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Provider-Prioritized Domains of Quality in Pediatric Home-Based Hospice and Palliative Care: A Study of the Ohio Pediatric Palliative Care and End-of-Life Network

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Abstract

Background: Children receiving hospice and palliative care (HPC) differ from adults in important ways. Children are more likely to have rare diagnoses, less likely to have cancer, have longer lengths of stay on hospice, and are more likely to be technology dependent than adults. The National Consensus Project (NCP) in Palliative Care established domains of quality for HPC, but these domains have not been evaluated for applicability in children.

Objectives: This study aims to establish consensus stakeholder-prioritized domains of high-quality pediatric home-based hospice and palliative care (HBHPC).

Design: Mixed methods design.

Setting/Subjects: Providers from the Ohio Pediatric Palliative Care and End-of-life Network.

Measurements: Using a modified Delphi technique, providers were surveyed regarding the NCP quality domains for HPC.

Results: There was strong consensus on the applicability of each domain to the participants' practices (median scores ranged from 0.97 to 1.0 with interquartile ranges=0). Consensus on the rank importance of the eight domains was not achieved. Qualitative data included challenges with NCP domain 3 (Psychological and Psychiatric Aspects of Care). It was recommended that titles should remain consistent with adult standards, but domain definitions should be broadened for pediatric HBHPC. Continuity and coordination of care should be added as a ninth domain of quality in pediatric HBHPC.

Conclusions: All eight NCP domains were validated in pediatric HBHPC. A ninth domain, Continuity and Coordination of Care, was also added. Ranking the domains was not recommended as consensus indicated weighting them as equally integrated standards. Future studies are needed to evaluate parent- and patient-prioritized domains of quality in pediatric HBHPC and to validate and map pediatric-specific indicators to these domains.

Keywords: domains; home-based hospice and palliative care; pediatric palliative care; quality

Introduction

HOSPICE CARE is considered the standard of quality compassionate care for people facing life-limiting illnesses. Many of the 43 thousand children who die annually in the United States are eligible for hospice care, but the traditional adult hospice model was neither designed for nor influenced by the needs of children. Studies indicate that the

few children who do receive hospice care are a unique population, with different needs than adults who receive hospice care. In the largest review of children enrolled in hospice care, based on data from the CHOICE network of hospices, a remarkable 42.6% of hospice enrollment diagnoses for children were encountered only once during the four-year interval studied. This diversity presents unique challenges to hospice agencies which already lack access to pediatric

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specialists.¹ Children are more likely to revoke hospice care at least once, but among those who remain on hospice, children are more likely to die at home than adults.^{1,2} Finally, children have significantly longer lengths of stay on hospice than adults, which may be related to the unpredictable nature of life-limiting conditions in children.^{1,2} This highlights the notion that adult hospice rules, based on specific prognostic factors, are inappropriate when applied to children. Despite these differences, quality guidelines for hospice and palliative care (HPC) were developed primarily for adult patients and do not adequately consider the children receiving HPC.³

In Ohio, a state whose demographics are representative of the broader U.S. population, amany children with life-limiting diseases are cared for by specially designed in-home pediatric palliative care (PPC) programs based in pediatric institutions, while others are cared for by traditional adult-oriented hospice agencies. Indeed, home-based PPC is a growing "field within a field" of PPC, with emerging evidence that children enrolled in such programs experience improved quality of life, reduced length of stay, and decreased costs related to inpatient admissions, and are more likely to die at home. Thus, the term "home-based hospice and palliative care" (HBHPC) encompasses children with life-limiting illness who are cared for at home, not just those who receive traditional hospice care.

The National Consensus Project (NCP) for Quality Palliative Care first met in 2001 to discuss standardization of PC, with the goal of improving the quality of care provided to patients and families.³ The Clinical Practice Guidelines for Quality Palliative Care were published in 2001 and have been revised twice, in 2009 and 2013. The NCP Guidelines include eight domains, described in Table 1.³ Although the 2013 revision mentions that neonates, children, and adolescents with certain conditions should be considered for PC, this was the first time that children were specifically mentioned in these guidelines. In addition, the 2013 task force did not include patients, parents, or caregivers of children receiving HPC and included only one pediatrician.

