PENNSYLVANIA PLAN FOR ONCOLOGY PALLIATIVE CARE

DECEMBER 30, 2016

BACKGROUND

According to the American Cancer Society *Cancer Treatment and Survivorship Facts and Figures 2016*, the estimated number of cancer survivors in Pennsylvania as of January 1, 2016 is 711,240. A cancer survivor is defined as any person diagnosed with cancer from the time of diagnosis through the end of life. Goals of cancer treatment are to cure the disease or prolong survival with the highest quality of life as possible so survivorship carries more meaning than extension of life.

Palliative care is important to maximizing survivorship because it focuses on relieving suffering and improving quality of life for patients and their families. It is not intended to cure cancer as a disease but provide relief from symptoms, pain and stress. Ideally, palliative care is available at any disease stage and is not for end of life or terminally ill patients only.

Evidence has established the importance of pairing palliative care with the medical treatment of cancer in all care settings and should be provided along with curative treatments. It is an essential component for quality of life.

In 2014-2015, the Survivorship and Palliative Care Stakeholder Leadership Team (SLT) of the Pennsylvania (PA) Comprehensive Cancer Control Coalition, a working committee of the Pennsylvania Cancer Advisory Board (CAB), prioritized Objective 3.3 of the PA Comprehensive Cancer Control Plan (2013-2018) "Facilitate collaboration to increase attention to appropriate use of palliative care and improve quality of life."

Two strategies were prioritized to address Objective 3.3; implement three regionally based palliative care roundtables, and develop a Pennsylvania Plan for Oncology Palliative Care. The information gathered at the roundtables was used to inform the development of the plan.

The first roundtable was held in North East Pennsylvania (NE PA) in Scranton on June 9, 2015, the second was in South Central Pennsylvania (SC PA) in Lancaster on June 16, 2015, and the third was in South Western Pennsylvania (SW PA) in Blairsville PA on June 15, 2016.

ROUNDTABLE OBJECTIVES:

1. **Discuss the new paradigm of palliative care.**
2. **Recognize palliative care resources and tools that are available from organizations such as the Center to Advance Palliative Care (CAPC) and the Commission on Cancer (CoC).**
3. **Identify challenges, opportunities, and potential solutions to expand palliative care in Pennsylvania.**
4. **Identify policy opportunities to advance palliative care.**
5. **List strategies for Pennsylvanians to move palliative care forward.**

Simultaneously, stakeholders for a statewide planning task force were identified during the regional roundtables or by staff of the American Cancer Society and PA Department of Health (Appendix B) Stakeholders teleconferenced about drafting a plan and then met in Hershey, Pennsylvania on February 24, 2016 to discuss essential goals and objectives for the first statewide Pennsylvania Oncology Palliative Care Plan. The stakeholders also adopted the **NCCN (2016) definition of palliative care**:

> "Palliative care is a special kind of patient- and family-centered health care that focuses on effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures. The goal of palliative care is to anticipate, prevent, and reduce suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care begins at diagnosis and should be delivered concurrently with disease-directed, life-prolonging therapies, and should facilitate patient autonomy, access to information, and choice. Palliative care becomes the main focus of care when disease-directed, life-prolonging therapies are no longer effective, appropriate, or desired. Palliative care should be initiated by the primary oncology team and then augmented by collaboration with an interdisciplinary team of palliative care experts."

In addition, the stakeholders adopted the following definitions of primary versus specialty palliative care for patients with cancer.

PRIMARY PALLIATIVE CARE: Provided by the patient's existing care team, which may include medical, surgical or radiation oncologist, primary care physician, nurse practitioner, physician's assistant or non-medical providers such as social workers, therapists, pharmacist, counselor, chaplains or clergy who meet the palliative needs of a patient but do not have specialty palliative care training or certification.

