#### The Role of Social Work in End-of-Life and Palliative Care: Future Challenges and Opportunities

Ellen L. Csikai, Ph.D

Professor, School of Social Work, The University of Alabama Editor, Journal of Social Work in End-of-Life and Palliative Care

JCECC International Virtual Conference "Community End-of-Life Care: Sustainable Development and New Frontier"

June 18, 2021

### U.S. Growth in Palliative Care

- According to CAPC (2019), the U.S. shows continued growth in the overall number of hospital palliative care teams 72% of hospitals with fifty or more beds reporting a palliative care team available.
- In one year (2019-2020), hospice care among Medicare users (insurance for people over 65 years of age) in the U.S. increased by 4% from the year 2019 to 2020.
- More than  $\frac{1}{2}$  of all persons using Medicare who died in 2018 utilized hospice care.
- About  $\frac{1}{2}$  of all admissions were for less that 14 days. (NHPCO, 2020)

### **Global Growth in Palliative Care**

- Palliative care is expanding globally and seen in policy commitments,
  - However, service provision, supporting policies, education, and funding allotted does not and will not meet rapidly growing needs.
- Interdisciplinary palliative care is available for only 14% of the global population and beyond the U.S., is concentrated in European countries and also includes Canada, Australia, New Zealand, Japan and South Korea
- At the same time, a global increase in serious health-related suffering amenable to palliative care interventions of 87% is predicted by 2060.
  - Despite the undeniable growing need, palliative care is not reaching the levels required by at least half of the global population.

## Social Workers on Palliative Care Teams

- In hospice. social workers are well-accepted as a member of the inter-professional team (required in U.S.)
- Globally, social workers in many countries are not trained or recognized in the same way as U.S. and may not be considered as partners in palliative care.
  - For example, in some, psychologists are those deemed responsible for counseling while social workers attend to the concrete needs of patients/families.
- On hospital palliative care consultation teams, social workers are recommended and included in the ideal model, however not all teams have social workers exclusive to the team's activities

### **Traditional Social Work Roles in Palliative Care**

- Broadly, social workers provide psychosocial care to patients and families:
  - We are mental health providers who are trained to facilitate family meetings, manage family dynamics, and assess and treat anxiety and depression.
  - We provide counseling to patients, children, and families.
  - We assess for pain, spiritual needs, and advocate for a clear plan of care.
  - We have advance care planning conversations and help to locate resources for patients and families.

(Leff, 2021)



#### WHAT DO THEY DO?



#### PSYCHOSOCIAL ASSESSMENTS, INTERVENTIONS

Using a Whole-Person lens, we assess and support patients. environment & culture inform their perception and understanding? How do social determinents of health

#### BUILD BRIDGES OF UNDERSTANDING

Using a variety of skills, we help teams better understand where a patient is in their understanding. what they may need, their communication style, history, culture. We attend to family dynamics. We are involved in ongoing ACP discussions, networking with recourses and providers.





#### CRISIS INTERVENTION SKILLS

We are able to respond to immediate psychological crisis with potients, families and staff. This is true for adults, kids, pediatric patients and communities.

#### IMPROVE COMMUNICATION

Sometimes patients and families need helpunderstanding complex medical information. Our expert communication skills stort where the potient needs us to be and provides understandable information. We facilitate family meetings and consultations.





#### CLNICAL COUNSELING

We assess for anxiety, depression, PTSD, and more, then design a treatment intervention based on their needs. Interventions can melude psychotherapeutic practice CST, mindfulness practices. meaning making, legacy work, and more.



Solution State

at Minister Inspire Security in the

#### ADVANCE PRACTICE SKILLS

APHSWC advanced skills in this specialty, similar to ear nurse and physician colleagues.

#### KEY DOMAINS OF PRACTICE

He are noted to have primary responsibility for Domain 3: Psychological & Psychiatric Aspects of Care, according to Domains & Aspects of Care, Clinical Practice Guidelines 2018.