Pediatric HPC providers lack both pediatric-centered guidelines for high quality care and infrastructure to monitor quality of HBHPC across pediatric institutions and agencies. No single pediatric institution or organization serves enough children to accomplish generalizable research in this field; therefore, multi-institutional studies are required to enroll sufficient participants to ask and answer meaningful questions. The Ohio Pediatric Palliative Care and End-of-life Network (OPPEN) is a coalition of pediatric HPC providers from across the Ohio region. OPPEN members include HPC physicians, nurses, nurse practitioners, administrators, social workers, chaplains, child life specialists, music therapists, pharmacists, and holistic health therapists. In addition, six pediatric tertiary-care hospitals are represented: Akron Children's Hospital, Cleveland Clinic Children's Hospital,

Rainbow Babies and Children Hospital, Dayton Children's Hospital, Nationwide Children's Hospital, and Cincinnati Children's Hospital Medical Center. OPPEN provides the unique opportunity to leverage infrastructure of multiple pediatric HPC programs for research efforts in PPC.

In this study, we sought to establish provider-prioritized domains of quality in pediatric HBHPC. This mixed-methods study aimed to establish consensus stakeholder-prioritized domains of high-quality pediatric HBHPC amongst OPPEN members. The primary hypothesis was that the eight NCP domains of quality palliative care would need to be modified or augmented for applicability for children receiving HBHPC.

Methods

This modified Delphi study was submitted to the Cincinnati Children's Hospital Medical Center Institutional Review Board and deemed exempt from IRB review (Study ID 2016-1354). In the spring of 2016, the 63 members of the OPPEN e-mail listserve were surveyed using a web-based platform (RedCap).

The survey (Appendix 1) first introduced domains of care previously identified by the NCP of the National Quality Forum.³ Participants were asked to reflect on these domains in the context of pediatric HBHPC. The first questions inquired whether any domains of high-quality care that are important in HBHPC were absent from these lists. Panelists were asked to list any missing domains and explain their reasoning. They were then asked to rank domains of care that are the most important in the delivery of patient and familycentered HBHPC, based on the initial list of NCP domains, in addition to any free-text responses. Participant location (city), primary location of practice (i.e., academic hospital, private hospital, freestanding hospice), and professional role (e.g., physician, social worker) were collected to ensure a heterogeneous group of participants. Survey results were analyzed by the research team using qualitative and quantitative methodology to identify group consensus and minority opinions. Interquartile ranges were calculated to identify the rank order of domains.

The next round was conducted using a nominal group technique with panelists at the OPPEN meeting in April, 2016. The list of remaining domains, their ratings, minority opinions, and items achieving consensus was distributed to panelists. Participants reflected upon their responses in relation to the group. The facilitator (RT) asked one participant at a time to state a single thought to the group, regarding agreement or disagreement, in a round-robin manner, and ideas were recorded on a flip chart. Deveryone was given the opportunity to voice ideas, going around the room in order, until no new ideas were generated. Results of final voting were presented to the group for reflection and were

Table 1. Summary of Ranges According to Different Aspects of Care

	Structure and process	Physical	Psychological and psychiatric	Social	Spiritual and religious	Cultural	End of life	Ethical and legal
Median (range) IQR	3.5 (1–8)	1.5 (1–7) 1	3 (1–8) 2.75	4 (1–7) 1.75	5 (2–8) 2	6 (1–8)	5 (1–8) 3	7 (3–8)

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considered the consensus opinion regarding providerprioritized domains of high quality care in pediatric HBHPC.

Results

A total of 20 OPPEN members (32% response rate) participated in the first survey. The group was composed of physicians (n=11; 55%), nurses/nurse practitioners, (n=5, 25%), and Other (Social worker, bereavement coordinator, child life specialist, and pharmacist, n=4; 20%). The majority were from academic hospital systems with affiliated homecare or hospice programs (n=14; 70%); also represented were Not-for-Profit Hospices (n=5; 25%) and Other (Hospice pharmacy organization, n=1, 5%).

