



**APA ANNUAL CONVENTION**

August 3-6, 2017 | Washington, D.C.

# Psychologists and End of Life: Contributions to Training, Research, Practice, and Policy

APA Working Group on End of Life Issues and Care



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# A Summary of APA's Efforts in the End-of-Life Arena

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## Early Efforts

- Over time, APA had been involved in discussing end-of-life issues and supporting hospice care
- The U.S. Supreme Court announced it would hear two cases related to physician-assisted death in 1995 (*Vacco v. Quill* and *Washington v. Glucksberg*)
- Psychologists were involved in developing an *amicus curiae* brief on mental health issues for the cases and asked APA to be a co-signer
- APA refused, in part because the organization had not issued any official statements on the topic of end-of-life issues or decision-making

## APA's Activities

- Early work started in 1997 and resulted in a public statement
  - Prior to Supreme Court rulings, in April of 1997, the APA Public Communications Office / Public Interest Directorate, established a working group
  - Purpose was to create a briefing paper on mental health issues involved in physician-assisted dying and other end-of-life decisions that could be used to inform news media
  - The paper was converted into a public brochure entitled “Terminal Illness and Hastened Death Requests: The Important Role of the Mental Health Professional”
  - Later published as a journal article in *Professional Psychology: Research and Practice* (Farberman, 1997).

- February 1998, the APA Board of Directors authorized the formation of the Working Group on Assisted Suicide and End-of-Life Decisions (Working Group) and charged it with the following tasks:
  1. Examine the role of psychology in end-of-life decisions and quality of care issues;
  2. Address the invisibility of psychology around the issue of end-of-life decisions and recommend methods to increase the visibility of psychology and the role of psychologists in this arena;
  3. Consider and make recommendations on whether it might be appropriate for APA to take a position on the issue of assisted suicide and end-of-life decisions.

- 6 member Working Group met several times from 1998-2000 and developed 3 products
  - The Report to the Board of Directors of the American Psychological Association from the Working Group on Assisted Suicide and End-of-Life Decisions
    - Appendix F: Issues to Consider When Exploring End-of-Life Decisions
  - APA Resolution on End-of-Life Issues and Care
  - APA Resolution on Assisted Suicide
  - Available at the APA's EOL website:  
<http://www.apa.org/pi/aging/programs/eol/index.aspx>

- 2001-2007 APA convened an Ad Hoc Committee on End-of-Life Issues (highlights)
  - Sponsored 2 Congressional briefings
  - Developed several fact sheets (e.g., diversity, SES)
  - Developed CE Workshop for APA convention
  - Published an article in *PPRP*
  - Co-sponsored an international conference
  - Received nearly \$1M in grant funding to develop a set of 10 online and print version CE modules
  - Coordinated a Children and Adolescents Task Force that issued a report in 2005
  - Examined reimbursement options for Psychologists in Hospice under Medicare
  - Conducted a series of national surveys

- EOL CE Module Participation

|                                                                         |     |
|-------------------------------------------------------------------------|-----|
| Overview of End-of-Life Issues for the Mental Health Provider           | 321 |
| Assessment and Treatment of Psychological Distress near the End-Of-Life | 174 |
| Assessment and Treatment of Pain                                        | 109 |
| Diagnosis and Treatment of Cognitive Changes at the End of Life         | 62  |
| Grief and Bereavement                                                   | 214 |
| Religious and Spiritual Issues At the End of Life                       | 94  |
| Family Caregiving Issues at the End of Life                             | 91  |
| Team Work in End-Of-Life Care                                           | 62  |
| Law and Ethics Associated With Care at the End of Life                  | 114 |
| Advance Care Planning: Module 10                                        | 66  |

## Current Efforts

- Working Group on End-of-Life Issues and Care has been in place for about 18 months
  - Main focus has been on reviewing and updating the Resolutions on End-of-Life Care and on Assisted Suicide
  - The End-of-Life Care Resolution was updated significantly to reflect growing attention to palliative care
  - The title of the Assisted Suicide Resolution was changed to Assisted Dying but the content was largely unchanged
  - Presenting this Symposium at the APA Convention
  - Discussing developing articles in the *Monitor*, manuscripts for professional journals, CE options, fact sheets, blog postings, and collaborations with other groups (inside and outside of APA)



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# Psychology's Contribution to Training and Research

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# Psychology, Palliative Care & the Training Pipeline

## PSYCHOLOGY ABBREVIATIONS

**PsyD****Doctor of Psychology**

Doctoral degree, an applied clinical degree, completion typically involves practical experience and research in the field. Usually takes from 4-7 years to earn (plus undergraduate & master degree).

