Appendix IV: Scoping Review

The NCP Guidelines includes a selected bibliography of articles identified in a scoping review designed to identify resources to support the recommendations and conclusions in this document. Concurrently with the review of this document a systematic review to accompany the NCP Guidelines was completed.

As a result, the bibliography in this document is in no way comprehensive. It is a list of selected citations from a variety of journals organized by domain and topic. In addition to the eight domains, the literature review focused on:

- Pediatric palliative care
- Bereavement and grief

The literature review also focused on the six key themes:

1. Comprehensive assessment
2. Caregiving
3. Care coordination
4. Care transitions
5. Culture
6. Communication

Both qualitative and quantitative studies are included, as well as published consensus statements, expert opinions, and statements from professional organizations.

Scoping Review Methodology

This systematic review used Academic Search Complete, AgeLine, Alt. HealthWatch, CINAHL Complete, Health Source: Consumer Edition; Health Source: Nursing/Academic Edition, MEDLINE, PsychArticles, Psychology and Behavioral Science Collection, PsychInfo, and Social Work Abstracts databases to search for evidence-based literature across the eight domains as listed within the Clinical Practice Guidelines for Quality Palliative Care, 3rd edition.

This database search was limited to peer-reviewed journal articles published between January 1, 2007 and September 17, 2017. All searches were conducted using the following search terms in exact string order: “palliative care or end of life care or terminal care or dying or advanced illness or serious illness” and “united states or us.” A total of 21,533 articles were identified across all eight domains and the three additional searches using the search terms defined below.

Domain 1: Structure and Processes of Care

The initial search on the structure and processes of care was conducted using various search term iterations to gather literature related to cross-cutting themes within this domain, including: “structure,” “culture,” “access to care,” “education,” “interdisciplinary,” “finance,” “quality,” “workforce,” “triggers,”
Appendix IV: Scoping Review

"population health," "communication," and "education." Upon removal of duplicate articles, a total of 2,436 separate titles and abstracts were retrieved for further review.

A subsequent search for domain, structure and process of care, was conducted using the following search terms in exact string order: “palliative care or end of life care or terminal care or dying or advanced illness or serious illness” and “united states.” Various search term iterations were used to gather literature related to cross-cutting themes within this domain, which include: “rural,” "urban," “interdisciplinary,” and “pediatric.” Upon removal of duplicate articles and screening of titles and abstracts, a total of 129 separate articles were retrieved for inclusion.

Domain 2: Physical Aspects of Care

The physical aspects of care search included the following search terms to gather literature related to cross-cutting themes within the domain, including: “cultur*1,” “symptom,” “communication,” “pain,” “activities of daily living or ADLs,” “illness or disease or syndrome or condition,” “dementia,” “heart failure,” “pulmonary,” “cancer,” “ALS,” “Parkinson’s,” “stroke,” “kidney,” “liver,” “frailty,” “assessment,” “care goals,” and “care plan.” An asterisk symbol was placed at the end of “cultur” to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,522 separate titles and abstracts were retrieved for further review.

Domain 3: Psychological and Psychiatric Aspects of Care

An initial search on psychological and psychiatric aspects of palliative care was conducted using various search term iterations to gather literature related to cross-cutting themes within this domain, including: “cultur*1,” “depression,” “communication,” “dementia,” “delirium,” “anxiety,” “hopelessness,” “behavioral disturbances,” “substance use disorder,” “PTSD or post-traumatic stress disorder,” “post-illness psychosis,” “dual diagnosis,” “psychiatric,” “grief or bereavement,” “aid in dying or assisted suicide or euthanasia or hasten death,” “suicide,” “disability,” “assessment,” “care goals,” and “care plan.” An asterisk symbol was placed at the end of “cultur” to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,336 separate titles and abstracts were retrieved for further review.

Domain 4: Social Aspects of Care

The social aspects of care literature search included the following cross-cutting terms relevant to this domain, including: “psychosocial,” “cultur*,” “communication,” “family systems theory,” “social determinants of care or social determinants of health,” “loneliness,” “social work*,” “empathy,” “motivational interviewing,” “assessment,” “care goals,” and “care plan.” An asterisk symbol was placed at the end of “social work” to broaden the search by finding words that start with the same root respectively (eg, social worker, social working). Upon removal of duplicate articles, a total of 1,715 separate titles and abstracts were retrieved for further review.

Domain 5: Spiritual, Religious, and Existential Aspects of Care

The first search related to content in the spiritual aspects of care domain included selected search terms, including: “spiritual,” “cultur*,” “communication,” “religious or religion or religiosity,” “existential,” “beliefs,” “values,” “chaplain or clergy or spiritual caregiver,” “assessment,” “care goals,” and “care

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1 Where indicated, an asterisk symbol was placed at the end of the search term to broaden the search by finding words that start with the same root (eg, cultural, culture, cultures, social worker).
Appendix IV: Scoping Review

An asterisk symbol was placed at the end of “cultur” to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,393 separate titles and abstracts were retrieved for further review.

