Serious Illness Care - More, Earlier, Better Conversations

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Faculty Introductions

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Disclosure Information

No disclosures or conflicts of interest to report
Objectives

- Introduction to the Serious Illness Conversation Initiative
- Review the components of the Serious Illness Conversation initiative
- Practice using a structured, person-centred approach to goals-of-care conversations
- Explore the systems change strategy recommended by Ariadne Labs and the work that is being done in British Columbia
Exercise 1

Think about a challenging serious illness conversation you have had with a patient and their family.

What is one thing you did well?

What is one thing you would like to do differently?
How Do We Define “Serious Illness”

A condition that:

- Carries a high risk of death over the course of a year
- Has a strong negative impact on QOL and functioning in life roles
- Is highly burdensome to a person and his/her family

Kelley, AS Jrl Pall Med 2014
What is a serious illness conversation?

A clinician-initiated discussion that:

- Asks patients about values and goals using a structured format
- Shares prognosis, *when* appropriate
- De-emphasizes treatments and procedures
- Occurs early in the course of a serious illness
- Provides a foundation for making decisions in the future
- Should be reviewed/revisited over time
- Is valuable and therapeutic even if medical decisions are not being made

A Serious Illness Conversation is not...

- A conversation solely focused on medical decisions
- A MOST conversation
- A code status conversation

BUT

- Can be used to inform medical decisions and care planning, *when* appropriate
- Are valuable even if a patient is already DNR/No CPR
- Can and should come **before** a MOST conversation
- Can be used even if a patient has a MOST as a way of revisiting values, goals, and decisions
Many patients do not discuss their goals with clinicians

• Fewer than one third of patients with end-stage medical diagnoses discussed EOL preferences with physicians

• Patients with advanced cancer:
  • First EOL discussion occurred median 33 days before death
  • 55% of initial EOL discussions occurred in the hospital

• Conversations often fail to address key elements of quality discussions

Heyland DK Open Med 2009; Mack AIM 2012; Wright 2008
Early conversations about goals of care benefit patients & families

Are associated with:

- Enhanced goal-concordant care
- Time to make informed decisions & fulfill personal goals
- Improved quality of life
- Higher patient satisfaction
- Better patient and family coping
- Eased burden of decision-making for families

- More and earlier hospice care
- Fewer hospitalizations
- Improved bereavement outcomes

Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Detering BMJ 2010; Zhang Annals 2009
• Palliative care – with strong emphasis on quality communication – is a high-value intervention

• Better quality of life
• Less use of aggressive care
• 25% increase in survival
• Lower costs
• Primary focus of intervention – communication, patient education, planning for care

BUT:
• Not enough palliative care clinicians to reach all patients
• Scalable interventions targeted at non-palliative care clinicians needed for universal access to serious illness conversations

Advance Care Planning for Adults in BC

“More, Earlier, Better Conversations”

Integration of a Palliative Approach
Serious Illness Care Intervention is an approach to improving conversations & care

- **Tools**
  - Serious Illness Conversation Guide
  - Clinician Reference Guide
  - Patient preparation materials
  - Family Comm. Guide

- **Education**
  - Train the Trainers
    - 8 hour training sessions
  - Train Clinicians
    - 2.5-hour clinician training sessions

- **Systems Change**
  - Patient Screening
  - Reminder System
  - Conversation using the Guide
  - Documentation template in EMR
  - Patient & Family Resources

Measurement and Improvement (QI)
The ‘surprise’ question in advanced cancer patients: A prospective study among general practitioners

Matteo Moroni¹,², Donato Zocchi³, Deborah Bolognesi¹, Amy Abernethy⁴, Roberto Rondelli⁵, Giandomenico Savorani⁶, Marcello Salera³, Filippo G Dall’Olio⁷, Giulia Galli⁷ and Guido Biasco³,⁷, on behalf of the SUQ-P group³

“Would you be surprised if this patient died in the next year?”