There was strong consensus on the applicability of each domain to the participants' practice (median scores ranged from 0.97 to 1.0 with interquartile ranges = 0). The results from the rank ordering of domain importance are presented in Table 1. Consensus on the rank importance of the eight domains, determined by having an interquartile range <1.0, was not achieved at this stage. Qualitative data included challenges with NCP domain 3 (Psychological and Psychiatric Aspects of Care), with three participants commenting that psychiatric assessments are lacking, partially due to the lack of psychiatric staff. These participants noted that psychosocial assessments were completed, but those requiring evidence-based screening or assessment for Diagnostic and Statistical Manual of Mental Disorders-Version V (DSM-V) diagnoses were not. One participant noted challenges in confirming if their team was meeting the social and cultural needs of the patient and family (NCP domains 4 and 6). Several potential additional domains were named for future consideration, including: bereavement, memory making, and legacy building; care of teams and staff involved in pediatric palliative care patients and families; community-based structures, processes, training, and readiness; financial/economic; and continuity and coordination of care.

The next round was conducted using a nominal group technique of panelists at the OPPEN meeting in April, 2016. A total of 14 OPPEN members participated in the panel; 7 (50%) had also participated in the survey. This group was primarily composed of physicians (n=7, 50%; RN/DNP n=4, 26%; SW n=2, 14%; layperson n=1, 7%; pharmacist n=1, 7%). The rank order of the eight NCP domains was discussed at length. The consensus was that ranking the domains in importance was possibly detrimental to the field and could, during budget cuts or in under-resourced programs, lead to lower ranked domains being cut. In addition, different families may rank domains differently. Therefore, placing the list in a rank order was felt to be less important than identifying a broad list of domains that fully encompasses high-quality care in pediatric HBHPC.

The possible need for changing domain titles was also discussed. The panel determined that titles should remain consistent with adult standards, but that domain definitions should be broadened for use in pediatric HBHPC. Finally, the list of potential additional domains listed above was discussed. The panel's consensus was that each additional topic fit was within at least one of the eight existing NCP domains, with the exception of continuity and coordination of care, which should be added as a ninth domain of quality in pediatric HBHPC.

Discussion

We found consensus for face and content validity for the eight NCP domains, as currently titled for use in pediatric HBHPC. In addition, a ninth domain with face and content validity was added through consensus: Continuity and Coordination of Care. A primary goal of PPC, in addition to improving quality of life for the child and the family, is to provide "continuity of care that bridges different events and care locations." In their report on PPC, the American Academy of Pediatrics specifically recommended in 2000 that PPC programs ensure that care is seamless across all settings, with continuity and consistently of caregivers of multiple disciplines.11 Pediatric HBHPC has been found to reduce total hospital length of stay, with speculation that the benefit of PPC and hospice care may result from improved care coordination, resource management, and technology avoidance while patients are admitted. While continuity of care is an important aspect of care for both adult and pediatric providers, it had not previously been highlighted as its own domain of quality in PC.

It is estimated that as many as five million children are living with life-threatening illnesses in the United States. 12 Children receiving HBHPC frequently live with complex chronic conditions, which require resource-intensive care. Pediatric hospice enrollees are significantly more likely to be technology dependent and to live longer on hospice, compared to adults. 1,2 It follows, then, that in addition to PC, general/complex care pediatrics, programs supplying durable medical equipment (DME), and multiple teams such as neurology, gastroenterology, and pulmonology are routinely involved in the care of these children. Care coordination is tailored to the needs of each unique family, but may include assistance with medication refills, arranging DME for home use, scheduling care conferences with multiple teams, and communicating goals of care with all providers. Coordinating the child's care among these teams frequently falls on the primary caregiver or the medical home. HBHPC teams who follow patients longitudinally and across healthcare settings are well positioned to relieve some of this burden.

