Quagmires in Care Transitions:
Guiding patients and families in preparedness planning

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Aziz Ansari DO, SFHM, FACP
Stacie Levine MD, FAAHPM
Maudette Carr MSW, LSW
Disclosures

• No Significant financial relationships to disclose
Objectives

• Define preparedness planning (PP) and its difference from Advance Care Planning (ACP)

• Identify domains to improve the effectiveness of PP
  – Balancing Hope and Truth telling
  – Allowing patients to share their story
  – Knowing limits in a conversation
  – Earning trust in care transitions

• Explain how to use PP in Advanced Heart Failure and LVAD placement
Why is this Important?

- Many disease states such as advanced heart failure, dementia, and COPD have a very difficult prognostication with varying degrees of complication severity making it difficult to have a “yes” or “no” answer for treating future complications.
Defining Preparedness Planning

• A process that explores a patient’s goals, values, and preferences regarding treatment options in complex illnesses
  – Assisting patients in thinking about psychosocial and financial considerations
  – Addressing caregiver concerns
  – Assessing quality of life determinants
  – Addressing potential ethical issues

• Helping patients and families formulate a plan to maintain quality of life and optimize quantity of life

Swetz et al. Mayo Clinic Proceedings 2011
Defining Preparedness Planning

• It does contain all elements of typical ACP such as naming a POA, establishing goals of care and defining unacceptable states of being

• Different from ACP in that there is *more in-depth and detailed discussions*
  – Patient’s wishes if specific scenarios are encountered such as needing dialysis or suffering a stroke in advanced heart failure compared to the standard “vegetative state” statement in an advanced directive

Swetz et al. Mayo Clinic Proceedings 2011
Defining Preparedness Planning

• Requires in depth knowledge of clinical scenarios and knowing what risks are greater in different patient types
  – COPD with advanced heart failure vs. COPD alone

• Requires collaboration with specialists and interdisciplinary team to ensure that consistent messaging is being delivered

• Active listening and gaining trust
Effective Preparedness Planning: The Serious Illness Conversation Guide
A tested structure for communication: 7 questions to guide EOL care


Adapted from Stacie Levine, MD
## Serious Illness Conversation Guide

<table>
<thead>
<tr>
<th>CONVERSATION FLOW</th>
<th>PATIENT-TESTED LANGUAGE</th>
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<tbody>
<tr>
<td><strong>1. Set up the conversation</strong></td>
<td>“I’m hoping we can talk about where things are with your illness and where they might be going — is this okay?”</td>
</tr>
<tr>
<td>Introduce the idea and benefits</td>
<td>“What is your understanding now of where you are with your illness?”</td>
</tr>
<tr>
<td>Ask permission</td>
<td>“How much information about what is likely to be ahead with your illness would you like from me?”</td>
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</table>
| **2. Assess illness understanding and information preferences** | **Prognosis:** “I’m worried that time may be short.”  
| | or “This may be as strong as you feel.” |
| **3. Share prognosis** | “What are your most important goals if your health situation worsens?” |
| Tailor information to patient preference | “What are your biggest fears and worries about the future with your health?” |
| Allow silence, explore emotion | “What gives you strength as you think about the future with your illness?” |
| **4. Explore key topics** | “What abilities are so critical to your life that you can’t imagine living without them?” |
| Goals | “If you become sicker, how much are you willing to go through for the possibility of gaining more time?” |
| Fears and worries | “How much does your family know about your priorities and wishes?” |
| Sources of strength | “It sounds like _________ is very important to you.” |
| Critical abilities | “Given your goals and priorities and what we know about your illness at this stage, I recommend...” |
| Tradeoffs | “We’re in this together.” |
| Family | |
Serious Illness Conversation Guide: Clinician steps

• Set up
  ✓ Thinking in advance
  ✓ Is this okay?
  ✓ Do I have all the information, including prognosis?
  ✓ What is the benefit of doing this for patient and family
  ✓ No decisions need to be made today
### Serious Illness Conversation Guide: Seven steps

<table>
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<tr>
<th>Step</th>
<th>Questions to ask</th>
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<tr>
<td>1. Understanding</td>
<td><em>What is your understanding now of where you are with your illness?</em></td>
</tr>
<tr>
<td>2. Information preferences</td>
<td><em>How much information about what is likely to be ahead with your illness would you like from me?</em></td>
</tr>
<tr>
<td>(some patients like to know about time, what to expect, or both)</td>
<td></td>
</tr>
<tr>
<td>3. Goals</td>
<td><em>If your health situation worsens, what are your most important goals?</em></td>
</tr>
<tr>
<td>4. Fears/Worries</td>
<td><em>What are your biggest fears and worries about the future of your health?</em></td>
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## Serious Illness Conversation Guide: Seven steps