Figure 1. Days of survival in 1 year for ‘Yes’ and ‘No’ groups (Kaplan–Meier) and comparison of the survival between the two groups (Log-rank test).
Patient prepared for conversation

Options include sending out the pre-visit letter or... talking to the patient to prepare them for the conversation
Dana Farber Serious Illness Care Program Randomized Trial

- Cluster randomization of MDs to usual care or to training in Serious Illness Conversation Guide
- Patients in whom answer to Surprise Question is ‘no’
- N=426

Primary endpoints:
- Delivery of goal-concordant care
- Degree of peacefulness

Secondary endpoints:
- Therapeutic alliance
- QOL
- Anxiety
- Depression
- Behavioral impact
- Quality of communication
- Family perception of patient life priorities
- Quality of Dying and Death

Courtesy of Dr. Rachelle Bernacki
A Systematic Intervention to Improve Serious Illness Communication in Primary Care RCT

- More serious illness conversations
- Better serious illness conversations
- More accessible in the health record
- Training feasible and effective

Joshua R. Lakin, Luca A. Korisanszky, Rebecca Cunningham, Francine L. Maloney, Brandon J. Neal, Joanna Paladino, Marissa C. Palmor, Christine Vogeli, Timothy G. Ferris, Susan D. Block, Atul A. Gawande and Rachelle E. Bernacki

A Systematic Intervention To Improve Serious Illness Communication In Primary Care

Health Affairs 36, no.7 (2017): 1258-1264
doi: 10.1377/healthaff.2017.0219

SOURCE Authors’ analyses of electronic health record data retrieved from institutional databases generated from routine clinical care.
Clinician and Patient have Conversation following the Guide

<table>
<thead>
<tr>
<th>Serious Illness Conversation Guide</th>
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<tbody>
<tr>
<td><strong>CONVERSATION FLOW</strong></td>
</tr>
<tr>
<td>1. Set up the conversation</td>
</tr>
<tr>
<td>- Introduce purpose</td>
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<tr>
<td>- Prepare for future decisions</td>
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<tr>
<td>- Ask permission</td>
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<tr>
<td>2. Assess understanding and preferences</td>
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<td>3. Share prognosis</td>
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<td>- Frame as a “wish…worry”, “hope…worry” statement</td>
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<td>- Allow silence, explore emotion</td>
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<tr>
<td>4. Explore key topics</td>
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<tr>
<td>- Goals</td>
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<tr>
<td>- Fears and worries</td>
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<tr>
<td>- Sources of strength</td>
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<td>- Critical abilities</td>
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<td>- Tradeoffs</td>
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<td>- Family</td>
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<td>5. Close the conversation</td>
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<tr>
<td>- Summarize</td>
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<tr>
<td>- Make a recommendation</td>
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<td>- Check in with patient</td>
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<td>- Affirm commitment</td>
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<tr>
<td>6. Document your conversation</td>
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<tr>
<td>7. Communicate with key clinicians</td>
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</tbody>
</table>

Organized as 2 parts: Checklist & Language (version 3)
Having a Serious Illness Conversation

[Link to YouTube video]

BC Centre for Palliative Care
Conversation Flow

1. Set up the conversation
   - Introduce the purpose
   - Prepare for future decisions
   - Ask permission
   - Offer rationale

2. Assess illness understanding and preferences
   - “What is your understanding now of where you are with your illness?”
   - How much information about what is likely to be ahead would you like from me?
3. Prognosis

“I want to share with you my understanding of where things are with your illness...

Options:

• Uncertain
• Time
• Function
• Explore previously disclosed prognosis
Some Specific Communication Tips

3 W’s: Wish (or Hope), Worry, and Wonder

Patient: “Will I make it to my granddaughter’s graduation in 2 years?”

Clinician:
  ○ “I wish that things were different; I worry that that’s not likely.”
  ○ “I hope that you can, but I worry that it may not be possible.”
  ○ “I wonder if there are things you can do to prepare in the event you can’t be there.”