This study specifically examined domains of quality for HPC provided in a child's home and did not seek to examine HPC provided in a hospital or ambulatory setting. Other literature describes "community-based pediatric palliative care programs (CBPPC)," which are "provided outside of the hospital setting with the goal of offering PPC resources and services in private residences, community-based clinics or settings" and which "provide continuity of care for patients who journey between inpatient and outpatient settings, optimizing quality of life across the care continuum." Many of the pediatric-specific HBHPC programs in OPPEN provide care in the ambulatory setting, as well as at home; practically, we understand HBHPC and CBPPC to be similar care models. Therefore we believe that the domains of quality identified in this study would be applicable to CBPPC programs, as well as to hospices caring for children. While there may be overlap in domains of quality among pediatric HBHPC, inpatient PPC, and ambulatory PPC, this study did not seek to evaluate care provided outside of the home. Further studies are warranted to evaluate how providers may define domains of quality in other settings. In addition, this study evaluated the perspectives of HBHPC providers and not those of caregivers or patients; future studies are also warranted to understand how caregivers and children define quality in HBHPC.

To our knowledge, this is the first study to leverage the infrastructure of a consortium of pediatric HPC providers for clinical research, the Ohio Pediatric Palliative Care and Endof-life Network (OPPEN). This study is uniquely strengthened by the breadth of professional roles and diversity of programs represented in OPPEN.

In the words of the NCP, "Quality is an underlying goal of palliative care." Ultimately, PPC providers seek to provide the highest possible quality of care to children in all settings. This is the first study to validate provider-prioritized domains of quality in PPC. Identifying these domains is the first step toward designing systems that will enable the provision of high-quality PPC to children in all settings while tailoring care to each unique child and family. Future studies should focus on caregiver and patient perspectives, identify validated pediatric outcomes within these domains, and identify patient-centered outcomes in pediatric HBHPC. Only then will PPC providers be able to map variation in care, create benchmarks, and improve the care provided to children receiving PPC in all settings.

Conclusions

The eight domains of quality identified by the NCP were validated by pediatric providers for use in pediatric HBHPC, and a new ninth domain was added: Continuity and Coordination of Care. Children receiving HBHPC are frequently medically complex, with multiple medical teams involved. HBHPC teams are well positioned to positively impact the continuity and coordination of care for these patients between medical teams and across medical settings. Ranking the domains was not recommended as the panel felt they should be considered as equally integrated standards. To our knowledge, this was the first study to leverage the infrastructure of a statewide PPC consortium in clinical research. Future studies are needed to fully define each of these nine domains specifically for pediatrics, to evaluate parentand patient-prioritized domains of quality in pediatric HBHPC, and to map indicators validated in pediatrics to these domains.

Author Disclosure Statement

No competing financial interests exist.

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APPENDIX 1. STAKEHOLDER-PRIORITIZED DOMAINS OF QUALITY FOR HOME-BASED PALLIATIVE AND END-OF-LIFE CARE:
A SURVEY OF THE OHIO PEDIATRIC PALLIATIVE AND END-OF-LIFE NETWORK

Background

"Domains" of care are broadly defined as areas within which to develop outcome and process measures for palliative care and hospice programs. In 2013 the National Consensus Project (NCP) for Quality Palliative Care, a task force, including membership from the American Academy of Hospice and Palliative Medicine (AAHPM), Center to Advance Palliative Care (CAPC), Hospice and Palliative Nurses Association (HPNA), National Hospice and Palliative Care Organization (NHPCO), National Association of Social Workers (NASW), and National Palliative Care Research Center (NPCRC), published the third edition of "Clinical Practice Guidelines for Palliative Care". This document describes core concepts and structure for quality palliative care, including eight domains of practice.

