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Defining 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: In 2017, the Ohio Pediatric Palliative Care and End-of-Life Network (OPPEN) published nine domains of high-quality care for pediatric home-based hospice and palliative care (HBHPC). Eight domains established by the National Consensus Project (NCP) were validated for pediatric HBHPC, and a ninth domain of ''Continuity and Coordination of Care'' was added.
Objective: The aim of this study was to establish definition criteria for each of these domains.
Design and Setting: Using a modified Delphi technique, providers from the OPPEN were surveyed regarding definitions drawn from the NCP domain criteria. For the ninth domain, new definition criteria were generated *de novo* based on qualitative responses.
Results: Definition criteria were established for the nine domains of quality in HBHPC previously identified. In the course of analysis, Bereavement Care was established as a 10th domain of quality, and definition criteria generated.
Conclusions: This is the first study to define domains of quality for pediatric HBHPC, and the second to leverage the infrastructure of a pediatric HPC statewide consortium toward this work. Future studies are needed to establish parent and patient-prioritized domains of quality in pediatric HBHPC, and to map indicators validated in pediatrics to these domains.

Keywords: home-based; hospice; palliative care; pediatrics; quality

Introduction

The National Consensus Project (NCP) for Quality Palliative Care defines palliative care (PC) as ''patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering.''[1] Children with life-limiting illnesses and their families require physical, emotional, and spiritual care from diagnosis through death and into bereavement. Pediatric hospice care differs significantly from the adult model of hospice care, designed to care for adults with a life expectancy of less than six months. Children who enroll with hospice are significantly less likely to have cancer and significantly more likely to use technology than adults on hospice.[2,3] Once enrolled, children also have significantly longer lengths of care in hospice than adults.[2,3] With the advent of new technologies, some previously fatal conditions have been transformed into chronic illnesses of childhood. Many of these children are eligible for home-based or community-based PC programs, focused on enhancing quality of life, for years before they would be eligible for the traditional model of hospice care. Thus, pediatric home-based hospice and palliative care (HBHPC) is an emerging subspecialized field within the broader umbrella of pediatric HPC, which also includes hospital-based PC programs and perinatal PC.

HBHPC differs meaningfully from inpatient, hospital-based palliative care. The constitution of the interdisciplinary teams is different: many home-based programs rely heavily

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on nurses with dedicated social work, child life, music therapy, and pastoral care, and less on physicians. Alternatively, many inpatient teams rely more heavily on physicians, social workers, and nurse practitioners, with ancillary services more commonly provided by the inpatient unit. Children at home may be relatively well for years before they approach the end of life or an acute event occurs; children in the hospital are acutely or chronically ill. Palliative plans of care developed longitudinally in the home versus acutely in the hospital reflect these contrasting circumstances. Thus, pediatric HBHPC is an organized multidisciplinary method of providing management of pain and symptoms, decision-making guidance, and spiritual and psychosocial care in the home. However, the development and implementation of high-quality pediatric HBHPC systems is difficult. Research is limited, and evidence-based quality improvement measures are lacking. Because no single pediatric institution or organization serves enough children to conduct generalizable research, multi-institutional studies are necessary. The Ohio Pediatric Palliative Care and End-of-Life Network (OPPEN) is a coalition of pediatric HPC providers across Ohio. The infrastructure of OPPEN is now being leveraged toward collaborative research in pediatric HPC, to include studies specific to pediatric HBHPC.

Until recently, quality guidelines for HPC were developed primarily for adult patients.[4] In 2001 the NCP for Quality Palliative Care developed their Clinical Practice Guidelines for Quality Palliative Care, with the goal of standardizing and improving the quality of care.[4] While the original guidelines did not address pediatric HPC, the 2013 revision mentions that neonates, children, and adolescents with certain conditions should be considered for PC. Yet the 2013 task force did not include patients, parents, or caregivers of children receiving HPC, and included only one pediatrician. In 2017, OPPEN took the first step toward providing quality domains specific to pediatric HBHPC, establishing nine domains of high-quality care for pediatric HBHPC.[5] These domains validated the eight NCP domains of quality HPC for applicability to children receiving HBHPC, and augmented them with the addition of a ninth domain of ''Coordination of Care.''[6]

This study is the next step in the development of these domains. The aim of this study was to establish definition criteria for the nine domains established by our earlier research using a modified Delphi technique.

