

Introduction to Palliative Care

Glossary

Serious Respiratory Illness

 Any pulmonary condition (or set of conditions) that carries a high risk of mortality, negatively impacts a person's daily function or quality of life, and/or imposes excessive strain on their caregivers

Patient-Centered Care

- Grounded in mutual respect, bidirectional communication, shared decision-making, and collaboration among the clinicians, patient, and family members
- The goal is to ensure that the priorities, preferences, and values of the patient are upheld in all aspects of care delivery
- Providing patient-centered care is shown to reduce healthcare utilization and costs while maintaining quality of care

Palliative Care

- Both an approach to care and an interprofessional subspecialty
- The goal is to improve the quality of life in serious illnesses and reduce suffering for patients and their families
- Provided throughout the illness trajectory, along with disease-directed therapies, via the delivery of holistic patient- and family-centered care
- Delivered by front-line respiratory clinicians (primary palliative care) and experts (specialty trained palliative care) as indicated by patient and family needs
- Focuses on management of pain and other distressing symptoms, information and decision support, spiritual support, psychological support, and practical support
- This care can be delivered by teams that may include but are not limited to nurses, advanced practice providers
 (APPs), physicians, social workers, care managers, pharmacists, respiratory therapists, chaplains, occupational
 or physical therapists among others, depending upon the care setting

Hospice

- Specific component of palliative care (and a medical insurance benefit) that is provided to seriously ill patients
 and their families at the end of the illness trajectory when life expectancy is 6 months or less and they are no
 longer seeking disease-directed treatment
- Patients enrolled in hospice receive care and support in all domains of palliative care (see palliative care) and medications for symptom relief, durable medical equipment, some home health assistance, and bereavement support for the family after their loved one's death
- Patients can receive hospice care across settings such as in the home (most common), skilled nursing facilities, assisted living facilities, and rarely in the hospital

Introduction to Palliative Care

Glossary

Advance Care Planning

- A process where a person discusses their individual goals, values, and preferences regarding healthcare with their healthcare provider, and potentially their surrogate(s), in the context of their health status
- Ideally it should occur throughout the illness trajectory and be revisited when/if values and clinical situations change
- The goal is to prepare patients and surrogates (if designated), to make decisions about future care that are consistent with the patient's preferences and values
- May or may not result in the creation of documents (advance directives, POLSTs, MOLSTs, etc.) that reflect the
 outcomes of the ACP process

Palliative Care Bow Tie Model



The bow tie model of 21st century palliative care. Canadian Virtual Hospice; 2015. Available from: http://www.virtualhospice.ca/

The Bow Tie Model of 21st Century Palliative Care Hawley, Philippa H. Journal of Pain and Symptom Management, Volume 47, Issue 1, e2 – e5

Introduction to Palliative Care

Glossary

Ohter Rererences

Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, Blanchard C, Bruera E, Buitrago R, Burla C, Callaway M, Munyoro EC, Centeno C, Cleary J, Connor S, Davaasuren O, Downing J, Foley K, Goh C, Gomez-Garcia W, Harding R, Khan QT, Larkin P, Leng M, Luyirika E, Marston J, Moine S, Osman H, Pettus K, Puchalski C, Rajagopal MR, Spence D, Spruijt O, Venkateswaran C, Wee B, Woodruff R, Yong J, Pastrana T. Redefining Palliative Care-A New Consensus-Based Definition. J Pain Symptom Manage. 2020 Oct;60(4):754-764. doi: 10.1016/j.jpainsymman.2020.04.027. Epub 2020 May 6. PMID: 32387576; PMCID: PMC8096724.

Kelley AS, Bollens-Lund E. Identifying the Population with Serious Illness: The "Denominator" Challenge. J Palliat Med. 2018 Mar;21(S2):S7-S16. doi: 10.1089/jpm.2017.0548. Epub 2017 Nov 10. PMID: 29125784; PMCID: PMC5756466.

Millenson, M., Shapiro, E., Greenhouse, P. & DeGioia, A. Patient- and Family-Centered Care: A Systematic Approach to Better Ethics and Care. AMA J Ethics. 2016;18(1):49-55. doi: 10.1001/journalofethics.2017.18.1.stas1-1601

Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, Matlock DD, Rietjens JAC, Korfage IJ, Ritchie CS, Kutner JS, Teno JM, Thomas J, McMahan RD, Heyland DK. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage. 2017 May;53(5):821-832.e1. doi: 10.1016/j.jpainsymman.2016.12.331. Epub 2017 Jan 3. PMID: 28062339; PMCID: PMC5728651.

Sullivan DR, Iyer AS, Enguidanos S, Cox CE, Farquhar M, Janssen DJA, Lindell KO, Mularski RA, Smallwood N, Turnbull AE, Wilkinson AM, Courtright KR, Maddocks M, McPherson ML, Thornton JD, Campbell ML, Fasolino TK, Fogelman PM, Gershon L, Gershon T, Hartog C, Luther J, Meier DE, Nelson JE, Rabinowitz E, Rushton CH, Sloan DH, Kross EK, Reinke LF. Palliative Care Early in the Care Continuum among Patients with Serious Respiratory Illness: An Official ATS/AAHPM/HPNA/SWHPN Policy Statement. Am J Respir Crit Care Med. 2022 Sep 15;206(6):e44-e69. doi: 10.1164/rccm.202207-1262ST. PMID: 36112774; PMCID: PMC9799127.