"Indicators" are specific tools that quantitatively assess specific healthcare structures, processes, or outcomes. The eight domains of care identified by the NCP were utilized by the Measuring What Matters Campaign, a consensus project of the AAHPM and HPNA, which aimed to recommend a concise portfolio of valid, clinically relevant crosscutting indicators for internal measurement of HPC. The Measuring What Matters (MWM) campaign identified ten indicators that mapped to five of the domains of care identified in the NCP guidelines. These indicators were published in 2015.

Neither the NCP domains nor the MWM indicators were designed specifically for pediatric palliative and hospice care, and neither has been evaluated by pediatric providers in our field. Therefore, the primary goal of this project is to evaluate the following: How appropriate are the domains of care identified by the NCP in pediatric home-based palliative and end-of-life care? The secondary goal is to identify any other domains of care that may be absent from the NCP domain set. Future studies will focus on mapping indicators to the domains identified in this project.

The primary goal of this project is to evaluate the following: How appropriate are the domains of care identified by the NCP in pediatric home-based palliative and end-of-life care? The secondary goal is to identify any other domains of care that may be absent from the NCP domain set. Future studies will focus on mapping indicators to the domains identified in this project.

Participation in this study is completely voluntary and Ohio Pediatric Palliative Care and End-of-life Network (OPPEN) membership will not be impacted by study participation. You may discontinue participation at any time without penalty. Your responses to this survey will only be viewed by members of the Cincinnati Children's study team. This study is considered to be minimal risk with no direct benefit to participants. If you have any questions regarding the study, please contact Rachel Thienprayoon, MD at 972-839-7997. If you have general questions about your rights as a research participant, or questions, concerns, or complaints about the research, you can call the Cincinnati Children's Hospital Medical Center Institutional Review Board at 513-636-8039.

Completing this survey serves as your consent to participate in this study. This survey should take about 20 minutes.

Section I. Demographic Information

- 1. What is your title?
 - Physician
 - Social worker
 - Chaplain
 - Nurse
 - Nurse practitioner
 - Child life/music therapy
 - Other (please specify)
- 2. In what setting do you primarily practice?
 - Academic hospital system, with affiliated home care or hospice program
 - Private hospital system
 - For profit hospice
 - Not-for-profit hospice
 - State agency
 - Other (please specify)
- 3. In what city/region do you primarily practice?
 - Akron
 - Cincinnati
 - Cleveland
 - Columbus
 - Dayton
 - Kentucky
 - Michigan
 - Other

Section II. NCP Palliative Care Domains and Measuring What Matters Campaign Indicators

If you would like to refer to the NCP Guidelines during the course of this survey, please click the following link to open in another window: www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf

Domain 1: Structure and Processes of Care

"Clinical Implications: Palliative care occurs across the health spectrum. It necessitates the involvement of an interdisciplinary team that is trained and supported to do the work. Care focuses on promoting the physical, psychological, social, and spiritual domains of quality of life. It is delivered in a safe environment with respect for the patient's and family's values, preferences, and wishes. The palliative care program strives for best practices inclusive of quality assessment and performance improvement."

- 4. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, is this domain applicable to the care you provided?
 - Yes
 - No
 - Unsure

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or you are unsure of whether this domain is applicable, in pediatric HBHPC?

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Domain 2: Physical Aspects of Care

"Clinical Implications: Physical comfort represents a core feature of compassionate care. Expert pain and symptom management sets the foundation of palliative care and promotes psychological, social, and spiritual quality of life."

- 5. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, is this domain applicable to the care you provided?
 - Yes
 - No
 - Unsure

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or you are unsure of whether this domain is applicable, in pediatric HBPELC?

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Domain 3: Psychological and Psychiatric Aspects of Care

"Clinical Implications: Psychological and psychiatric assessment and services occur systematically using evidence-informed screening, assessment tools, and interventions. Education for the patient, family, and staff is an essential element of management. Grief and bereavement services are fundamental aspects of palliative care for support staff, patients, and family. Services are appropriate to patients' and families' needs, goals, ages, culture, and level of development to reflect a multidimensional interventional strategy."

- 6. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, is this domain applicable to the care you provided?
 - Yes
 - No
 - Unsure

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or you are unsure of whether this domain is applicable, in pediatric HBPELC?

