suggestions

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