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<td>5. Function</td>
<td><em>What abilities are so critical to your life that you can’t imagine living without them?</em></td>
</tr>
<tr>
<td>6. Trade-offs</td>
<td><em>If you become sicker, how much are you willing to go through for the possibility of gaining more time?</em></td>
</tr>
<tr>
<td>7. Family</td>
<td><em>How much does your family know about you priorities and wishes?</em> (Suggest bringing family and/or HCPOA to next visit to discuss together)</td>
</tr>
</tbody>
</table>
Serious Illness Conversation Guide: Clinician steps

• Summarize and confirm
  “What I am hearing you say is that you want to live as long as possible but that if your heart and lungs fail you would like to be made comfortable without life support.”

• Make recommendations

• Document conversation where others can find

• Affirm commitment
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Effective Preparedness Planning: Balancing hope and truth telling

- Normalize the process
  - *Make it clear this is routine in complex advanced illnesses*

- Be mindful not to be very “grim” especially in nebulous situations

- Maintain hope or change the meaning of hope

- Be cognizant of the psychological effects on patients and families that PP conversations can have

- Pace the tragic news
  - Example of metastatic breast cancer in a young individual
Effective Preparedness Planning: Letting Patients/Families Tell their Stories

• Requires active listening (part of motivational interviewing)

• Use reflection statements as it allows to probe more into perceived resistance
  – Uncovers underlying motivations to perceived resistance and ambivalence

• Allows to gain trust when patients and families sense they are being heard
Effective Preparedness Planning: Knowing Limits of A Conversation

• Know when to stop
  – Not discussing all grim outcomes in one single visit

• Possess the ability to gauge emotional bandwidth so a conversation does not backfire

• Ask permission to take the next step in a conversation or how much detail they want to discuss of a particular scenario
Effective Preparedness Planning
Earning Trust in Care Transitions

• Practice cultural humility
  – *Remember that the patient and family is a stranger to the healthcare team in different transition points*

• Develop a relationship over time through the use of outpatient clinic if feasible

• Ask the patient and family what they understand of the visit and their expectations
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• Explain how to use PP in Advanced Heart Failure and LVAD placement
The Case

• You are part of the PC team and in clinic are asked to see a 70 year old male with advanced heart failure. He has refractory symptoms at rest and is a candidate for an LVAD. He has concurrent HTN, CKD stage III, and Diabetes

• In clinic, he and his significant other think they are here to fill out papers and say “I was told to come”

• How do you proceed?
PP in Advanced Heart Failure

• Treatment options are more complex and potential complications have wide range making a “all or nothing” approach inappropriate

• Use of LVAD’s for Destination therapy (DT) is increasing

• Vital to start a relationship early with a PC team to slowly and gradually discuss issues

• Requires collaboration with the whole team (cardiologist, surgeon, social worker, psychologist) to ensure uniformity in message delivery

Swetz et al. JPSM 2014
Measures to Consider in LVAD patients in a PP visit

• Overall goals and expectations
• Hemodialysis
• Stroke
• LVAD failure
• LVAD infection
• Artificial Nutrition and Hydration
• Blood transfusions
• Mechanical ventilation
• Rehab plans and caregiver support
• Social and religious concerns
• Naming HCPOA

Swetz et al. JPSM 2014
Major complication categories in LVAD patients

- Catastrophic complications
  - CVA
  - Bleeding
  - HD
  - Respiratory failure

- Debilitative co-morbid complications
  - Neurocognitive decline
  - Malignancy
  - Declining disease states

Swetz et al. JPSM 2014
Major complication categories in LVAD patients

- Device malfunction
  - Pump thrombosis
  - Drive line failure
  - Batteries
  - Travelling

- Inadequate quality of life
  - Many hospitalizations
  - Severe deconditioning requiring SNF
  - Nutritional issues
  - “Not getting better”
Back to the LVAD Case

• First explain what the goal of the PC team is

• Assure that you are working with the specialists

• Take gradual steps and not necessarily discuss every catastrophic complication and sign the advanced directives all in one visit
Discussion Time
Case #1

- Mr. J a 39 y/o male is admitted to your hospital for a second opinion regarding newly diagnosed pancreas cancer. He had been experiencing “heartburn” for three months and then went to an outside emergency room last week when his eyes appeared yellow. A CT scan confirmed a mass at the head of the pancreas with liver metastases. Because his bilirubin was elevated to 14, a stent was placed and he was discharged home to follow-up as an outpatient with oncology.