Domain 4: Social Aspects of Care

"Clinical Implications: Each patient and family has a unique social structure. Understanding the social fabric of the patient and family promotes coping. Interventions support the social structure, including culture, values, strengths, goals, and preferences. The assessment of social aspects of care is the responsibility of the interdisciplinary team,

which includes specialists in social aspects of care and pediatric populations."

- 7. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, is this domain applicable to the care you provided?
 - Yes
 - No
 - Unsure

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or you are unsure of whether this domain is applicable, in pediatric HBPELC?

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

"Clinical Implications: Spiritual, religious, and existential issues are a fundamental aspect of quality of life for patients with serious or life-threatening illness and their families. All team members are accountable for attending to spiritual care in a respectful manner. In order to provide an optimal and inclusive healing environment, each palliative care team member needs to be aware of his or her own spirituality and how it may differ from fellow team members and those of the patients and families they serve."

- 8. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, is this domain applicable to the care you provided?
 - Yes
 - No
 - Unsure

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or you are unsure of whether this domain is applicable, in pediatric HBPELC?

Domain 6: Cultural Aspects of Care

"Clinical Implications: Culture is a source of resilience for patients and families and plays an important role in the provision of palliative care. It is the responsibility of all members of the palliative care program to strive for cultural and linguistic competence to ensure that appropriate and relevant services are provided to patients and families."

- 9. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, is this domain applicable to the care you provided?
 - Yes
 - No
 - Unsure

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or 296 THIENPRAYOON ET AL.

you are unsure of whether this domain is applicable, in pediatric HBPELC?

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

"Clinical Implications: It is essential that the interdisciplinary team attends to the patient's and family's values, preferences, beliefs, culture, and religion to promote a peaceful, dignified, and respectful death."

- 10. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, is this domain applicable to the care you provided?
 - Yes
 - No
 - Unsure

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or you are unsure of whether this domain is applicable, in pediatric HBPELC?

Domain 8: Ethical and Legal Aspects of Care

"Clinical Implications: Ethical and legal principles are inherent to the provision of palliative care to patients with serious or life-threatening illness. Interdisciplinary team members must have an understanding of the central ethical principles underlying healthcare delivery in the context of their own professional practice setting and discipline. Palliative care teams must have access to legal and ethics expertise to support palliative care practice."

- 11. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, is this domain applicable to the care you provided?
 - Yes
 - No
 - Unsure

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or you are unsure of whether this domain is applicable, in pediatric HBPELC?

12. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their

families, over the *past six months*, please rank the importance of the following eight domains of care:

Structure and Processes of Care
Physical Aspects of Care
Psychological and Psychiatric Aspects of Care
Social Aspects of Care
Spiritual, Religious, and Existential Aspects of Care
Cultural Aspects of Care
Care of the Patient at the End of Life
Ethical and Legal Aspects of Care

If you answered No or Unsure, can you describe how or why you believe this domain is not applicable, or you are unsure of whether this domain is applicable, in pediatric HBPELC?

- 13. In considering pediatric patients you have cared for in home-based palliative and end-of-life care, and their families, over the *past six months*, are there any broad areas of care that you believe are absent from this list?
 - Yes
 - No

If no, please skip to #14 If yes, please list any domains you believe are absent here:

14. If you added any broad areas of care to the previous list, how do they rank in importance with the previous eight domains? Please re-rank the list here:

Structure and Processes of Care
Physical Aspects of Care
Psychological and Psychiatric Aspects of Care
Social Aspects of Care
Spiritual, Religious, and Existential Aspects of Care
Cultural Aspects of Care
Care of the Patient at the End of Life
Ethical and Legal Aspects of Care

We may send out an e-mail inviting you to participate in one additional follow-up survey. We will only send this survey to OPPEN members who participated in this current survey. Please provide us with your e-mail if you are willing to be contacted for one additional survey. You will receive the e-mail prior to the OPPEN meeting in April.