**PhD****Doctor of Philosophy in Psychology**

Doctorate degree, typically required for research or clinical psychology careers. Usually takes 4-6 years to earn (plus undergraduate & master degree).

**MS****Master of Science in Psychology**

Graduate degree, typically takes 2-3 full-time years to earn (plus undergraduate degree), may require more science courses & research than an MA in psychology program.

**MA****Master of Arts in Psychology**

Graduate degree, typically takes 2-3 full-time years to earn (plus undergraduate degree), may require more liberal arts & humanities courses than an MS in Psychology program.

**BS****Bachelor of Science in Psychology**

Undergraduate degree, typically takes 4 full-time years to earn, usually requires more science & math than a BA in psychology.

**BA****Bachelor of Arts in Psychology**

Undergraduate degree, typically takes 4 full-time years to earn, usually requires more liberal arts courses than a BS in psychology.

# Training Models in Psychology and Palliative Care

- Most training opportunities occur within the internship and postdoctoral training years, but some graduate school programs also offer practicum experiences
- Psychology training models and how they fit into interprofessional palliative and hospice care
  - Clinical scientist
  - Scientist-practitioner
  - Practitioner scholar

# Training Settings and Content Areas

- Home-based or hospital-based palliative & hospice care consults
  - aid in dying
  - grief & bereavement
- Home, clinic-based or traditional psychotherapy settings
  - psychotherapeutic treatments for people with serious illness (meaning-centered, Dignity, Legacy interventions)
- Elder Law Clinics and Elder Law Attorney Practices
  - decision making
  - capacity evaluation

# **Ethics, Professional Competencies and Interprofessional Teams**

- Professional boundaries
  - With colleagues
  - With patients and their families
- Teamwork and communication
- Autonomy v. protecting safety in at risk older adults
- Capacity issues

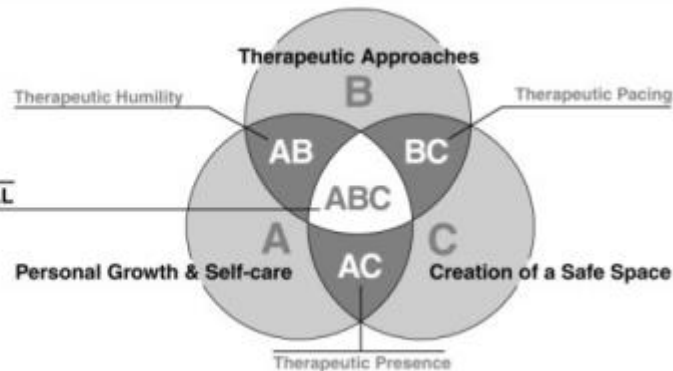
# Therapeutic Effectiveness

## (Chochinov et al. 2013)

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Model of  
**Therapeutic Effectiveness**