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). As previously described,[5] the OPPEN email list includes pediatric providers of multiple professional roles from across the Ohio region. In the spring of 2017, OPPEN members were surveyed through email using a web-based platform (REDCap)[7] regarding definitions for the nine domains of quality HBHPC established previously[5] (Appendix 1). Survey results were analyzed by the research team using a modified Delphi technique with three iterations[8–10] to identify group consensus and minority opinions. In the first round, surveys were emailed to all OPPEN members using REDCap. Participants were asked to indicate their level of agreement with the definition of each domain on a four-point Likert-style scale ranging from ''completely disagree'' to ''completely agree,'' and, to describe any of the elements of the definition that were not applicable; what elements were missing from the definition; and what elements would better define or refine the definition for pediatric HBHPC. A 10th domain, Bereavement Care, was added after this round.

The second survey (Appendix 2) was sent three months later to resolve differences and evaluate criteria of the 10th domain. Participants were given the consensus list of ten domains and definitions, which had been revised based on feedback from the first round. Participants were asked to rank the importance of including specific criteria within each domain, using a seven-point Likert-style scale ranging from ''critical'' to ''not important.'' Participants were also asked the extent to which they believed that each of the defining criteria defined the domain as worded, using the same seven-point Likert-style scale. Medians and interquartile ranges were calculated for each response; IQR values of less than 2.5 were considered to indicate consensus. Free responses were analyzed qualitatively. The third round was conducted in a member-checking meeting utilizing a nominal group technique,[11,12] to identify consensus regarding qualitative responses and to resolve minority opinions. Specific methods have been described previously.[5] The meeting was performed with members of OPPEN in September of 2017. New ideas generated from that meeting were distributed through email to all OPPEN members in a final round and consensus was confirmed, after which the domains and criteria were considered finalized.

Results

A total of 22 providers participated in the first round of this study, 13 providers participated in the second round, 5 providers participated in the member-checking meeting and 6 members responded to the final email. Demographic information for each round is provided in Table 1. The need for Round 2 was to determine if consensus existed after free

TABLE 1. DEMOGRAPHIC INFORMATION OF STUDY PARTICIPANTS

	Round 1 (N=*22*)		*Round 2* (N=*13*)		*Round 3* (N=*5*)		*Final round* (N=*6*)	
Professional role	N	%	N	%	N	%	N	%
Physician	10	45.5	6	45.2	3	60.0	2	33.3
Nurse practitioner	5	22.7	2	15.4	1	20.0	1	16.7
Nurse	3	13.6	3	23.1	1	20.0	1	16.7
Chaplain	1	4.6	1	7.7				
Social worker	1	4.6	1	7.7			2	33.3
Nurse scientist	1	4.6						
Pharmacist	1	4.6						
Location of practice								
Academic hospital/ HBHPC program	16	72.7	8	61.5	5	100.0	6	100.0
Private hospital	2	9.1						
Nonprofit hospice	2	9.1	4	30.8				
University	1	4.6	1	7.7				
Hospice pharmacy	1	4.6						

HBHPC, home-based hospice and palliative care.

responses from Round 1 were integrated into the domains and defining criteria. An *a priori* decision had been made that the criteria for consensus (IQR <2.5) would not be revised after the Delphi process began. The consistency of scores between the first two rounds led to the decision to have the third round use a nominal group process to achieve consensus through discussion rather than a subsequent scored round. Appendix 3 provides median scores and interquartile ranges for the importance of each criteria and agreement with the criteria as worded. As wording changed between rounds, general topics are included for brevity rather than specific wording for each round. In Round 1, the results regarding criteria within the 10th domain of bereavement care refer to the wording of those criteria within other domains. Qualitative feedback drove the creation of the 10th domain, and the results of Round 2 are the responses to the criteria now within the domain of Bereavement Care.

In the final round of the study, 100% of respondents confirmed all criteria as worded. A glossary of terms explaining the rationale for using specific words or phrases in the final definitions, based on qualitative data generated in all rounds, is provided in Table 2. Domains and defining criteria, achieved after four rounds of the consensus-building process, are provided in Table 3.