Primary palliative care elements:

- Basic pain and symptom management
- Basic management of depression and anxiety
- Basic management of financial, social or spiritual distress
- Basic discussion about goals, prognosis, and suffering

SPECIALTY PALLIATIVE CARE: Provided by an interdisciplinary team with specialty palliative care training and/or certification, delivered upon referral/consult request. Teams may include physicians, nurse practitioners, physician assistants, social workers, therapists, pharmacists, counselors, chaplains or clergy, and volunteers in inpatient, outpatient, or home-based settings.

Specialty palliative care elements:

- Management of refractory pain and other symptoms
- Management of more complex depression, anxiety, grief, social or spiritual distress
- Complex discussion about goals, prognosis, and suffering
- Complex advance care planning

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This Plan is the result of their discussion and three Goals were identified. The following pages list the Goals with one or more objectives, example action plans, and potential evaluation indicators.

GOAL 1:

Promote a statewide gold standard for palliative care services available to adults and children with cancer

Objective 1: Adopt the NCCN (2016) definition of palliative care for people with cancer

Objective 2: Define statewide standard for essential elements and accessibility of palliative care services (Appendix A)

Indicator: Pennsylvania Palliative Care Standard with essential elements and accessibility approved by statewide and regional stakeholders (document)

Source: *Statewide Pennsylvania Oncology Palliative Care stakeholders*

ACTION PLAN:

1. Convene an ad hoc task force to align essential palliative care elements as outlined by CAPC (Center to Advance Palliative Care), NCCN (National Comprehensive Cancer Network), ASCO (American Society of Clinical Oncology) and American College of Surgeons by (date)

2. Support participation in Commission on Cancer and ASCO QOPI (Quality Oncology Practice Initiative) Certification to ensure self-assessment for areas of improvement, benchmarking against a national aggregate, and utilization of national practice guidelines

Objective 3: Promote standards and essential elements for palliative care service delivery

ACTION PLAN:

1. Advertise these essential elements and certification programs to areas of low palliative care access
2. Support efforts to create standards for palliative care delivery such as JCAHO palliative care certification for hospital and community based palliative care.

PLAN (cont):

GOAL 2:

Identify palliative care needs in adults and children with cancer and resources available

Objective 1: Endorse standard screening of patients with cancer from the time of diagnosis in accordance with NCCN guidelines for assessing palliative care needs

ACTION PLAN:

1. Identify appropriate screening mechanisms (such as the Edmonton Symptom Assessment Scale (ESAS) or NCCN Distress thermometer) for distress including physical, spiritual, psychological, financial, social and cognitive distress
2. Identify mechanisms to assess patients' goals, values, understanding, and expectations related to living with a serious illness including advance care planning and POLST (Pennsylvania Orders for Life Sustaining Treatment)
3. Identify appropriate intervals for screening in both primary and specialty palliative care
4. Provide education on the application of and response to PC screening instruments to estimate life debilitating symptoms,
5. Explore the use of electronic health records to improve regular screening and referral for palliative care services
6. Explore state registry role in if and when screening and referral was done—evaluation pilot

PLAN (cont):

GOAL 2 (cont):

Objective 2: Endorse involvement of health care professionals in a national registry of palliative care services

ACTION PLAN:

1. Encourage involvement in CAPC national registry for both inpatient and outpatient palliative care service availability
2. Support free electronic dissemination of national CAPC registry information for providers and public
3. Educate providers and the public about available national PC registries, their access, and inclusion criteria

Objective 3: Consider the effectiveness, benefits, and disadvantages of initiating a statewide PA PC registry

ACTION PLAN:

1. Determine inclusion criteria in other statewide PC registries
2. Assess how PA Hospice Network Registry fits with a PA PC statewide registry
3. Support state and regional organizations in identifying onsite or offsite palliative care service availability to include in a possible PA PC statewide registry
4. Identify inclusion criteria in a PA PC statewide registry
5. Discuss how data collected by the PA DOH Cancer Registry related to PC or QOL metrics can contribute to a PA PC statewide registry and the evaluation of implementation the PA Cancer Plan with the Cancer Data Advisory Committee