OPTIMAL THERAPEUTIC POTENTIAL

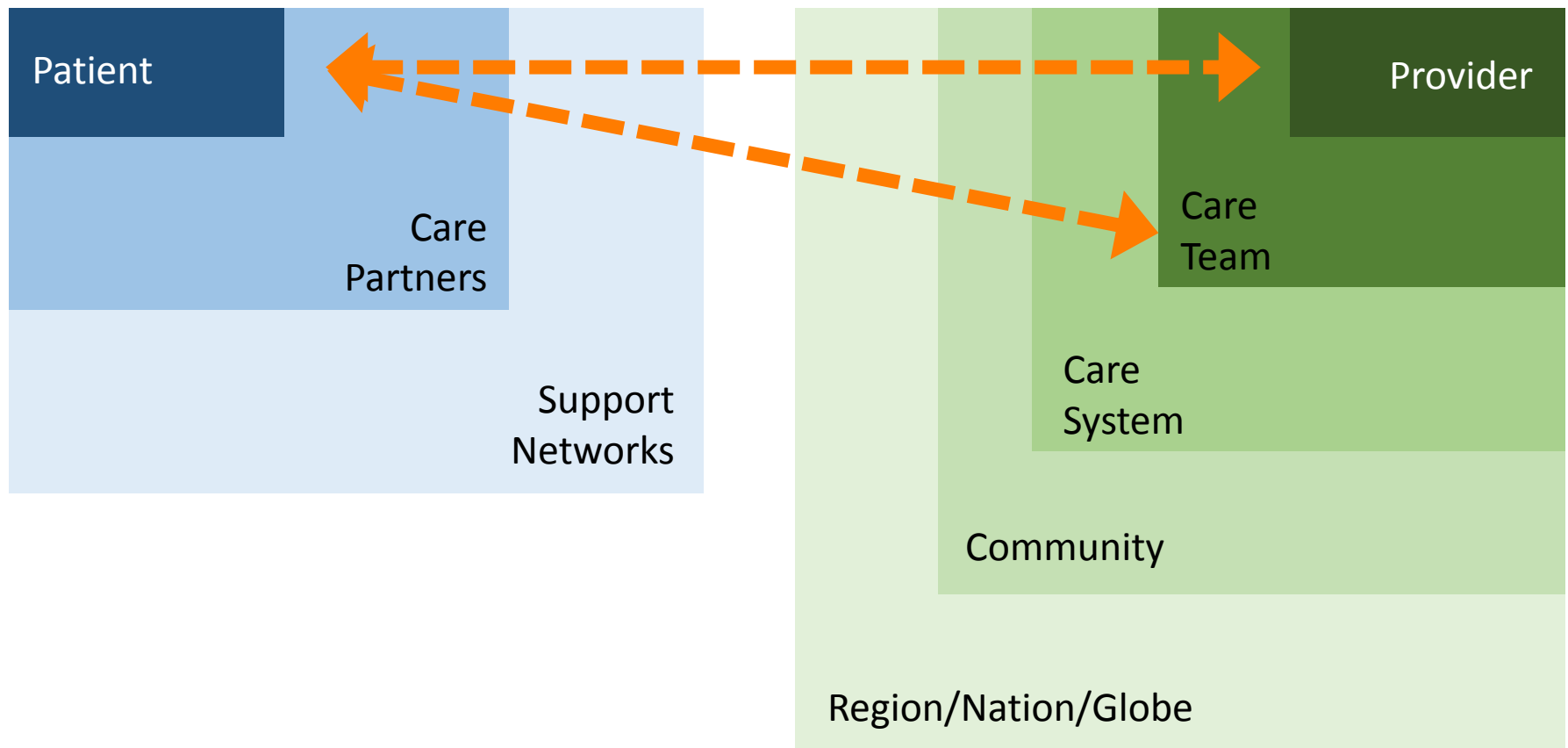


- Therapeutic Pacing (BC)
- Therapeutic Presence (AC)
- Therapeutic Humility (AB)

# Behavioral Research to Date

- Major focus has been in psycho-oncology
- Important work in other areas
  - decision making
  - capacity evaluation
  - psychotherapeutic treatments for people with serious illness
  - aid in dying
  - grief & bereavement
  - diversity & disparities

# A Framework for Research Needs & Opportunities



# Examples of Behavioral Research Opportunities

## Symptom management

- pain
- dyspnea
- bereavement

## Decision making

- treatment choices
- capacity
- goals of care

## Communication

- diagnostic disclosure
- sharing care preferences with family members
- interprofessional collaboration

## Assessment

- reliability & validity
- cultural relevance
- norms

## Education & training

- effective public information campaigns
- competency achievement

# Opportunities for Interprofessional Research

## Medicine

- How does framing effect patient interpretation of prognostic information?

## Nursing

- Can a brief, nurse-delivered bedside mindfulness intervention reduce pain?

## Social Work

- How can an assessment of family dynamics lead to more effective treatment planning meetings?

## Pharmacy

- Does continued illicit substance use influence adherence to a palliative pharmacologic regimen?

## Chaplaincy

- What is the relationship between spiritual beliefs and fear of dying and fear of death?