○ I know you've said that you don't want information about prognosis, my dilemma is that you might be making different decisions if you had that information.
Helpful phrases

• I’m concerned that in spite of the treatment we’re giving you I might have to share some more difficult information with you soon.”

• I’m worried that even with aggressive treatment we may be getting to a place where we can’t control this disease and time may be short.

• We need a Plan B

• We’re in a different place now
4. Explore Goals and Fears
   • “What are your most important goals/fears if your health situation worsens?”

5. Explore Sources of Strength
   • “What gives you strength as you think about the future with your illness?”

6. Explore function, tradeoffs and family
   • “If you become sicker, how much are you willing to go through for the possibility of gaining more time?”
   • “What abilities are so critical to your life that you can’t imagine living without them?”
   • “How much does your family know about your priorities and wishes?”
Close Conversation & Document

7. Close the Conversation
   - Summarize and recommend
   - Check in with the patient
   - Affirm commitment

8. Document and communicate with key clinicians
Family Communication Guide

Give the family booklet to the patient and discuss how to talk to family.

Talking about your illness with loved ones and caregivers

This booklet can help you talk with your loved ones about your illness and the future. It is based on what you have already talked about with your clinician.

Talking about your illness with friends and family may not be easy, but it will help them understand what is important to you. It will also help them support you and your decisions.

Before you talk to your loved ones, think about when and where you want to talk. Choose a time and place when you feel relaxed. Be sure you have time to talk for a while. You can use the words in this guide, or use your own words — whatever is easier for you.
Interdisciplinary Team Roles

- **Identify** high risk patients who would benefit from having a serious illness conversation
- **Prepare patient**: Pre-visit letter or talking to the patient
- **SIC**: discussing patient’s understanding of their current state of health
  - exploring the patient’s wishes, values and goals
  - providing emotional support
- **Provide resources** to help the patient speak with their family
- **Recommend** follow up appointments; Home care support, family meetings etc
- **Document**: Ensure documentation is accessible across settings
**Common misstep: Not discussing prognosis**

<table>
<thead>
<tr>
<th>The purpose of prognostication is…</th>
<th>To help patients start planning process ‘just in case,’ not to be right or wrong</th>
</tr>
</thead>
</table>
| Discussing prognosis is hard; clinicians are afraid of… | • Being wrong/losing patient trust  
• Provoking anger, anxiety or sadness |
| Research on prognostication demonstrates that… | • Most patients want to know their prognosis  
• Pts realize that clinicians are not perfect prognosticators  
• Prognostic information can reduce anxiety & depression (*knowledge is power*)  
• Patients do not “die sooner” |
Common misstep: Getting off track

The order of the questions is important…

The topics addressed might not feel right at first…

The first priority is learning about the patient’s values & goals…

• Conversation Guide questions & order of the questions are based on research

• Reverting to what you are comfortable talking about is natural

• Discussion of treatments, interventions and the care plan comes after the serious illness conversation rather than in the middle
So you hate role play – a taste
Role-plays

15 minutes for a “taste” of the role play
  • To go through the first few questions of the guide
  • And time to debrief
  • This is a safe place

Time-outs are allowed
  • The clinician role or the facilitator may call time-outs

Debriefing
  • Clinician shares first
  • Then the patient
  • Then the observer
Implementation is a Journey

PHASE ONE: BUILD FOUNDATION
1. Convene an Exploratory Committee
2. Assess Readiness
3. Engage Leaders and Colleagues
4. Determine Program Goals
5. Recruit Implementation Team
6. Create Drivers for Program Use
7. Construct Budget and Obtain Approval

PHASE TWO: PLAN IMPLEMENTATION
2. Plan Outreach and Communication Strategy
3. Develop a Training Plan for Frontline Clinicians
4. Recruit Master Trainers
5. Develop/Modify the EMR
6. Prepare for Quality Control
7. Prepare for Monitoring and Evaluation
8. Support & Educate Customized Clinic Workflow for Conversation

