Providing Bereavement Care in Response to Experiences of Continued Presence

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Experiences of Continued Presence: ECPs

- Sensory ECPs experienced through one of the five senses, such as seeing the apparition of a loved one or hearing their voice
- Intuitive ECPs experienced as an intuitive sense or feeling of someone's presence
 - Usually the person having the ECP can identify who they believe is present, even if they can't see or hear them
 - "I just felt that my mother was here in the room with me"

Techniques for Responding to Comforting ECPs

- Studies have shown that responding to comforting ECPs should be centered on eliciting communication about them and accepting their significance to patients and their families
- Name
- Normalize
- Validate
- Explore

Responding to Comforting ECPs: Name

What to say when naming an ECP:

- Did your experience feel real to you?
- Was your experience meaningful?
- You're not showing any signs of confusion or delirium, so it probably wasn't a hallucination. Do you think it might have been a spiritual experience?

Responding to Comforting ECPs: Normalize

Normalization - process in which an idea or experience becomes accepted as normal

- ECPs are common, well-documented experiences, and should be viewed and responded to accordingly
- What to say to normalize an ECP:
 - Other people have shared similar experiences with me.
 - You're not alone; that's a common experience.
 - You don't have to worry; that's very normal.

Responding to Comforting ECPs: Validate

Validate – acknowledge and accept another person's feelings or experiences without judgement

What to say to validate an ECP:

- It sounds like that was a very meaningful experience for you.
- It sounds like you felt (comforted, safe, loved, etc.) during your experience. Reflect their feelings back to them.

Responding to Comforting ECPs: Explore

Explore – ask relevant questions or invite the person to process out loud in order to help them better understand or find meaning in their experience

• Exploration requires curiosity, openness, genuine interest, time, and a willingness to help the person come to their own conclusions, rather than interjecting your opinions or viewpoints.

Responding to Comforting ECPs: Explore

What to say to explore an ECP:

- What was that experience like?
- How did it feel?
- Can you tell me more about that?
- What do you think it meant?
- How did you feel afterwards?
- What does that mean to you?
- How do you feel now?

Responding to Distressing ECPs

- The majority of ECPs are comforting to the person who experiences them, but there are documented cases of distressing ECPs
- Responding to distressing ECPs requires a very different approach than responding to comforting ECPs
- However, appropriately responding to distressing ECPs can still result in post-bereavement growth.

Case Study: Distressing Experience of Presence

Case Study: Julie Strassman, Doctoral Project, 2022

- DJ Partnered woman in her 30s; identified as lesbian
- Raised Mormon; estranged from family due to sexual orientation
- Active in affirming faith community: United Church of Christ
- Grandmother died, and DJ was not allowed to attend the deathbed vigil or the funeral due to family estrangement

Case Study: Distressing Experience of Presence

- Not long after her grandmother's death, DJ had an ECP
- DJ saw her grandmother in her bedroom, appearing as a wispy, ghostly presence. DJ reported that her grandmother didn't speak or gesture, and her facial expression was neutral. She was standing and slightly leaning toward DJ.
- DJ interpreted her ECP as meaning that both her grandmother and God were condemning her for being a lesbian.

Case Study: Distressing Experience of Presence

- DJ consulted her pastor about her distressing ECP
- Her pastor responded with the pastoral care techniques of empathetic listening and validation, as well as reframing
- DJ's pastor suggested an alternate meaning:
 - "Perhaps your grandma's here now to show that she loves you."

 Perhaps this is a way for God to show that God loves you."
- DJ was open to her pastor's suggested alternate meaning, and eventually interpreted her ECP as comforting, not distressing

Responding to Distressing ECPs

- Spiritual care training for bereavement professionals
- Fostering relationships with spiritual care providers in the community
- Reframe the experience explore alternate meanings of the person's experience and suggest positive interpretations
 - It could mean that. What else do you think it might mean?
 - I'm not sure. I wonder if maybe it means...
 - Do you think it could also mean...

What questions do you have about providing bereavement care in response to Experiences of Continued Presence?

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