# Professional Resources

- Funding agencies and requests for applications
  - American Cancer Society
  - National Institute on Nursing Research
  - National Institute on Aging
  - National Cancer Institute
  - Templeton Foundation
- Journals
  - *American Journal of Hospice & Palliative Medicine*
  - *Journal of Pain & Symptom Management*
  - *Journal of Palliative Medicine*
  - *Aging and Mental Health*
  - *Health Psychology*
  - *Journals of Gerontology*
  - *Patient Education & Counseling*
- Research networks
  - Hospice, Palliative, and End-of-Life Care Interest Group (GSA)
  - Research Interest Group (AAHPM)
  - Palliative Care Research Cooperative Group



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# Issues of Diversity in Palliative and End-of-Life Care

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# Background

- APA Ethical Principles of Psychologists and Code of Conduct
  - Principle E: Respect for People's Rights and Dignity
- Guidelines on Multicultural Education, training, Research, Practice, and Organizational Change for Psychologists
  - Guideline #5
- Working Group approach to Diversity

# Race and Ethnicity

- Knowledge/information
- Mistrust
- Communication
- Religion/spirituality
- Cultural Values

# Gender

- Care recipient demographics and experiences
- Impact of traditional gender roles on behavior
- Care partner experiences

# LGBTQ

- Access to palliative and end-of-life care
- Historical discrimination in health care
- Religion/spirituality
- Identifying and including partner and family

# Disability

- Social determinants of the disability experience
- Health care disparities
- Complex lifetime systems of care/support poorly replicated by admission to skilled care at the end of life
- Treatment preferences
- Health care providers' assumptions may not match their patients' views

# Age

- Children/Adolescents
- Adults
- Care partners across the lifespan

# Diversity and Assisted Dying

- Racial/ethnic differences in attitudes towards Aid in Dying
- Concerns of disability rights advocates
- Gender

# Implications of Psychology Practice

- Knowledge
- Support quality communication with family that is consistent with cultural preferences
- Develop awareness of end-of-life views of diverse cultural communities
- Attend to intersecting identities at the individual level of care
- Support culturally sensitive alternatives to traditional palliative and end-of-life care
- Advocate for changes in organizational, disciplinary, and social policies to promote equitable access to desired end-of-life care

# Resources

## Publications

- American Psychological Association. (2002). Ethical principles of psychologists and code of conduct. *American Psychologist*, 57(12), 1060-1073.
- American Psychological Association. (2003). Guidelines on multicultural education, training, research, practice, and organizational change for psychologists, *American Psychologist*, 58(5), 377-402.
- “Palliative and End-of-Life Care for African Americans,” 2016 special issue of the *Journal of Palliative Medicine*, Volume 19, number 2.
- Acquaviva, K. D. (2017). *LGBTQ-inclusive hospice and palliative care: A practical guide to transforming professional practice*. New York: Harrington Park Press.

# Resources

## Websites

- Office of Minority Health, U.S. Dept. of Health and Human Services: <https://minorityhealth.hhs.gov/>
- The Cross Cultural Health Care Program: <http://xculture.org/>
- Diversity Rx: <http://www.diversityrx.org/topic-areas/culturally-competent-care>
- “End of Life Decisions” site of the National Resource Center on LGBT Aging: <http://www.lgbtagingcenter.org/resources/resources.cfm?s=7>
- “Palliative Care Fast Facts and Concepts” fact sheet site of the Palliative Care Network of Wisconsin: <https://www.mypcnow.org/fast-facts>

Examples of fact sheets related to diversity:

- #78 - Cultural Aspects of Pain
- #138 - Peds Grief and Development
- #204 - African American End of Life Issues
- #216 - Asking About Cultural Beliefs
- #275 - LGBT Issues in Palliative Care



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# Psychology's Contribution to Practice

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# General Considerations for Practice in Palliative Care

- Existing skills and knowledge adapted, applied in new ways, new settings
- Competencies in basic palliative care vs. specialty/advanced practice
- Emphasis on interprofessional practice, care coordination; systems perspective (family, health care)
- Considerable constraints
  - Outcomes measurement; value added
  - Billing, reimbursement

# Key Domains of Practice in Palliative Care

- Psychological, Sociocultural, Spiritual, & Interpersonal Factors in Chronic, Serious Life-Limiting, Terminal Illness
- Normal, Abnormal Grief, Bereavement
- Goals of Care/Advance Care Planning
- Assessment of Physical Mental Health Conditions
- Psychotherapy for Individuals with Chronic, Serious or Terminal Illness
- Assessment and Treatment of Families
- Interdisciplinary Teams, Consultation, Professional Self-Care

# Intersection between Geriatrics & Palliative Care

## Geriatrics

Diagnosis, treatment, prevention of disease; problems common to older adults (frailty, disability, incontinence, cognitive impairment, sensory impairment); maximize independence, ADLs