Table 2. Glossary of Terms

HBHPC program	This term was intentionally chosen instead of IDT. It is used throughout the domain criteria for consistency. The HBHPC program includes traditional clinical members of the IDT (physicians, nurses, social workers, chaplains, and others) and also reflects those in leadership positions in the program, such as a hospice medical director, clinical director, nursing manager, and others, who may or may not regularly attend IDT meetings and/or see patients.
Shared decision making	This term reflects the inclusion of not only the HBHPC team members, but also the patient's primary providers and the child and family, in working together to develop the care plan.
Volunteers	Volunteers are required for hospice licensure and the term is thus carried over from the NCP domains. However, in the context of pediatric HBHPC programs, volunteers may require specific pediatric or homecare training and may be employed in different ways than in the traditional adult hospice model. This term is left vague for those reasons.
Relevant HBHPC outcomes	This term was chosen to reflect both those outcomes, which are evidence based, established in the field, and allow benchmarking, and those which are relevant to the pediatric HBHPC program stakeholders in specific programs.
Serious or life-threatening illnesses	This term was chosen over ''life-limiting illness'' to reflect that HBHPC is not limited to those children who are expected to die, but should be available to all children with serious illness. It also reflects that survival outcomes and prognoses in many areas of pediatrics are rapidly evolving as new technologies and therapies become available.
Child/children	For these purposes, ''child'' includes all people from the neonatal period through age 18. ''Patient'' as mentioned in the NCP criteria has been changed to ''child'' throughout this document.

NCP, National Consensus Project; IDT, interdisciplinary team; HBHPC, home-based hospice and palliative care.

Discussion

The aim of this study was to establish definition criteria for each of the nine domains of quality previously validated by OPPEN for pediatric HBHPC.[5] In the course of analysis, Bereavement Care was established as a 10th domain. These ten domains, and their definition criteria, form the basis of high-quality pediatric HBHPC. As previously described, this list is not rank ordered according to importance[5]; each of the domains is considered to be of equal significance in the care of children receiving HBHPC.

Domain 1: Structure and processes of care

These criteria, focusing on the structure of the HBHPC program, depart from the NCP criteria[4] in several ways. Most children who die with hospice are cared for by traditional adult hospice programs.[13] Yet pediatric hospice care is a distinct entity from adult hospice care. Children who die with hospice are significantly less likely to have cancer and significantly more likely to use technology than adults on hospice.[2] In a review of nearly 1000 pediatric hospice enrollees, 42.6% of hospice enrollment diagnoses were encountered a single time over the time interval studied.[2] In that same review, 97% of adult hospice enrollment diagnoses appeared more than once; thus, children in hospice care suffer from a remarkably diverse range of serious illnesses when compared with adults. Pediatric PC also fundamentally differs from adult PC in that it involves parents in decision making and is attentive to developmental differences as children grow and develop.[14] Pediatric PC providers are accustomed to caring for those children with rare and complex illnesses who are likely to need and use HBHPC. Pediatric PC providers are also skilled at navigating complex social situations and in coordinating care for children living with technology at home. For these reasons, the importance of including specialized pediatric HPC expertise in the care of these children not just once, but in an ongoing basis, is purposefully emphasized in the first criterion.

The American Academy of Pediatrics (AAP), in their statements about PC for children, emphasize that respect for the child means partnering with the child, in a developmentally appropriate way, to elicit the child's understanding of their illness and preferences for treatment.[15,16] The importance of involving the child in the development of the care plan is highlighted in several criteria under this domain.

Table 3. Finalized Provider-Prioritized Domains of Quality in Pediatric Home-Based Hospice and Palliative Care, and Defining Criteria, following Four Rounds of Consensus Building