### Practice strategies

- <u>Challenge:</u> Solving Emerging Problems
  - Pandemic and consequences
  - Individual or family problems that arise during hospice or palliative care treatment
  - Health system inequities exposed

#### • <u>Opportunities</u>

- Remain flexible in approaches to new individual, family, and societal problems as they arise.
- Be open to and encourage collaborative solution
- Form research partnerships between agency and with community
- Lead efforts in problem-solving 'real' solutions to create equitable health systems

## Consequences of the COVID-19 pandemic

- Increased need for palliative care
- Increased need grief and bereavement support for individuals, families, and health professionals.
- Increased isolation
  - Patients from family (all health settings affected)
  - Patients from health professionals, including social workers (Hospice, some NHs not allowing outside health professionals, such as hospice) .

How did the pandemic change palliative social work practice?

- Greater attention on alternative ways to connect:
  - Patients with families video apps, online
  - Social workers with patients, families, and health professionals
    telemedicine
  - Social workers with each other online discussion forums

### <u>Opportunity</u>: Call for a National Grief Strategy (U.S.) by SWHPN and NHPCO

• A national grief strategy would aim to expand access to mental health resources and develop "grief literacy" among American citizens.

# What have we learned from practice in the pandemic?

#### Opportunity: Expand evidence base

- Evaluate which new practices from pandemic were effective and should now be incorporated into 'normal' practice.
  - Re-visit models of care what worked during COVID and what didn't
  - What were barriers to effective practice were highlighted during this time and how can they be addressed?
- Engage in research to support the effectiveness of the new practices.
  - Further evaluate what worked and what didn't work.
  - How to address the barriers?

# Ongoing Education about Palliative Care

Social workers need to coordinate interprofessional teams to provide education regarding:

- Incorporating principles of palliative care in every day practice, including primary and community care clinics, among all health professionals in all settings
- Improving communication through training for health professionals
- Ethical decision making and resolution of ethical problems among health professionals.
- End-of-life decisions, hospice and palliative care in the community

# Social Work Leadership

- <u>Challenge</u>: Recognition of social workers as leaders
  - Not traditionally in leadership roles within health settings, as social work is not the dominant discipline
  - Health professionals and organizations may not fully appreciate the knowledge and skills of social workers.

#### • <u>Opportunity</u>:

- Volunteer for leadership opportunities within the agency
- Develop avenues for collaboration with other health professionals in practice
- Outreach in community
- Advocacy for ensuring equity and access to quality end-of-life and palliative care
- Develop collaborations for research especially that evaluates practice and can be shared with administrators

### Professional self-care

- <u>Challenge</u>: Social work supervision and connecting with other social workers
  - Many social workers are the only social worker in the organization or are otherwise separate from other social workers in the institution. work in isolation from other social workers and do not receive social work supervision.

- <u>Opportunity</u>: Organize local groups of hospice and palliative social workers
  - Create 'communities of practice"
    - a way of organizing a group of professionals with a common goal or topic that unites the community together through "mutual engagement in a joint enterprise" (Jacobs & Endersby, 2019, p. 124).
    - can be face-to-face or virtual for broader reach
    - Example: SW-PALL-EOL Listserv organized in the U.S. a virtual community of practice

- <u>Opportunity</u>: Join and participate in professional organizations in the field as well as inter-professional
  - Face-to-face or virtual through interest group meetings and social media sponsored by the organization
  - Examples: Social Work Hospice and Palliative Care Network (paid member organization; with subscription included to the *Journal of Social Work in End-of-Life and Palliative Care*)

World Hospice and Palliative Care Social Work Network – newly formed and open to all (organizer – Carina Oltmann contact at carinaoltmann7@gmail.com

- Challenges and Opportunities will continue to emerge in hospice and palliative care social work
- Key is to be open to new opportunities and roles that will enhance the standing of social work and ultimately enhance quality of life for patients and families who need us.

Social workers are ESSENTIAL!

### References

- Center for the Advancement of Palliative Care (2021). America's Care of Serious Illness: 2019 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals: Summary report card. <u>https://reportcard.capc.org</u>
- Jenkins, D. M., Endersby, L. (2019). Leadership Education: Illuminating a Community of Practice. *New Directions for Student Leadership*. Vol. 2019, Issue 164, 123-139.
- Leff, V. (March, 2020). On the Value of Social Work in Palliative Care. https://www.pallimed.org/2021/03/on-value-of-social-work-in-palliative.html

#### Thank you for your attention!