PALLIATIVE CARE IS A HUMAN RIGHT FOR PEOPLE LIVING WITH DEMENTIA

Dr. Stephen Connor, Worldwide Hospice Palliative Care Alliance, and Dr. Carl Becker, Kokoro Research Center, Kyoto University
The need - a global perspective

- >1 million deaths/week
- 33-40 million need palliative care ½ at EOL
- Families (at least 2-4 each)
- <10% of need for PC met,
- 14% @ EOL, SO:
- 18 million die in pain, many with Dementia
WHO Definition of Palliative Care

- Prevention & relief of suffering to maintain QOL
- Requiring Appropriate assessment & treatment
- Focus on but not limited to chronic & terminal patients
- Diagnosis to death/bereavement
Adult Need for PC Worldwide

- Alzheimer and other dementias: 1.65%
- Cirrhosis of the liver: 1.70%
- Kidney disease: 2.02%
- Diabetes mellitus: 4.59%
- HIV/AIDS: 5.71%
- Chronic obstructive pulmonary disease: 10.26%
- Tuberculosis: 0.80%
- Parkinson disease: 0.48%
- Rheumatoid arthritis: 0.27%
- Multiple sclerosis: 0.04%

- Cancer (Malignant Neoplasms): 34.01%
- Cardiovascular diseases: 38.47%

N = 19,228,761
Questions to Address

1. What is the case for palliative care for people living with dementia (PLwD)?
2. What makes palliative care a human right?
3. What are the barriers to palliative care access?
Questions to Address

4 What are the ethics of access to palliative care for PLwD?
5 How can we deliver primary palliative care to PLwD earlier in the trajectory of caring?
6 How can we better support family members and other care partners?
1 What is the case for palliative care for people living with dementia (PLwD)?

- Dementia often causes premature mortality
- Dementia burdens patients with symptoms
- Dementia burdens caregivers both physically & mentally
- Ethical issues are more pronounced
2 What makes palliative care for PLw dementia a human right?

• Access to palliative care is believed to be a human right generally
• ICESCR ICESCR (International covenant on economic, social, & cultural rights) extends the right to sparing avoidable pain and maximizing dignity in death.
• Highest attainable health includes pain relief
• “Timely, appropriate, preventative, curative, & palliative health services”
Palliative care is person-centered care; must recognize what PLwD would want!
3 What are the barriers to palliative care access for PLwD?

- Difficult prediction and prognostication
- Difficult communication—level of pain?
- Facilities for PLwD often lack palliative experts
- Lack of primary caregiver retards decisions
4 What are the ethics of access to palliative care for PLwD?

• Not making PC available for PLwD would be unethical

• Treatment decisions
  – Feeding tubes
  – Ventilation/hydration
  – Antibiotics
  – Resuscitation
  – PAIN RELIEF PRIMARY
5 How can we deliver palliative care to PLwD earlier in the trajectory of caring?

- Increasing the capacity of primary care providers to integrate palliative care (PC) into practice
  - Increased PC education for all health professionals
  - Shifting existing resources from acute to primary palliative care – advanced illness management
- Increased capacity to deliver home-based care
- Available, accessible, and affordable medicines
How can we better support family and other care partners?

- Family want to feel they’re doing the best
- Assessment must include family input
- Care plans can be individualized case by case
- Praise family contributions; give them respite!
Summary

• Palliative care is a human right for PLwD
• Palliative care is ethical people centered care
• We can overcome barriers to palliative care; should introduce palliation in primary care
• Long term support for family and caregivers is key to good outcomes for PLwD
For details about this presentation email: sconnor@thewh pca.org

Thank you!