- Domain 1: structure and processes of care
  - Defining criteria
    - A HBHPC program caring for children should make ongoing use of specialized pediatric hospice and palliative care expertise to meet the unique needs of this population.
    - A comprehensive and timely assessment of the child and family forms the basis of care.
    - Members of the HBHPC program will elicit and document preferences of the child to the degree possible using developmentally appropriate tools.
    - The care plan is based on the identified and expressed preferences, values, goals, and needs of the child and family and is developed with shared decision making through professional guidance and support for the child–family decision making.
    - The HBHPC program provides services to the child and family consistent with the care plan. In addition to chaplains, nurses, physicians, and social workers, other therapeutic disciplines who provide HBHPC services to children and families may include: case managers, child life specialists, nursing assistants, nutritionists, occupational therapists, recreational therapists, respiratory therapists, pharmacists, physical therapists, bereavement specialists, psychologists, speech and language pathologists, and complementary/integrative therapies, including but not limited to massage, art, music and/or aromatherapists.
    - The HBHPC program is encouraged to use appropriately trained and supervised volunteers.
    - Support for education, training, and leadership and professional development is available to all members of the program.
    - In its commitment to quality assessment and performance improvement, the HBHPC program develops, implements, and maintains an ongoing data-driven process that reflects the complexity of the organization and focuses on relevant HBHPC outcomes.
    - The HBHPC program recognizes the emotional impact of the provision of HBHPC on the team providing care to children with serious or life-threatening illnesses and their families and develops strategies to monitor, prevent, and intervene on an ongoing basis.
    - Community resources ensure continuity of the highest quality HBHPC across the care continuum.
    - The physical environment in which care is provided meets the preferences, needs, and circumstances of the child and family, to the extent possible.
- Domain 2: physical aspects of care
  - Defining criteria
    - The HBHPC program assesses and manages physical symptoms, including pain, and their subsequent effects in a timely manner, based on best available evidence.
    - The assessment and management of symptoms and side effects are tailored to the child's and family's goals, in the context of their disease status, to maximize quality of life.
    - Children and families are educated in the assessment of pain and other symptoms and in how to manage other physical aspects of care.
- Domain 3: psychological and psychiatric aspects of care
  - Defining criteria
    - The HBHPC program assesses and addresses psychological and psychiatric aspects of care, based upon the best available evidence, to maximize child and family coping and quality of life.
    - The assessment and management of psychological and psychiatric aspects of care recognize the unique stress on the child living with this illness, and on the family in caring for a child with a serious or life-threatening illness.
    - The assessment and management of psychological and psychiatric aspects of care recognize that stress may manifest in ways that are both physical and psychological.
- Domain 4: social aspects of care
  - Defining criteria
    - A comprehensive, family-centered interdisciplinary assessment (as described in ''Structures and Processes of Care'') identifies the social determinants of health, as well as the resources, needs, and goals of each child and family to maximize child–family strengths and well-being.
    - The specific needs of the sibling(s) are assessed and addressed.
    - The plan of care may address the school environment and consider advance care planning, which may include but not be limited to DNR orders in a school setting; interacting with school nurses, educators, and classmates; durable medical equipment (DME) at school; and transportation.
- Domain 5: spiritual, religious, and existential aspects of care
  - Defining criteria
    - The HBHPC program ensures that spiritual, religious, and existential dimensions of care for both the child and family are assessed and addressed, recognizing that there may be significant differences between the child and family.
    - A screening for spiritual struggle, distress, or spiritual needs of the child and family is performed, and a spiritual assessment is performed.
    - Chaplains, ideally with pediatric experience, conduct spiritual assessments, participate in determining use of spiritual screening tools, and mediate conflicts involving spirituality/religiosity, and medical decision making.
    - The HBHPC program facilitates religious, spiritual, and cultural rituals or practices as desired by the child and family, especially at and after the time of death.
- Domain 6: cultural aspects of care
  - Defining criteria
    - The HBHPC program provides care to each child, family, and community in a culturally and linguistically appropriate manner.

(*continued*)

Table 3. (Continued)

- The HBHPC program supports children and families by approaching medical decisions in ways that are respectful of their culture and values.
- The HBHPC program is a resource to other providers in navigating cultural practices as they relate to child care.
- The HBHPC program meets and maintains its cultural and linguistic competence according to accepted standards.

Domain 7: care of the child at the end of life
- Defining criteria
  - The HBHPC program educates families on the expectations and the process of dying and normalizes the experience when appropriate.
  - The HBHPC program identifies, communicates, and manages the signs and symptoms of children at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of children and families.
  - In collaboration with the child and family, the HBHPC program develops, documents, and implements a care plan regarding desire for treatments and procedures, preference for site of care, signs and symptoms, child and attendance of family and/or community members at the bedside at the end of life.
  - In the context of the child's end of life, the specific needs of the sibling(s) are assessed and addressed.
  - Post-death care is delivered in a respectful manner that honors the child's and family's culture and spiritual/religious practices.

Domain 8: ethical and legal aspects of care
- Defining criteria
  - The child's or parent's/legal guardian's goals, preferences, and choices are respected within the limits of applicable state and federal law, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.
  - The child's assent to the care plan is elicited and documented when possible.
  - In the event of unresolved conflict between child's and parent's goals, between the family and treatment team, and/or if the child withholds assent, the HBHPC program may act in consultation with a bioethics committee, and the outcome of that consultation is documented.
  - The HBHPC program identifies, acknowledges, and addresses the complex ethical issues arising in the care of children with serious or life-threatening illness.
  - The provision of HBHPC occurs in accordance with professional, state and federal laws, regulations, and current accepted standards of care.

