NHPCO Project ECHO Equity Where It Matters

Key Takeaways: Mental Health Implications in Serious Illness and End Of Life Care May 4, 2023

Key points:

- Stigma, prejudice, and discrimination against people with behavioral health concerns can look like a negative/discriminatory attitude and beliefs from the public, as well as stigma, internalized shame from the individual themselves.
- Language is important in the context of our work. Labels Stick.
- Good family functioning uses problem-solving skills, open communication, role assignments for the
 members of the family and respect for others. Poor family functioning often includes high levels of
 conflict, lack of cohesion, they are disorganized without family roles and have overall poor
 communication.
- David Olson's Circumplex Model suggests that balanced levels of cohesion and flexibility offer the healthiest family functioning and balanced levels of cohesion and extremes in flexibility describe problematic family functioning.
- Families which show balanced levels of engagement and openness to change tend to score higher on measures of listening skills, self-disclosure, and demonstrating respect and regard in communication.

Actionable Steps:

- Remember that there are multiple "patients" in any given situation the actual patient, the family, the hospice/PC team, and the hospice/PC organization.
- Ensure that you are addressing all their needs (comprehensive patient centered care).
- Consider establishing orientation and competency content around treating the entire family and not just the patient.
- Ensure that you are providing ongoing education and training around the appropriate use of language in avoiding labels.

Conversation Starters:

- How would you assess and describe the relationship between patients and their families, as well as family flexibility, cohesion, communication?
- How would hospice staff balance patients' need from their families?
- What techniques have you used when faced with a complicated family system?

Participant Perspectives:

- "It sometimes helps for the family to hear from the patient directly what is important to them their fears, needs, etc."
- "The family is our "second" patient their past stories, beliefs and relationship with the patient have an impact on care."
- "The dynamics so often change when the family and patient are separated."
- "The approach with the daughter needs to be very empathetic and discussing her fears about her father's deteriorating medical condition to help her start to process how she feels. You don't know yet if that family dynamic or cultural issues are impacting the way the daughter is speaking up and that would require some thought as well.



- "I think I'd rather say the daughter is being "appropriately chaotic. This must be an incredibly difficult time for her that it's easy for us to label as we see it every day, but this is her life, and these moments will live with her forever while we get to be the ones to walk away much easier."
- "Maybe we can reframe her from the "difficult daughter" to the "heartbroken daughter."
- "Sometimes we call a situation with these characteristics an REG "requires extra grace."
- "Case reviews help train others in the organization so not all issues will be placed on the shoulders of the SW. This field is a TEAM approach, and we all work together to make each and every member better in the services that are provided."

References:

- Implementation of Artificial Emotions and Moods in a Pedagogical Agent:
 https://www.sciencedirect.com/topics/psychology/circumplex-model#:~:text=The%20Circumplex%20model%20has%20two,levels%20for%20all%20the%20people
- The Olson Circumplex Model: A systemic approach to couple and family relationships: https://psychology.org.au/publications/inpsych/2011/february/sanders
- Garg, R., Chauhan, V., & Sabreen, B. (2018). Coping styles and life satisfaction in palliative care. Indian journal of palliative care, 24(4), 491.
- Portoghese, I., Galletta, M., Larkin, P., Sardo, S., Campagna, M., Finco, G., & D'Aloja, E. (2020).
 Compassion fatigue, watching patients suffering and emotional display rules among hospice professionals: a daily diary study. BMC palliative care, 19, 1-7.
- NHPCO Access and Inclusion https://www.nhpco.org/resources/access-and-inclusion/
- Hospice Through the DEI Lens: A Research Study Identifying Barriers to Hospice Care in Underserved Communities, National Hospice and Palliative Care Organization.
- NHPCO Diversity Tools and Resources https://www.nhpco.org/education/tools-and-resources/diversity
- Culturally and Linguistically Appropriate Services (CLAS) https://thinkculturalhealth.hhs.gov/clas
- CMS Framework for Health Equity https://www.cms.gov/about-cms/agency-information/omh/health-equity-programs/cms-framework-for-health-equity