PLAN (cont):

GOAL 3:

Expand access to palliative care services for adults and children with cancer from the time of diagnosis

Objective 1: Establish methods of educating health care providers and public about Palliative medicine

ACTION PLAN:

1. Provide palliative care continuing education events for health care professionals
2. Identify organizations in place to provide educational programming and coordinate efforts across the state, such as PA Hospice and Palliative Care Network; Pediatric Palliative Care Coalition, American Cancer Society, and hospital-based programs
3. Incorporate and increase palliative care education into medical curricula for health care providers
4. Create a regional PC speaker's bureau to offer resources and speakers to colleges, universities, and health care education programs
5. Engage Accountable Care Organizations in public education initiatives
6. Educate the public about the benefits of palliative care
7. Promote hospice and palliative care certification and credentialing for health care providers, such as physicians, physician assistants, nurse practitioners, nurses, social workers, and chaplains
8. Provide a website as an online home for PA Palliative Care to house resource information and serve as a clearinghouse for palliative care educational opportunities across the state
9. Engage legislators in public education initiatives by offering them specific roles and involvement
10. Implement a palliative care discussion program for communities (similar to Closure series) to be held in churches or community centers as community forums
11. Create palliative care materials in print, video, or social media that can be accessed by the public and institutions for distribution (similar to NINR Palliative Care: Conversations Matter campaign)

PLAN (cont):

GOAL 3 (cont):

Objective 2: Increase knowledge among health care providers and the public about the essential elements, benefits and indications for primary and specialty palliative care services

ACTION PLAN:

1. Educate health care providers and the public about essential elements of primary palliative care (as established in Goal #1) with emphasis on communication skills including skillful discussions about goals of care, advance care planning, and POLST (Pennsylvania Orders for Life Sustaining Treatment) by (date)
2. Educate health care providers and the public about availability of primary palliative care services in their systems/regions
3. Educate health care providers and the public about specialty palliative care, skills, and availability of specialty palliative care services and indications for specialty palliative care consultation
4. Create a simple, easy to use guidelines of essential elements and/or version of the NCCN Guidelines for use in outpatient settings
5. Target education to areas of the state where gaps in PC services exist
6. Encourage palliative care participation at oncology tumor boards

PLAN (cont):

GOAL 3 (cont):

Objective 3: Increase CAPC Palliative Care Report Card for PA hospitals from 68% ("B") grade to 80% ("A") grade

Indicator: # of hospitals with inpatient Palliative Care programs

Source: *Center to Advance Palliative Care (CAPC) annual palliative care registry (www.getpalliativecare.org)*

ACTION PLAN:

1. Consult with CAPC to obtain details about those hospitals who do not offer PC services
2. Consult with CAPC on how other states increased their Report Card grades
3. Analyze criteria that CAPC used to eventually rate Palliative Care services as a nominal variable by (date)
4. Include stakeholders from hospitals offering 'no Palliative Care' program in regional PC Roundtable activities by (date)
5. Distribute a resource packet with websites and NCCN Guidelines for Palliative Care to key stakeholders in hospitals 'not offering Palliative Care'
6. Develop plan to increase the number of inpatient palliative care programs in Pennsylvania

PLAN (cont):

GOAL 3 (cont):

Objective 4: Increase palliative care providers available to patients early in cancer continuum

ACTION PLAN:

1. Support increase in outpatient palliative care specialty clinics, either standalone or embedded in oncology clinics
2. Support efforts to increase training programs for palliative care specialists including the proposed federal Palliative Care and Hospice Education Training Act
3. Support development of telemedicine systems throughout Pennsylvania to provide palliative care to cancer patients living in rural areas
4. Recommend models of what certifications that health care providers ideally should hold to deliver PC services in different settings including rural and urban settings
5. Build partnerships with local hospices and home health agencies to refer to palliative care teams to provide palliative care outreach
6. Build partnerships with religious communities, community agencies (such as spiritual support services, meals on wheels, psychiatric and psychological support services to refer to palliative care
7. Widen distribution of low literacy patient directed information brochures and pamphlets concerning palliative issues, end of life care, available resources, advance directives, and POLST documents
8. Establish regional palliative medicine specialty consult centers to coordinate multidisciplinary PC community resources. These could be both site specific and telemedicine availability when necessary.