QOL; function; team-based; complex patients; consideration of social system; advance care planning;

Advanced illness & end of life across lifespan; symptom management; attention to care transitions; bereavement

## Palliative Care

# Palliative Care Practice: Representative Examples

- Assessment
- Intervention
- Goals of Care/Advance Care Planning
- Interprofessional Practice



# Assessment

- Psychologists have a unique skill in assessment which is needed and applicable to palliative and end-of-life care
- Skills such as:
  - Mood assessment
  - Brief cognitive assessment
  - Bio-psychosocial-spiritual integrated evaluation
  - Capacity evaluation

# Assessment

- Psychologists have also been involved with pain and sleep assessment, and these well established methods can be altered to address care needs across the continuum of the palliative population
- Assessment skills can also be applied in a similar manner to other physiological symptoms as well

# Common Symptoms Assessed

- Pain
- Energy
- Appetite
- Dry mouth
- Weight
- Drowsiness
- Constipation
- Sleep difficulties
- Difficulty concentrating
- Dyspnea
- Nausea
- Worry
- Sadness

# Assessment

- Assessment can occur across settings within primary care, specialty clinics, acute care, palliative outpatient clinic, and in-home
- Assessment usually incorporates not only the patient, but also family, friends, and associated caregivers as palliative care provides services and support to all involved
- Evaluate grief and bereavement needs for patients and families

# Intervention

- Limited evidence base in palliative care
  - Reasonable extrapolations with assumption of similar theory of human behavior, mechanisms of change
  - Application of psychological principles vs. manualized approach
- Flexibility
  - Rapid, unpredictable pace, need to “seize the moment”
  - Therapy goals may be focused, time limited, each session to stand on own (accommodate prognosis of hours, days, weeks, months)
  - Modifications to accommodate medical status, complicated medical management

# Intervention

- Focus on normative and pathological reactions; reducing distress, promoting adaptation amongst system (individual, family, health care team), managing psychological and physical symptoms
- Requires high degree of cognitive flexibility, distress tolerance, tolerance for ambiguity
- Possible greater pull for self-disclosure, although guidelines in service of patient still apply
- Potential for stronger emotional, countertransference responses
- Relative emphasis on self-awareness, self-reflection, self-care
- Power of bearing witness

## Intervention: Existential distress

- Identify aspects of identity that transcend illness/functional decline; understand disease context and see the person they have been, rather than disease with which they live
- Explore and intervene upon religious/spiritual beliefs, evaluations of self-worth, sources of meaning/purpose, ways to continue to contribute that accommodate the illness, values and legacy; sources of suffering and distress
- Sit with suffering, raise possibility that life can have meaning in the midst of suffering. Bear witness, validate, affirm the individual's humanity-complete with flaws, regrets, failings, goodness, resiliencies, and fundamental worth to others
- Avoid trying to "fix" or lessen the feeling

## Intervention: Existential distress

- Utilize the team and take advantage of interdependence of skills/knowledge
- Engage in goals of care conversations early and often
- Consider the following therapeutic approaches
  - Life Review
  - Acceptance & Commitment therapy
  - Meaning-Centered Group Psychotherapy
  - Dignity Therapy
  - Legacy Interventions (e.g. Legacy Project)

## Goals of Care Conversations

- Conducting discussions with patients and families about their values, goals and preferences for care is vital to providing patient–centered and patient-focused care
- Defines Quality of Life for the individual and develops a vision and map to assist with navigating care
- Often incorporates or leads to advance care planning

# Goals of Care Conversations

- Goals of Care conversations require:
  - Excellent communication skills
  - Understanding of cultural influence
  - Understanding of decision-making processes
  - Knowledge of coping styles as they may apply to diagnosis, prognosis and decision-making
  - A dynamic process
- Consider evidence base approaches
  - E. g. FAmily CEntered (FACE) pediatric Advance Care Planning

# Interprofessional Practice

- Significantly overlapping roles and shared focus on bio-psycho-social-spiritual
  - Navigate shared and unique skills, advocate for own discipline while respecting perspective/role of others
  - Shared ownership, transdisciplinary vs. interdisciplinary care