- A few weeks later, he promptly went to your hospital because of weakness and confusion and family wants to start chemotherapy “now”. On admission his bilirubin was 16 and creatinine was elevated to 2.0 (from baseline of 0.9 last week). He denies symptoms, his mental status is very clear and there has been no functional decline. However, it is apparent from the primary team that his condition will worsen significantly over the next few days.

- Palliative care is consulted to support patient and family and navigate the conversation around his impending death.
Case #1 Themes

• Balancing hope and truth telling

• Provide concrete medical information to the decree the patient and family want it

• Move from searching for a miracle to acceptance of end of life

• Redefine hope
Case #2

• Mr. T 95 year old male with FAST 7C advanced dementia admitted to home palliative care after G tube placement, which was requested by the family after he suddenly stopped eating.

• He has 24 hour caregivers and 6 sons and daughters who understand their father is at the end of his life, but couldn’t bear the thought of not giving him anything to eat.

• They are somewhat suspicious of healthcare providers as they were told his prognosis was 7 years at diagnosis which was 15 years ago.

• He is starting to have low grade temperatures and the family wishes to consult with the palliative care team about next steps in his medical care.
Case #2 Themes

• Knowing how much to push

• Possessing the knowledge of the role of antibiotics in end stage dementia and when to convey disease-specific prognostic information/details

• Challenges of the team in getting all kids on the same page

• Education around complications of artificial nutrition and hydration

• Address cultural/religious concerns in lieu of previous experiences
Case #3

- The family of Ms. K, a 17 year old SC injury patient, have asked the palliative care team assist them with the care of their daughter.

- She sustained a C3-4 injury after diving into shallow water three months ago and is now quadriplegic.

- She has recently been discharged home from acute rehab under the care of her mother and father. She had to defer college until her health has stabilized. In addition to neuropathic pain, she has been expressing emotional distress about her situation. She has a good relationship with her physiatrist and psychologist who you have not met.
Case #3 Themes

• Letting the patient tell their story

• Parent’s feelings need to be explored

• Patient and family lives radically changed

• Explore anger and possibly any guilt

• Lost
Ms. C is a 76 y/o with lung CA, CHF and COPD (on home O2), CVA, CAD referred to Palliative Care for ACP and goals of discussion. Both the HCPOA and POLST are completed. The patient has not agreed to a DNR because she is scared. Patient lives alone and has 4 children. One son lives next door, POA lives out of state, and other son comes by daily. The patient also has a 95 year old mother who she worries about. Her quality of life is not optimal due to continued dyspnea. She is able to get around with a walker.

She sees her oncologist who orders a PET scan, which shows a new LLL nodule. She is advised by her oncologist to have a repeat lung biopsy and CT scan for staging. She was told that the procedure “could puncture her lung” and that there is a high likelihood she could be intubated indefinitely after the biopsy because of her poor lung reserve. Incidentally a possible pathological fractured 7th rib is discovered on CT scan.

Patient has complete faith in her oncologist and at the same time is reaching for support with the palliative care team. Family has not been told about new lung nodule, including the POA, because the patient does not want to “worry” her family.
Case #4 Themes

• Worries about overstepping the oncologist
  – *Mixed messaging*

• Balance patient autonomy and family members not knowing the whole picture

• Acknowledge mixed feelings of patient

• Conflict of what to do next

• Fractured communication

• Fear
Case #5

• Mr. B is an 65 year old male with metastatic prostate cancer to the bone, severe COPD, CAD, and chronic pain. Over the past year he has experienced worsening functional decline and weakness, with a mechanical fall that led to a hospital admission. Imaging showed widely metastatic disease that is worsening despite anti-androgen therapy.

• As a former army sergeant he has always been proud and wants to remain alone in his home. His closest relative is his daughter and POA who lives out of state. Mr. B’s oncologist does not believe he is deriving any further benefit from cancer therapies and advises home hospice.

• The patient and daughter feel this hospitalization is a minor setback and that with some inpatient physical therapy at a SNF he should be able to return home “good as new.” The palliative medicine team is consulted to further clarify goals and discuss his future.
Case #5 Themes

- Earning Trust and managing expectations especially around care transitions
- Maintaining control and dignity
- Discord between what doctor is saying and what patient/daughter want
- Truth telling vs. false hope
- Coping capability (lives alone)