Interactive End-of-Life Education

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Objective

- At the conclusion of this workshop, participants will be able to:
  - Understand the art of “being present”
  - Identify what brings them comfort and joy
  - Value the importance of discussing end-of-life issues
This session...

- **Interactive End-of-Life Education Using a Board Game**, consists of information on communication at the end-of-life, the art of listening and “being present”, and the time to assess what is most important in life. This information can then be shared to benefit others.
A Time to Reflect
The Elephant in the Room
by Terry Kettering

There’s an elephant in the room.  
It is large and squatting, so it is hard to get around it. 
Yet we squeeze by with “How are you?” and “I’m fine...” 
And a thousand other forms of trivial chatter. 
We talk about the weather. 
We talk about work. 
We talk about everything else... 
Except the elephant in the room. 
We all know it is there. 
We are thinking about the elephant as we talk together. 
It is constantly on our minds.
For, you see, it is a very big elephant.
It has hurt us all.
But we do not talk about the elephant in the room.
Oh, please, say her name.
Oh, please, say “Barbara” again.
Oh, please, let’s talk about the elephant in the room.
For if we talk about her death,
Perhaps we can talk about her life.
Can I say “Barbara” to you and not have you look away:
For if I cannot,
then you are leaving me alone…
in a room…
with an elephant
Tough Conversations…

How do we deal with the elephant in the room?
Caring with empathy

- Active listening
- Verbal
- Non-verbal
- Being “present”
- Be focused on the patient and sitting in silence
Statements that Facilitate Empathy

Queries

- "Would you (or could you) tell me a little more about this?"
- "What has this been like for you?"
- "Is there anything else?"
- "Are you OK with that?"
- "Hmmm..."
Clarification

- “Let me see if I have this right.”
- “I want to make sure I really understand what you’re telling me. I am hearing that…”
- “I don’t want us to go further until I’m sure I’ve gotten it right.”
- “It sounds like I just heard…”
- “When I’m done, if I’ve gone astray, I’d appreciate it if you would correct me. Ok?”
FEAR...

What are our fears
What holds us back from having tough conversations...

- Not sure how to answer the questions
- First time looking at your own mortality
- You don’t want to talk about the possibility of a loved one dying
- Cultural differences
- What if their beliefs differ from mine
The rush to reassure “it’ll be ok…” or “Don’t worry…”
Not understanding the culture, religions or “world” of the patient
Injecting our own biases and values
Advising, giving solutions, preaching
Interpreting, analyzing
Warning, threatening, questioning, interrogating
Are we giving facts
Are we withdrawing and having difficulty with the conversation…

Conversation halters-Be aware ---
Difficult questions from clients

- Why me?
- How long do I have to live?
- Why didn’t they catch this earlier?
- Should I try some experimental drugs? I’ve heard they work.
- What would you do?
Questions to Ask Clients

- What do you know about your illness? Is there any more you would like to know about?
- What’s most important to you at this point in your life?
- What are your most important relationships?
- What do you think is most important to your family?
- What brings you comfort and joy?
More questions to ask Clients...

- Do any spiritual or religious practices bring you comfort? Can you describe them to me?
- How does your culture affect decisions about medical treatment?
- What are your customs and beliefs about birth, illness and death?
- How can I help address these issues while I care for you and your family?
A time to interact...

- Listen to scenario,
- Break up into groups of two
  - One person is the client-ask the questions on the scenario slide
  - One person is the service coordinator-listen, respond
- Then reverse roles
45 yr old female newly diagnosed with breast cancer. Patient has a 10 and 14 yr old daughters. Husband is overwhelmed and doesn’t want to talk about the diagnosis and patient feels all alone.

• Questions…
  • Why me?
  • Will I see my girls grow up?
  • What would you do?
Reflection...How did that feel?

- What was it like to be the client?
- What was it like to actively listen to the client?
- Were there any conversation halters?
- What is the key to communication?
What to Say when You don’t know What to Say...

LISTEN!!!
Time to Play The Game!

- Stand and stretch
- You will be in groups of 4
- Instructions will be explained prior to playing
- Get ready to assume the role of a patient!
Introduction to The Path of Life® The Journey of Living at the End-of-Life® Board Game

- **Object of the game:** For participants to assume the role of a patient confronted with a terminal illness at the end-of-life making many decisions which are shared through personal and group reflections. The game focuses on living life not dying.

- **Goal:** To have a greater understanding of decisions and challenges people encounter when faced with a terminal diagnosis and the possibility of focusing on the joy of living in spite of their current situation.
Game Instructions

- **Process of the game**: 3 Booklets used in game per patient
  - Each participant chooses a color and patient identified on the game board
  - *The participants each read their patient scenario out loud (in booklet with name)*
  - The participant who roles the lowest number starts the game.
  - Begin with your token placed at the base/point of the heart closes to the edge of the game board-you begin moving clockwise (to the left) of the heart after you each read your scenarios
Begin playing the game

- You are now assuming the role of the patient!
Debrief

1. What is the first thing that comes to mind about playing the patient in this game?
2. What did you experience when you as the patient experienced your mortality event, diagnosis and prognosis?
3. How did you begin making decisions on what treatment options you chose?
4. How did the other players assuming their own patient role influence your progression through the game and the decisions you made?
5. What was the first thing that came to mind when you began rolling the joy dice?
6. What was your comfort level with end-of-life discussions during the game?
Going forward

- What is your understanding of the art of “being present”?
- What did you discover that brings you comfort and joy?
- What do you see as the value of having end-of-life discussions?
- What will you take going forward personally and in your role as a service coordinator?
Questions?
Thank You!
Reference


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