A subsequent search was conducted to capture other topics relevant to the domain content: “chaplain,” “chaplaincy,” and “spiritual care.” Upon removal of duplicate articles, a total of 348 separate titles and abstracts were retrieved for further review.

**Domain 6: Cultural Aspects of Care**

An initial search on the cultural aspects of care was conducted using the following search terms: “cultural,” “cultur*,” “communication,” “intersectionality,” “transcultural,” “cultural humility,” “culturally inclusive,” “radical respect,” “competence,” “disparities,” “race or racial or race or ethnicity,” “socioeconomic status,” “gender identity or sex,” “sexual orientation,” “sexuality,” “interpreters or medical interpreters,” “immigrant,” “cultural brokers,” “language,” “literacy,” “assessment,” “care goals,” and “care plan.” An asterisk symbol was placed at the end of “cultur” to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 3,103 separate titles and abstracts were retrieved for further review. An additional 16 articles were identified after a hand-checked review of references by the writing dyad following the initial database search.

**Domain 7: Care of the Patient Nearing the End of Life**

An initial search specific to Domain 7 was conducted to gather literature related to cross-cutting themes within this domain, including: “hospice,” “cultur*,” “communication,” “eligibility,” “comfort measures,” “prognosis or prognostication,” “hope,” “life closure,” “terminal illness,” “terminal sedation or palliative sedation,” “advance care planning or advanced directive,” “POLST or physician orders for life sustaining treatment,” “aid in dying or assisted suicide or euthanasia or hasten death,” “funeral,” “assessment,” “care goals,” and “care plan.” An asterisk symbol was placed at the end of “cultur” to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,739 separate titles and abstracts were retrieved for further review.

**Domain 8: Ethical and Legal Aspects of Care**

The search related to ethical and legal aspects of care included the following search terms: “ethics or ethical principles,” “cultur*,” “communication,” “legal,” “decisional capacity,” “cognitively impaired,” “consent,” “shared decision making,” “safety or risks,” “disability,” “futile care,” “advanced care planning,” “aid in dying or assisted suicide or euthanasia or hasten death,” “assessment,” “care goals,” and “care plan.” An asterisk symbol was placed at the end of “cultur” to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,336 separate titles and abstracts were retrieved for further review.

**Additional Searches**

Additional searches were conducted to retrieve articles within the following content areas: pediatrics, care transitions and coordination of care, and grief, bereavement and survivorship. These searches were conducted using the same databases and inclusion criteria as in the aforementioned eight domains.
Appendix IV: Scoping Review

**Pediatrics**

The pediatrics search focused on the following content areas: “pediatrics,” “neonatal,” “grief,” and “care coordination.” Upon removal of duplicate articles, a total of 118 separate titles and abstracts were retrieved for further review.

**Care Transitions and Coordination of Care**

The literature search related to care transitions and coordination of care focused specifically on these two content areas within the context of palliative care: “care transitions” and “care coordination.” Upon removal of duplicate articles, a total of 261 separate titles and abstracts were retrieved for further review.

**Grief, Bereavement, and Survivorship**

An initial search on grief, bereavement, and survivorship was conducted to explore the differences between grief and bereavement and review the literature related to survivorship. The following terms were included: “grief,” “bereavement,” and “survivorship.” Upon removal of duplicate articles, a total of 1,097 separate titles and abstracts were retrieved for further review.

**Review and Inclusion Process**

A three-stage review process was used to determine whether or not articles were included in the final bibliography. During the first-stage, all titles and abstracts were reviewed for relevancy based on the article title. During the second stage, abstracts of the remaining articles were read. At the third-stage, writers requested articles to review to determine if the article was applicable to the domain content.

**Domain 1: Structure and Processes of Care**

**Access**


Jones BW. The need for increased access to pediatric hospice and palliative care. *Dimens Crit Care Nurs*. 2011;30(5):231-235.


Appendix IV: Scoping Review

Meier DE. Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Quarterly*. 2011;89(3):343-380.


**Communication**


Appendix IV: Scoping Review


Appendix IV: Scoping Review


Culture


Appendix IV: Scoping Review

Shreve, S. Hospice and palliative care by the VA, beyond the VA. Generations. 2010;34(2), 49–56.


Decision-Making


Appendix IV: Scoping Review


Education

Nurse


Appendix IV: Scoping Review

Physician


Appendix IV: Scoping Review

Social Work


Pharmacist


Interdisciplinary Education


Appendix IV: Scoping Review


Finances and Cost


Appendix IV: Scoping Review


Hospice


Teno J, Casarett D, Spence C, Connor S. It is “Too Late” or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. J Pain Symptom Manage. 2012;43(4):732-738. doi:10.1016/j.jpainsymman.2011.05.012.