# Conclusion

- Palliative Care is a practice area that has many unique aspects and often is practiced in non-traditional psychological practice settings
- Psychologists have numerous clinical competencies in assessment, intervention and communication that can elevate interdisciplinary Palliative care practice
- Many psychologists are currently contributing to aspects of this work across settings and with flexibility, support and a willingness to move outside of the box, can refine their practice
- Psychologists' unique and valuable contribution is much needed to impact the lives of numerous patients, families and caregivers during one of the most vulnerable and challenging times in their lives

## Resources

- On-line curriculum (e.g. ELNEC, EPEC) & Fast Facts
- Training opportunities (VA Interprofessional Fellowship program, internship training sites with Hospice/PC rotations)
- Listserves (VA palliative psychology group)
- Books, journal articles
- National Organizations (NHPCO, CAPC, AAHPM) newsletters, training activities, organizational memberships

Thank you!!!!

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# Palliative Care Policy Psychology's Role

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# Palliative Care Policy

## Psychology's Role

### Increase Psychology's Contribution to Palliative Care Policy

#### ➤ Under-represented

- Clinical care near end of life
- National conversation about clinical, training, research and policy priorities

#### ➤ In 1986 not a core discipline in Hospice Care

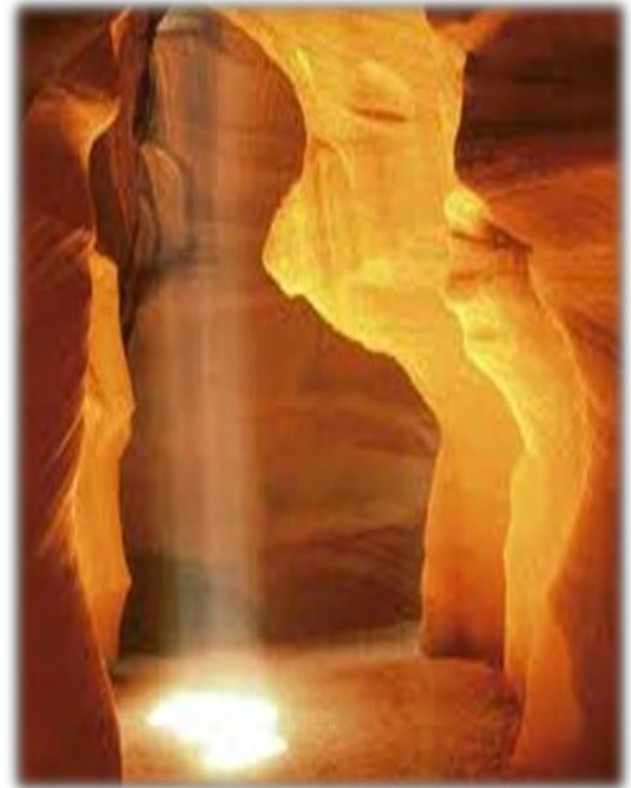
#### ➤ In 2017 not mentioned as an eligible health professional in the Palliative Care & Hospice



# Palliative Care Policy Psychology's Role

## Participate in Public Outreach

- APA has expertise in how to effectively campaign to increase public awareness to inform patients, families and health professionals about the benefits of palliative care and the services that are available
- Promote psychology's visibility in critical support of optimal QoL during serious illness & at EOL



# Palliative Care Policy

## Psychology's Role

Expand Professional  
Development &  
Workforce/Training

- Not enough  
psychologists with  
core competencies



# Palliative Care Policy Psychology's Role

## Education

- Psychologists in health care institutions and psychology faculty in medical schools can contribute to educating health care professionals
- Promote and encourage training in areas of palliative care and EOL issues within psychology training at all levels



# Palliative Care Policy

## Psychology's Role Policy

### Research

- Advance psychological research in palliative to assess and address psychological factors that have an impact on EOL decision-making
- Advocate for research that address disparities in access to and provision of palliative & end of life care



# Palliative Care Policy

## Psychology's Role with Minors

- Encourage psychologists who work with minors with advanced serious illness
- to obtain training at all levels in ethics related to
- decision-making by and care of minors who do not have legal rights,
- but are supported by public policy to be involved in decision-making about their medical care



# Palliative Care Policy

## Psychology's Role Ethical Concerns

- Encourage psychologists working with vulnerable populations
- Such as adults with limited capacity for autonomous decision making
- To obtain training at all levels of ethics
- Consistent with principles of justice & respect for people's rights & dignity