Domain 9: coordination of care
- Defining criteria
  - The plan of care for the child and family is developed, documented, regularly reviewed, and revised by the HBHPC program, with the wishes of the child and family and outcome goals clearly defined and agreed upon.
  - The HBHPC program provides continuity of care and coordination among medical providers, with emphasis on maximizing the child's goals and advocating for the child's and family's well-being in the context of complex medical systems.
  - When possible, the HBHPC program coordinates services that the child and family need during the HBHPC experience, which may include coordination of DME, medications, school needs, private duty nursing, etc.
  - The HBHPC program maintains regular, high-quality communication among medical providers and assists in the interpretation of multiple consultant perspectives.

Domain 10: bereavement care
- Defining criteria
  - A pediatric bereavement program acknowledges that grief begins with anticipatory grief and continues long after the child dies, and includes the child's family and those people outside of the child's family who are impacted by the child's death (e.g., staff, community physicians, foster parents, and others).
  - A core component of the HBHPC program is a grief and bereavement program available to children, families, and community members impacted by the child's death.
  - The qualifications of bereavement providers include understanding the developmental and psychological needs of the child patient, siblings, parents, family, or classmate/friend(s).
  - Specific bereavement interventions are provided throughout the child's life and on an ongoing basis after the child's death.

The list of therapeutic disciplines which provide pediatric HBHPC services is expanded to include case managers and bereavement specialists, and to mention the field of complementary/integrative care. Comprehensive PC cannot be accomplished without a designated care coordinator or case manager, to maintain continuity and ensure that care is consistent with the family's goals and preferences.[15] Bereavement specialists are specifically mentioned in these criteria in light of the new stand-alone domain of Bereavement Care. Finally, there are times that the preferred location of death for a child cannot be achieved; the modifier "to the extent possible" was added to the final criterion to account for those scenarios in which a family's wishes are not medically feasible.

Domain 2: Physical aspects of care

Congruent with the NCP criteria, these criteria focus on the assessment and management of physical symptoms, including pain, in a timely manner. There is evidence that some children who enroll in adult hospice programs receive poor management of pain and other symptoms, resulting in hospice revocation and death in the hospital.[6] That many children die with pain and other symptoms has been well documented.[17,18] The focus of the criteria within this domain remains on treatment that is tailored to the child's and family's goals. Criteria also highlight that children themselves and their caregivers should be educated about how to assess and describe symptoms, to best communicate their needs with the HBHPC team caring for them, and about how to manage other aspects of their physical care.

Domain 3: Psychological and psychiatric aspects of care

As parents anticipate losing a child, they suffer significant physical, emotional, and psychological distress.[19,20] Siblings may manifest such stress in subtle ways, such as poor school performance or behavior changes. These criteria highlight the unique and profound stress a serious illness places on the child and on all members of the child's family, both in caregiving and in witnessing suffering. While the HBHPC program is not responsible for providing psychiatric treatment to family members who are not patients, it should be prepared to assess for strain in the family related to the child's illness, provide supportive care, and assist the family in finding additional resources when appropriate.

Domain 4: Social aspects of care

Siblings of children with life-threatening conditions require special attention and support.[16] The criteria of this domain specifically call out the importance of considering and addressing the needs of the siblings, as well as the school environment, when caring for children in HBHPC programs. Healthy People 2020 defines social determinants of health as the environments in which people live, work, play, worship, and age that affect a wide range of health, functioning, and quality of life outcomes and risks.[21] The health of a child is strongly intertwined with the health of his or her family; a serious illness in one child influences the health of his parents and siblings.[22] Additionally, children receiving PC may be at higher risk of financial stress than the general population, increasing the impact of the illness on the entire family.[23] Evaluation of social determinants of health should thus be a standard part of a family-centered interdisciplinary assessment, and attempts to mitigate such stressors should be incorporated into the care plan.