Palliative Care


Appendix IV: Scoping Review


Meier DE, Issacs SL, Hughes RG. *Palliative Care Transforming the Care of Serious Illness.* New York: Jossey Bass; 2010.


Appendix IV: Scoping Review


Populations

Geriatrics


Pediatrics


Appendix IV: Scoping Review


Jones BW. The need for increased access to pediatric hospice and palliative care. Dimens Crit Care Nurs. 2011;30(5):231-235.


Appendix IV: Scoping Review


**Professional Educational Resources**

**Hospice**


**Medicine**


**Nursing**

Appendix IV: Scoping Review

**Core Curriculum for the Hospice and Palliative Administrator.** Pittsburgh, PA: Hospice and Palliative Nurses Association; 2010.

**Core Curriculum for the Long-Term Care Nurse.** Pittsburgh, PA: Hospice and Palliative Nurses Association; 2012.

**Core Curriculum for the Licensed Practical/Vocational Nurse.** Pittsburgh, PA: Hospice and Palliative Nurses Association; 2010.


**Study Guide For The Licensed Practical/Vocational Hospice And Palliative Nurse.** Revised ed. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2010.

**Social Work**


Appendix IV: Scoping Review

Quality and Outcomes


Appendix IV: Scoping Review


Quality of Life

Appendix IV: Scoping Review


Pizzo P. Thoughts about dying in America: Enhancing the impact of one’s life journey and legacy by also planning for the end of life: Table 1. Proceedings of the National Academy of Sciences. 2016;113(46):12908-12912. doi:10.1073/pnas.1614266113.


Appendix IV: Scoping Review


**Research**


**Settings of Care**

**Emergency Department**


**Intensive Care Unit**


Appendix IV: Scoping Review


Long-Term Care


Appendix IV: Scoping Review


Outpatient


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Technology


Volunteers


Domain 2: Physical Aspects of Care

Illness/Conditions

Cancer


Appendix IV: Scoping Review


Appendix IV: Scoping Review


Dementia

Appendix IV: Scoping Review


Heart Failure


Appendix IV: Scoping Review


Appendix IV: Scoping Review

Wingate S, Bain KT, Goodlin SJ. Availability of data when heart failure patients are admitted to hospice. *Congest Heart Fail.* 2011;17(6):303-308.

## Pulmonary Conditions


Appendix IV: Scoping Review


Other


Appendix IV: Scoping Review


**Physical Aspects**


**Symptoms**

**General**


Appendix IV: Scoping Review


Dyspnea


Appendix IV: Scoping Review


Nausea


Pain


Appendix IV: Scoping Review


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Other


Appendix IV: Scoping Review

Domain 3: Psychological and Psychiatric Aspects of Care


Anxiety


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**Assessment Communication**


Beach, PR, White BE. Applying the evidence to help caregivers torn in two. *Nursing*. 2017;45(6): 30-37.


Appendix IV: Scoping Review


Appendix IV: Scoping Review


**Delirium**


**Depression**


Appendix IV: Scoping Review


Appendix IV: Scoping Review

Grief


Mental Health


Other Psychological Symptoms

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Domain 4: Social Aspects of Care


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Domain 5: Spiritual, Religious, and Existential Aspects of Care


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Medical Student Section. Addressing Patient Spirituality in Medicine, American Medical Association Resolution 2016, Resolution 004.


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Appendix IV: Scoping Review


Domain 6: Cultural Aspects of Care


Appendix IV: Scoping Review


Appendix IV: Scoping Review


Appendix IV: Scoping Review


Evans B, Ume E. Psychosocial, cultural, and spiritual health disparities in end-of-life and palliative care: Where are we and where do we need to go. *Nurs Outlook.* 2012;60(6):370-375.


Appendix IV: Scoping Review


Appendix IV: Scoping Review


Appendix IV: Scoping Review


Appendix IV: Scoping Review


Reese D. University-community-hospice partnership to address organizational barriers to cultural competence. *Am J Hosp Palliat Care*. 2011;28(1).


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Appendix IV: Scoping Review


Domain 7: Care of the Patient Nearing the End of Life


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Appendix IV: Scoping Review


Appendix IV: Scoping Review


Teno J, Casarett D, Spence C, Connor S. It is “Too Late” or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. *J Pain Symptom Manage* 2012;43(4):732-738. doi:10.1016/j.jpainsymman.2011.05.012.


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Bereavement


Appendix IV: Scoping Review


Domain 8: Ethical and Legal Aspects of Care

Advance Care Planning


Blinderman CD, Krakauer EL, Solomon MZ. Time to revise the approach to determining cardiopulmonary resuscitation status. *JAMA.* 2012;307(9):917-918.
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Appendix IV: Scoping Review


Kon AA. The shared decision-making continuum. *JAMA.* 2010;304(8):903-904.


Appendix IV: Scoping Review


**Care Coordination**


Appendix IV: Scoping Review


Communication


Ethics


Appendix IV: Scoping Review


Legal


Appendix IV: Scoping Review


Endnote