

NHPCO Project ECHO

September 2021

Case presentation by Partners in Home Care, Inc.

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Disclosures

Disclosure

The planners and faculty disclose that they have no financial relationships with any commercial interest.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. Completion of this evaluation is required for Quality Connections credit. We ask all participants to take the survey as it will help us to improve future clinic sessions.

Today's Agenda

- Welcome and brief introductions
- Introduction of the case presenter and subject matter experts
- Brief didactic presentation related to the case
- Case presenter presents case details and specific questions or ponderings.
- Questions and clarifications – subject matter experts and participants
- Final thoughts and lessons learned - subject matter experts and participants

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants - introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Introductions

Case presenters

- Jenessa Babcock, DPT, COSQ, Manager of QAPI and Compliance
- Jesseca Letke-Cummins, RN, CHPN, Director of Clinical Practice
- Jacki Grogan, LCSW, Hospice Social Worker

Subject Matter Experts

- Fran Klouse, RN, St. Croix Hospice, MN
- Luis Cortes, DO, MS MBA, Hope Healthcare Services, FL
- Angela Alvarado, MS, MS-IS, APHSW-C, LBSW-IPR, Hospice Plus – Dallas, TX

Today's case study

Hospice clinical practice case

- **Significant caregiver burnout**

End-of-life Caregiving

- EOL caregivers provided more extensive care and reported more care-related challenges (e.g., physical difficulty) than non-EOL caregivers.
- Caregivers may assume new and potentially challenging tasks as the EOL approaches, including symptom management, engaging in difficult decisions about transitioning to long-term care or hospice, serving as a surrogate in medical decisions, and hiring paid caregivers.
- Many older adults experience complex transitions between health care settings at the EOL, or may incur multiple hospitalizations, ICU admissions, or receive life-sustaining treatments.
 - Service use may lead to high out-of-pocket spending for families as well as fragmented care, which further burden older adults and their caregivers.

End-of-life Caregiving

- Existing evidence suggests EOL caregiving demands are significant and that certain tasks, such as decision-making, are extremely stressful.
- EOL caregivers have been found to experience high levels of depression and anxiety.
 - There are consistent findings that EOL caregivers have high unmet needs themselves and that despite the high level of care they provide, use of supportive services (e.g., assistance with personal care or housework, use of respite care and support groups) is limited.

Caregiver Burnout

- Caregiver burnout is a state of physical, emotional and mental exhaustion.
- It may be accompanied by a change in attitude, from positive and caring to negative and unconcerned.
- Many caregivers also feel guilty if they spend time on themselves rather than on their ill or elderly loved ones.
- Caregivers who are "burned out" may experience fatigue, stress, anxiety and depression.

Caregiver Burnout Causes

- **Role confusion:** Many people are confused when thrust into the role of caregiver. It can be difficult for people to separate their role as caregivers from their roles as spouses, lovers, children, friends or other close relationships.
- **Unrealistic expectations:** Many caregivers expect their involvement to have a positive effect on the health and happiness of the patient. This may be unrealistic for patients suffering from a progressive disease, such as Parkinson's or Alzheimer's.
- **Lack of control:** Many caregivers become frustrated by a lack of money, resources and skills to effectively plan, manage and organize their loved one's care.

Caregiver Burnout Causes

- **Unreasonable demands:** Some caregivers place unreasonable burdens upon themselves, in part because they see providing care as their exclusive responsibility. Some family members such as siblings, adult children or the patient himself/herself may place unreasonable demands on the caregiver. They also may disregard their own responsibilities and place burdens on the person identified as primary caregiver.
- **Other factors:** Many caregivers cannot recognize when they are suffering burnout and eventually get to the point where they cannot function effectively. They may even become sick themselves.

Compassion Fatigue

- Most caregivers experience times when the fatigue and frustration of providing care for a loved one can border on caregiver burnout. Family caregivers are also susceptible to this occupational hazard.
- Compassion fatigue occurs when a care-giving relationship founded on empathy potentially results in a deep psychological response to stress that progresses to physical, psychological, spiritual, and social exhaustion in the family caregiver.
- They may not be administering high-level skilled nursing care, but they are still caring for someone in emotional and physical distress with limited options for providing comfort.
- While compassion fatigue exists on a spectrum, once one has developed a certain level of indifference or insensitivity to a care recipient, it is wise to step back from the caregiving role at least temporarily.

Warning Signs of Compassion Fatigue in Family Caregivers

- Feeling overwhelmed, exhausted and drained
- Avoidance and not wanting to be around your loved one (choosing to work late, daydreaming about no longer having to care for them, etc.)
- A decrease in patience and tolerance
- Angry outbursts that are uncharacteristic of your behavior
- Cynicism and hopelessness
- Heightened anxiety
- Impaired ability to make care decisions
- Difficulty sleeping
- Physical symptoms, such as headaches or gastrointestinal issues

Assessment Tools for Caregivers of Adults

Examples

- [Zarit Burden Interview](#)
- [Brief Measures of Secondary Role and Intrapsychic Strains](#)
- [Caregiver Reaction Scale](#)
- [Caregiver Self-Assessment Questionnaire](#)
- [Perceived Benefits of Caregiving](#)
- [Picot Caregiver Rewards Scale](#)

Measures for assessing Caregiving Coping

Examples

- [Revised Scale for Caregiving Self-Efficacy](#)
- [Perceived Support Scale](#)
- [Coping Health Inventory for Parents](#)
- [Cultural Justification for Caregiving Scale](#)

Support for the Caregiver

- Respite care
- Promotion of all hospice services
 - Volunteers
 - Homemaker services
 - Social workers
 - Spiritual Care Counselors
- Self-care education for the caregiver

References

- Ornstein, K. A., Kelley, A. S., Bollens-Lund, E., & Wolff, J. L. (2017). A National Profile Of End-Of-Life Caregiving In The United States. Health affairs (Project Hope), 36(7), 1184–1192.
<https://doi.org/10.1377/hlthaff.2017.0134>
- Compassion Fatigue: When Caregivers Go Beyond Burnout, Aging in Care
 - <https://www.agingcare.com/articles/compassion-fatigue-caregivers-beyond-burnout-196224.htm>
- Caregiver Burnout, Cleveland Clinic
 - <https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout>
- Coping with Caregiver Stress and Burden, American Psychological Association.
 - <https://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/stress-burden>

Case Presentation

SBAR (Situation, Background, Assessment, Recommendation)

You Too Can Present a Case!

- Could be in the hospice or palliative care space
- Quality focused
- Is relevant to today's hospice and palliative care environment
- What are we looking for in a patient-based case?
 - Poses difficult issues for the interdisciplinary team
 - May be an outlying or a frequent situation that involves clinical/ emotional/ psychosocial/ spiritual challenges
- What are we looking for in a process-based case?
 - May involve operational or clinical process issues
 - May affect patient care
 - Is a focus of quality improvement for the organization

Upcoming Project ECHO Sessions

Date	Time
September 29, 2021	3pm ET
October 26, 2021	3pm ET
November 30, 2021	3pm ET
December 21, 2021	3pm ET

Cases needed for 2022- <https://www.nhpcoco.org/projectecho/>

Thanks for joining.
We will see you next
month.