Domain 5: Spiritual, religious, and existential aspects of care

In this domain, the unique spirituality of a child and potential for differences between the child and family are highlighted.[24–27] The role of the chaplain, who ideally has pediatric experience, broadly includes the provision of direct spiritual, religious, or humanist support to patients, families, and HBHPC staff.[28,29] Chaplains should have knowledge of and access to developmentally appropriate spiritual screening and assessment tools for children, siblings, and family members.[30–32] Spiritual screenings are simpler means of identifying persons who might benefit most from chaplaincy care, and simple tools to screen for spiritual struggle are available for use by persons of multiple disciplines.[33] These means of screening make it feasible for smaller organizations to focus spiritual care efforts on patients or families who are at risk for spiritual struggle and who have identified needs, while recognizing that clinically trained, board-certified chaplains may be a limited resource. Positive screenings should be followed by a more comprehensive spiritual assessment and if warranted, development of a plan of care, which may include focusing on patient/family-identified questions, spiritual struggle, or rituals. Rituals may be especially critical for families to observe at the end of a child's life and should be facilitated, when possible, by the pediatric HBHPC program. Chaplains may also provide rituals or provide care by other means for the HBHPC staff.

Domain 6: Cultural aspects of care

These criteria are also expanded from the NCP guidelines. The importance of approaching medical decision making in ways that are culturally and linguistically respectful is highlighted. The HBHPC team, due to its multidisciplinary nature and perspectives gleaned from providing home-based care, may also have a critical opportunity to serve as a resource for other providers in navigating those cultural practices relating to the unique care of each child and family at the end of life.

Domain 7: Care of the child at the end of life

One of the important roles of pediatric HBHPC providers is to normalize the child's signs and symptoms during the dying process to parents or family members.[6] This reassurance that the child's signs of death are anticipated, and affirmation of what the parents witness, is distinct from identifying, communicating, and managing symptoms of children at the end of life. Additionally, pediatric HBHPC teams should plan, with the family, for the needs of siblings at the time of a child's death, remaining aware of and accounting for factors that place siblings at risk for complicated grief outcomes.[34–36]

Domain 8: Ethical and legal aspects of care

A child's goals and preferences may differ from his or her parents. As previously described, respect for the child requires eliciting their understanding of the illness, goals, and treatment preferences to the fullest extent possible, when developmentally appropriate and medically feasible.[15,16] If there is unresolved conflict between the family and treatment team, the parents are not felt to be acting in the child's best interest, or the child does not assent to a treatment plan, the HBHPC program may act in consultation with a bioethics committee, ideally one with pediatric expertise.

Domain 9: Coordination of care

The AAP recommends specifically that pediatric PC programs ensure that care provided to children is seamless across all settings, with continuity and consistently of caregivers of multiple disciplines.[15] These criteria focus on the fact that HBHPC programs provide continuity and coordination of care between medical providers and across all settings, with emphasis on maximizing the child's quality of life and advocating for the family's goals and values.

Domain 10: Bereavement care

As previously mentioned, participants emphasized the importance of pediatric bereavement care as a stand-alone domain. The death of a child has a profound impact on the parents, family, and community at large. Parental grief is intense, long, and characterized by extreme sadness and a sense of disconnectedness and isolation from others.[37] Bereaved parents are at a heightened risk of poor outcomes, including depression, anxiety, and other symptoms, posttraumatic stress, complicated grief, increased risk of hospitalizations, worse physical health, and increased mortality.[38–45] Thus, it is reasonable to conceptualize bereavement programs focused on pediatric loss within the framework of prevention, with the goal of helping bereaved parents and families navigate the changes faced as a consequence of their loss.[37] Bereavement care should therefore begin during a child's life with provision of support around anticipatory grief, and continue on an ongoing basis after the child dies, rather than explicitly beginning after the death. A grief and bereavement program should be available to the child, siblings, family, and also community members impacted by the child's death such as school mates and teachers, step- or foster parents, primary community physicians, grandparents, and others. Bereavement specialists should also understand the developmental stages of the child, siblings, and others impacted by the death, and are prepared to provide care for those that are developmentally appropriate.

In September of 2017, the National Institute for Health and Care Excellence in the United Kingdom (UK) published six quality statements and measures for end-of-life care for children, which closely resemble these guidelines.[46] The UK standards echo the importance of the availability of pediatric PC consultants for 24 hours a day,[46] as emphasized in the first domain of this study. The primary difference between these pediatric HBHPC domains in and the UK standards is that those standards include the statement that ''infants, children, and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.'' While many pediatric HBHPC programs do utilize a managing physician outside of the program, naming one specifically was not a priority of this group at this time. The UK quality standards also provide simple measurable indicators for each statement, such as ''the proportion of young people with a life-limiting condition who are involved in developing their advance care plan'' for the Quality Statement referring to advance care plans.[46] Mapping-validated indicators to these domains is part of our agenda, but was not the aim of this study.