REFERENCES:

National Consensus Project for Quality Palliative Care Guidelines <http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf> [accessed 27 June 2016]

NCCN Guidelines for Palliative Care <https://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf> [accessed 28 June 2016]

Commission on Cancer 2016 Cancer Program Standards https://www.facs.org/~/media/files/quality%20programs/cancer/coc/2016%20coc%20standards%20manual_interactive%20pdf.ashx [accessed 18 July 2016]

APPENDIX A. PENNSYLVANIA STANDARD FOR ESSENTIAL ELEMENTS AND ACCESSIBILITY OF PALLIATIVE CARE SERVICES

The Definition of palliative care described by the United States Department of health and Human Services (HHS) Centers for Medicare & Medicaid Services (CMS), the National Quality Forum(NQF) and National Consensus Project states:

> Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice.
>
> Per National Comprehensive Cancer Network (NCCN)2016 guidelines, palliative care should be initiated by the primary oncology team and then augmented by collaboration with an interdisciplinary team of palliative care experts." NCCN (2016) definition of palliative care

Patients with cancer and their designated family members or caregivers should have access to palliative care across clinical settings including inpatient, outpatient, long term care facilities and home. Services may be provided within the cancer organization or through community partnerships to provide all of the following:

1. **Interdisciplinary team that collaborates to assess patient and guide plan of care**
    - **Should include:**
        - Oncology provider: Physician or nurse practitioner
        - Social worker
        - Spiritual care provider
        - Dietitian
        - Nurse navigator, Care coordinator or Case manager

APPENDIX A (cont):

- **May include**
  - Specialty Palliative care provider
  - Grief and bereavement counselors
  - Physical therapist
  - Pharmacist
  - Lymphedema specialist Mental health professionals
  - Massage therapist
  - Child life specialist
  - Occupational therapists
  - Recreational therapists
  - Respiratory therapists
  - Art and music therapists
  - Speech language pathologist
  - Volunteers
  - Symptom management health care provider (physician, nurse practitioner, clinical nurse specialist or physician assistants.

2.Patient/Family Assessment (and/or screening) to include:

- Illness understanding including diagnosis and prognosis
- Co-morbidities
- Physical and psychological symptoms
- Functional status
- Social, cultural and spiritual assessment including strengths, needs & goals
- Advance care planning, including health proxy, advanced directives and out of hospital orders such as POLST and completion of documents
- Financial, prescription and insurance assessment
- Mechanism for re-assessing needs

3. Treatment plan that reflects or integrates the patient's and family's goals for treatment and preferences for communication as per National Consensus Project for Quality Palliative Care Clinical Practice Guidelines.

- Ensure the patient and family understanding of disease: consequences, symptoms, side effects, treatments and functional impairment
- Regular reassessment of whether treatment plan remains in line with their goals

4. Evidence based management of symptoms (See NCCN guidelines for Palliative Care)

- Physical symptoms including pain, shortness of breath, nausea, fatigue, anorexia, insomnia, restlessness, confusion, swelling and constipation
- Psychological and psychiatric symptoms including depression, anxiety, delirium, cognitive impairment

APPENDIX A (cont):

5. **Specialty Level palliative care by board certified physician and/or nurse practitioner for refractory symptoms or difficult goal setting**

6. **Care of patient at the End of life symptom management/support and post-death care**