# Palliative Care Policy

## Psychology's Role Supporting Partners

- Advocate to preserve concurrent care (access hospice benefits at the same time as disease-directed therapy), if the ACA is repealed
- Advocate for psychology to be a core discipline in hospice and palliative care through Medicaid and Medicare to improve psychosocial QoL of dying individuals and their families



# Palliative Care Policy

## Psychology's Role Advocacy

Support APA's Advocacy for passage of the Palliative Care & Hospice Education and Training Act (PCHETA)

- Expand training in palliative medicine beyond physicians to include doctoral level psychologists and residents
- Expand Academic Career Awards to include board certified psychologists who have a faculty appointment at an accredited school of medicine
- Build connections with other disciplines

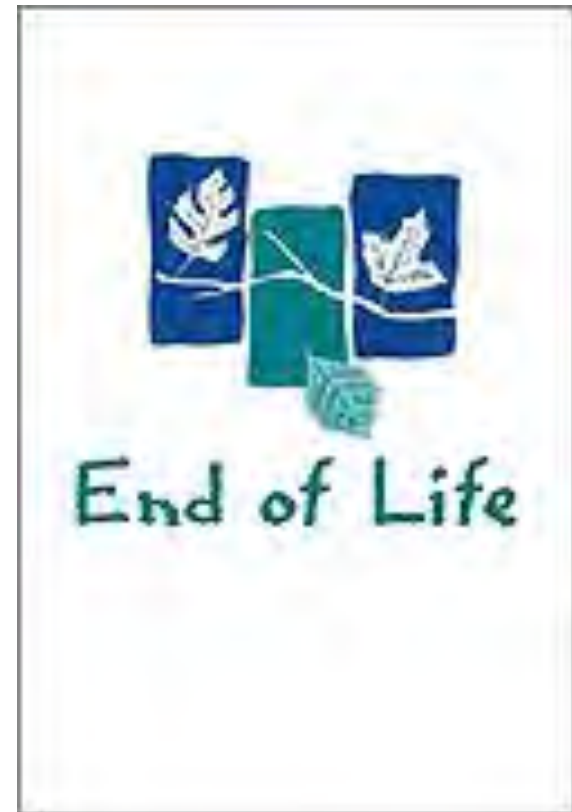


# For More Resources

Symposium Presentations,  
Resolutions, References,  
Fact Sheets and Reports:

APA webpage on End of  
Life Care:

<http://www.apa.org/pi/aging/programs/eol/index.aspx>





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Discussant, “Psychologists and End of Life: Report from the APA Working Group on End of Life Issues and Care”

William E. Haley, PhD  
University of South Florida



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# Discussant

William E. Haley

## My goals

- Brief mention of key elements of the presentations
- Other challenges

# Discussant

William E. Haley

My compliments!

- 1. Werth, History
- 2. Allen & Carpenter, Training and Research
- 3. Gill & Goy, Diversity
- 4. Kasl-Godley & Shead, Practice
- 5. Lyon, Policy

