Advisory Council on Palliative Care MINUTES

Friday, December 12, 2014 10-11 AM Legislative Office Building 300 Capitol Ave., Hartford, CT

Present: Wendy Furniss, DPH; Colleen Mulkerin, Hartford Hospital; Patricia Trotta, VNAHC; Joseph Andrews, CT Hospice; James Prota, CT Hospice; Karen Mulvihill, Danbury Hospice; Diana Cameron, VNAHC, Biree Andemariam, UCONN HC; Victoria Odesina, UCONN HC; Barbara Morrison, Yale Hospital;

Conference Call: Karen Mulvihill, WCHN; Cynthia Roy, Regional Hospice; Kay Marron, Regional Hospice

Public: Joanne Kuntz, UConn Health; Kerry Moss, CCMC; Beth Leslie, Office of Protection & Adv.; Charles Rothenberger, RS&L; Natalie Cullen, American Cancer Soc.; Michael Culhane, CT Catholic Conf.

- I. Minutes Approved
 - Colleen Mulkerin motioned to approve; Wendy Furniss seconded the motion.
- II. Topics of Discussion
 - Testimony
 - 1) Kerry Moss, MD, CCMC
 - Pain and Palliative Medicine- Consult service
 - Hard concept for doctors who treat children- usually call with "immediate need" not proactively- metrics are hard
 - Clinical, education and smaller research components
 - 30 kids on service- consulted 50-100 last year
 - Pediatric education to hospice providers in state- networking
 - Advanced cancer, Epidermal bullosa, heart patients, congenital anomalies
 - Team approach- outpatient: not specific "clinic" but join oncology appointments etc.
 - Nursing Education also- plus MD's, students, PT's dieticians
 - Offer bereavement services for staff too
 - CCMC has first APRN interning in Palliative Care
 - Barriers- for family, concurrent care issues- can't have both usual home care providers and hospice providers at end of life- seamless network of end of life providers
 - "curative intent" stronger with kids- treatment and EOL care simultaneously
 - Pediatric rotation for Yale fellows may be at CCMC
 - Private payers should emulate T19

2) Joanne Kuntz, MD, UCONN

Barriers

- Lack of common shared language for practitioners to use to speak with patients and families
- PCP's lack skills for symptom management- Few palliative care doctors in CT
- Lack of general and provider understanding of palliative care- fear of the word
- Fear of transition from palliative care to "hospice" care= "giving up"
- Consultation program (inpatients only- rarely for outpatient clinic) at Hartford Hospital
- 35-40 consults/month; Dr. Kuntz has made 2 home visits
- Metrics- just got first 6 months of data (admission; discharge, diagnoses, etc.)
- ED docs "Choosing Wisely" campaign says don't avoid palliative care in ED though slows down throughout
- "Performance Status" (a.k.a. functional/ADL status)- more telling than diagnosis (e.g. Cystic Fibrosis) in determining need for palliative care
- NBS -> CF- palliative care from birth ->death
- Sickle cell patients- also a population requiring life- long palliative care

Discussion

- Palliative care in homecare setting- lack of T18 reimbursement for palliative (must be homebound)- T19 has minimal reimbursement
- Barrier: payer-driven lacks of benefits (e.g. regular medicine v. hospice benefit) payments regs. are barriers: 6 month time frame
- Electronic health record "alerts" may help change the culture of medicine

• Workgroups

- 1) Education and Research (Andemariam, Andrews & Prota)
 - Provided a handout- Recommendations outline
 - Discussed goals
 - Recommended another small group session in January or February
- 2) Benchmark & Data (Patricia, Karen & Diane)
 - Sent Survey to Hospitals- no responses
 - Contacting Hospitals

- 3) Advance Care Planning (Wendy & Colleen)
 - Wendy to share Interact Tool "Advance Care Plan Guide"
 - Public Relations consultation
 - CAPC links to Wikipedia
 - Incomplete tasks- will reconnect in January

III. Updates/Recommendations

- Work on another subcommittee workgroup meetings for January & February
- Find a family member/inside champion who is under Palliative Care
- Invite Stakeholders- waiting on some responses
- Recommend speakers to share their story
- Decide as a group who to contact- written vs. spoken testimony
- Use the list of questions as format on the report
- Wendy and Grisel will work on the report due to the Palliative Care Legislation sometime in early January
- V. Meeting adjourned at 11:15 am by Chair Mulkerin.