PHASE THREE: LAUNCH FACILITATOR TRAINING
3. Initiate & Conduct Clinician Training Workshops
4. Begin Facilitator Training
5. Identify Master Facilitators for Train the Trainer Events
6. Begin Master Facilitators Training
7. Debrief and Synthesize Lessons Learned
8. Plan for Performance Improvement

PHASE FOUR: EXPAND, SUPPORT & EVALUATE
4. Create a Plan for Program Expansion
5. Develop Best Practice Standards for EMR Documentation
6. Promote the Program
7. Expand to New Sites (Phased)
8. Coach Debrief & Improve
9. Plan for Sustainability
10. Evaluate Impact

Serious Illness Conversations Initiative
Implementation Roadmap for B.C.

Adapted from Ariadne Labs

BC Centre for Palliative Care
Phase 1: Get the support you need to plan for change

**Steps:**
1. Form a Workgroup
2. Assess Readiness
3. Engage Leaders & Colleagues
4. Determine Mission & Goals
5. Recruit Implementation Team
6. Select Pilot Sites (Start Small)
7. Construct Budget
8. Secure Drivers for Program Use

**“Courtship”**

- BC-CPC SIC Committee formed
- Interest from MoH, Doctors of BC, BCCA, BC Renal and front line clinicians
- Dr Bernacki Event Nov 2016 with leaders from 4 HAs – Grand Rounds web linked across province
- **Mission:** To improve the lives of all British Columbians with serious illness
- **Goal:** Increase documentation of GoC by 50% by Oct 2018
- Train the Trainer Event - May 25, 2017 – More in Fall 2017
- 2 HAs have expressed interest in moving the initiative forward with BC-CPC support
- **“Getting Serious”**
- 3 Year Budget Constructed
- CME accredited courses developed:
  - 8 hr Train the Trainer,
  - 2.5 hr Clinician Workshop
Phase 2: Plan implementation

Workstream 1: Tools

- Customize the Conversation Guide
- SICG adapted to be used with Substitute Decision Makers in Residential Care
  Clinical Reference Guide adapted by SIC Nurse Working Group (Canada) used by Allied Health Professionals
- Modify the EHR to add template
- Provincial working group developed to discuss adding a SICG template in Cerner
Workstream 2: Prepare for Quality Control: Customize Conversation Workflow

1. Clinicians Select Patients (Prognosis < 1 yr)
2. Clinician Training (Serious Illness Conversation Guide)
3. Patient Prepared for Conversation
4. Clinician Prompt (Email, Guide)
5. Clinician and Patient Have Conversation
6. Document in EHR
7. Family Communication Guide
Workstream 2: Plan for Monitoring & Evaluation

• How will we track high risk patients?

• How will we track if conversations are happening and are being documented in a template?

• How will we measure patient and clinician outcomes?

• What outcomes will we measure to determine impact?
  • Conversations - %
  • Documentation - %
  • Patient Deaths - #
Phase 3.... Training

Education

Identify Trainers
Train the Trainer full day event held May 25, 2017 with representation by invitation across all of BC (6 health authorities)

Develop Plan to Train and Coach Clinicians

Master Facilitators will coach new facilitators in Train the Trainer events – 1 planned for fall 2017
Trained facilitators facilitate Clinician Workshops
BCCPC provides the accredited teaching materials and support
Clinician Training in BC

• 5 of the 6 BC Cancer Agency Regional Centres across the province
  • 100% of attendees would recommend the Clinician Workshop to colleagues
  • 100% of attendees felt confident to train others in the use of the SICG

• Fraser Health Authority (FHA)
  • Family Practice
  • Residential Care

• Island Health: Training workshop planned

• Providence Health Care & Vancouver Coastal Health: Actively implementing with specific funding

• Interior Health: Developed a proposal to conduct SICG Clinician Workshops
Summary

- Learn more about the Serious Illness Conversation Guide

- Attend a Serious Illness Conversation Clinician Training Workshop near you

- Check out the Ariadne Labs Web Site
  https://portal.ariadnelabs.org/groups/community-of-practice/
Thank you!