# Palliative Care

Therapy with  
Curative Intent

Hospice

Bereavement  
Care

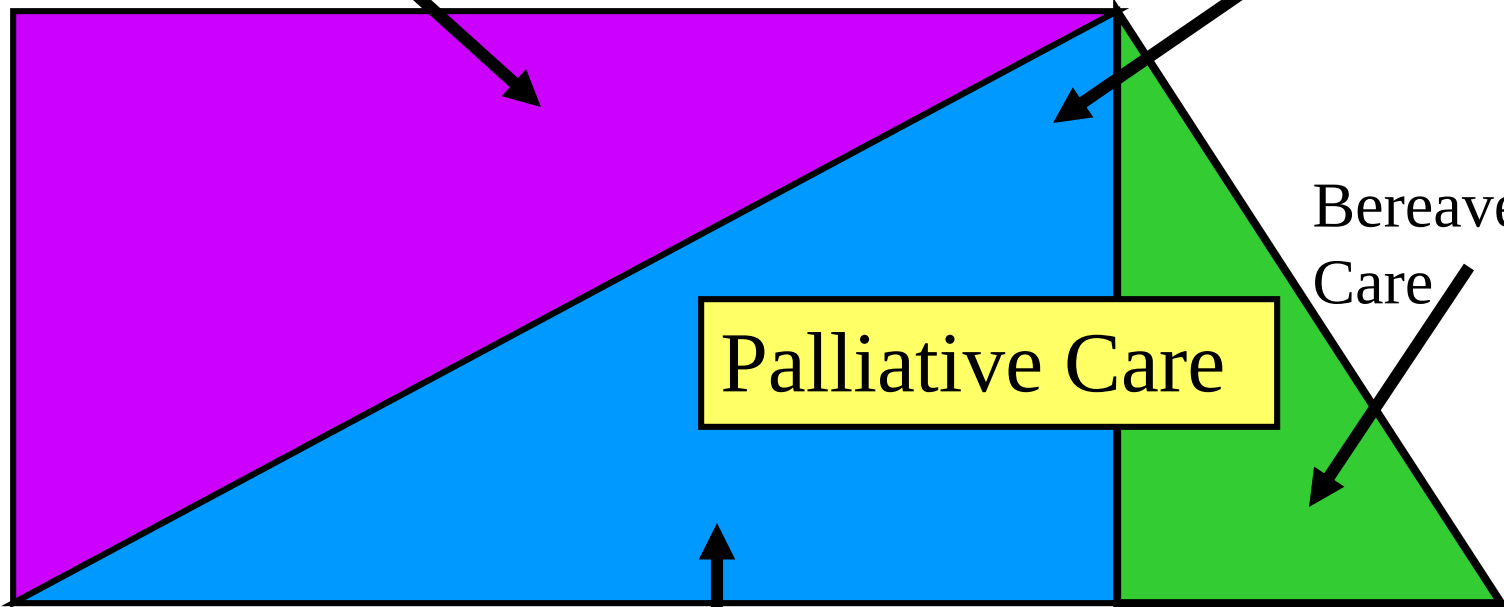
Palliative Care

Presentation

6m

Death

Symptom Rx Supportive Care



# Discussant

William E. Haley

## Other issues

- National Hospice and Palliative Care Organization
- Will psychologists be welcomed as additional providers?

## ENTRY POINT

Advance Care Planning With  
Alzheimer's — *Rebecca Gale*

## NARRATIVE MATTERS

Helping My Mother Die On Her Own  
Terms — *Dina Keller Moss*

## GRANTWATCH

Foundation Funding For Palliative &  
End-Of-Life Care — *Lee L. Prina*

AT THE INTERSECTION OF HEALTH, HEALTH CARE, AND POLICY

# Health Affairs

## Advanced Illness & End-Of-Life Care

## Evolving Care Patterns At The End Of Life

*Melissa D. Aldridge &  
Elizabeth H. Bradley*

PLUS *Profile Of 2.3 Million  
US End-Of-Life Caregivers*  
*Katherine Ornstein et al.*

Page 1175

## Quality Of Care

Quality In Community-Based  
Settings

*Joan M. Teno et al.*

Measuring Quality For Cancer  
Patients In Belgium

*Robrecht De Schreye et al.*

Page 1227

## One In Three US Adults Has An Advance Directive

*Kuldeep N. Yadav et al.*

PLUS *Understanding &  
Respecting Patients'  
Preferences*

*Amber E. Barnato*

Page 1244

## Global Evidence

Care, Spending & Site Of Death  
In Europe & Israel

*Martina Orlovic et al.*

End-Of-Life Spending In 9 Countries

*Eric B. French et al.*

Economic Disparities In England

*Brendan Walsh & Mauro Laudicella*

Page 1201

## Hospice

Increasing Veterans' Hospice Use

*Susan C. Miller et al.*

Profit Margins & Hospice Discharges

*Rachel Dolin et al.*

Racial Disparities In Hospice Care

*Rebecca Anhang Price et al.*

Page 1274

## A National Strategy For Palliative Care

*Diane E. Meier et al.*

PLUS *Improving  
Communication In Primary  
Care*

*Joshua R. Lakin et al.*

Page 1265

## Spending On High-Cost Dual Eligibles

*Julie P. W. Bynum et al.*

Page 1309

## WEB FIRST

## Health Spending By State, 1991-2014

*David Lassman et al.*

## Disparities In Medicare Advantage Readmissions

*Yue Li et al.*

# Discussant

William E. Haley

## CONCLUSION

- Three cheers for the Working Group!
- Suggest greater attention to bereavement
- Watch out for interprofessional challenges in hospice, NHPCO
- Strive for higher impact in our scholarship

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