    - Interdisciplinary assessment and management of physical, psychological and spiritual symptoms
    - Anticipatory guidance for family
    - After death care of patient and support to family

7. **Grief and Bereavement support for patients' designated family members or caregivers for a minimum of 12 months after the patient's death**

8. **Quality improvement plan and mechanism to address ethical or legal concerns**

9. **Mechanisms for staff support to support sustainability and prevent compassion fatigue and/or burnout**

10. **Continuing education for physicians, nurse practitioners, clinical nurse specialists and physician assistants on palliative, and end of life care Education for medical trainees on palliative, and end of life care Palliative care representation at the leadership level, such as Health Governing Bodies or Cancer Committees for organizations providing oncology care**

APPENDIX B: TASK FORCE MEMBERS

- **Chair: Kristine Braine Newport, MD, FAAHPM:** Palliative Medicine Physician, Palliative Medicine Consultants (a program of Hospice and Community Care)
- **Kathy Selvaggi, MD:** Director, Palliative Care Medicine, Butler Health Systems
- **Neil Ellison, MD:** Palliative Associate, Geisinger Health System
- **Chris Peters, MD:** Medical Director, Northeast Radiation Oncology Centers
- **Geoffrey Dunn, MD:** Department of Surgery & Medical Director of Palliative Care Consultation Service, UPMC Hamot
- **Patricia Maani-Fogelman, DNP:** Department of Thoracic/Pulmonary Medicine, Pulmonary-Palliative Clinic, Geisinger Health System
- **Shefali Parkikh, MD:** Attending-Pediatric Advanced Care Team, Children's Hospital of Philadelphia
- **Lonna Donaghue, MGA:** Executive Director, Pennsylvania Hospice and Palliative Care Network
- **Julia Bucher, RN, PhD:** Stabler Department of Nursing at York College of Pennsylvania
- **Lisa Simonian, DNP, CRNP, SANE-A:** Palliative Care Nurse Practitioner, UPMC Hamot
- **Jennifer Pruskowski, PharmD:** Associate Professor, University of Pittsburgh School of Pharmacy and Therapeutics; Palliative Care Clinical Pharmacy Specialist and Supportive Institute, UPMC
- **Margaret O'Grady, RN, MSN, OCN:** Director of Nursing, Jefferson Health; President, Pennsylvania Society of Oncology and Hematology; ACoS/CoC Consultant; Member PA Governor's Advisory Board for Cancer Prevention and Control
- **Betsy Hawley:** Executive Director, PA Pediatric Palliative Care Coalition
- **Deana Deeter, CRNP:** Penn State Hershey Pediatric Hospital Medicine
- **Rev. Jim Ingalls:** Chaplain, VNA Hospice of Philadelphia/Temple University Hospital Palliative Care

APPENDIX B: TASK FORCE MEMBERS(cont)

- **Lisa Capparella, MSS, LCSW, OSW-C:** Oncology Social Worker, Reading Health System
- **Mark Wojtowicz:** Manager, Innovation & Research, Geisinger Cancer Service Line, Geisinger Health System; Co-Chair, SLT Survivorship and Palliative Care work group
- **Candance Sanderson, MEd:** Community Engagement Manager, PA DOH
- **Diane Phillips:** Pennsylvania Government Relations Director, ACS-Cancer Action Network
- **Katherine Sharpe, MTS:** Senior Vice-President, Patient and Caregiver Support, ACS, Corporate Center
- **Lynne Padgett, PhD:** Strategic Director, Hospital Systems, ACS, Corporate Center
- **Diana Fox, MEd:** Senior Director, Hospital Systems, ACS, East Central Division
- **Aimee Anderson:** Senior Manager, Hospital Systems, ACS, East Central Division, Western PA
- **Stefanie Washburn, MSW:** Senior Manager, Hospital Systems, ACS, East Central Division, Eastern PA

“This publication was supported by Grant Number 5U58DP003937-05, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.”