As previously described,[5] many of the pediatric-specific HBHPC programs in OPPEN provide care across multiple settings: the home, the ambulatory setting, and in the hospital. As such, we believe the domains of quality identified here would be applicable to community-based pediatric PC programs as well as to traditional adult hospices that care for children.[5] Further studies are warranted to evaluate how providers may define domains of quality in other settings, particularly care provided by inpatient pediatric PC programs. Additionally, this study did not evaluate perspectives of caregivers or patients; future studies are warranted to understand how caregivers and children define quality in HBHPC.

The study has other limitations. Attrition was noted between Rounds 1 and 4 of this study. The significant decrease in responses from Round 1 to 2 was likely due to the length of the second survey, which was significantly longer than the first. The OPPEN meeting regularly scheduled for September 2017 had been canceled, but several OPPEN members attended a separate pediatric PC conference in Cincinnati that month. To complete the study, and because no further OPPEN meetings had yet been scheduled for Spring 2018, the decision was made to move forward with Round 3 and those OPPEN members who were present. Round 4 was a straightforward email survey seeking approval or disagreement with the final list; the response rate may have been low because providers who had not participated in previous rounds did not feel comfortable responding at this time. As this was a small study, including providers in a single region of the United States, findings may not be generalizable to HBHPC programs elsewhere.

This is the second study to leverage the infrastructure of the Ohio Pediatric Palliative Care and End-of-life Network (OPPEN), a consortium of pediatric HPC providers, for clinical research.[5] This work benefits from the breadth of professional roles and diversity of programs represented in OPPEN.[5] The next steps in this work are to identify caregiver-prioritized domains of quality in pediatric HBHPC and to map measurable indicators to each domain. Ultimately, this will enable pediatric HBHPC providers to measure outcomes, establish benchmarks of care, and to improve the quality of care provided to children receiving HPC in their homes nationwide.

Conclusions

The provision of high-quality care is a cornerstone of pediatric hospice and palliative medicine. We describe ten domains of high-quality pediatric HBHPC, and specific definition criteria for each domain. This is the first study to define domains of quality for pediatric HBHPC, and the second to leverage the infrastructure of a pediatric statewide consortium, the OPPEN, toward this work. Future studies are needed to establish parent and patient-prioritized domains of quality in pediatric HBHPC, and to map indicators validated in pediatrics to these domains. Only then will pediatric HBHPC providers be able to measure outcomes, establish benchmarks, map variability between sites, and standardize the care we provide children and their families who receive HPC at home.

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Author Disclosure Statement

No competing financial interests exist.

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Appendix 1: Ohio Pediatric Palliative Care and End-of-Life Network Survey Round 1

Defining Stakeholder-Prioritized Domains of Quality for Home-Based Hospice and Palliative Care: A survey of the Ohio Pediatric Palliative and End-of-Life Network.

Background

Before and during April 2016 of Ohio Pediatric Palliative Care and End-of-Life Network (OPPEN), OPPEN members came to a consensus regarding the domains of care, which are appropriate for pediatric home-based hospice and palliative care (HBHPC). All eight domains previously identified by the National Consensus Project (NCP) for Quality Palliative Care were retained, and one additional domain was added. The consensus list of domains of care applicable to pediatric HBHPC now includes:

Domain 1: Structure and Processes of Care
Domain 2: Physical Aspects of Care
Domain 3: Psychological and Psychiatric Aspects of Care
Domain 4: Social Aspects of Care
Domain 5: Spiritual, Religious, and Existential Aspects of Care
Domain 6: Cultural Aspects of Care
Domain 7: Care of the Patient at the End of Life
Domain 8: Ethical and Legal Aspects of Care
Domain 9: Coordination of Care (NEW)

To map measurable indicators to these domains, domains must first be clearly defined. The purpose of this survey is to query OPPEN members regarding the domain guidelines provided by the NCP, to refine them to develop consensus regarding succinct domain definitions, which are applicable to pediatric HBHPC.

More details for each guideline are available in this study. However, these NCP guidelines for each domain are used in this study as a starting point, to explore how pediatric palliative and hospice care providers conceive of these domains uniquely from those developed for the adults receiving palliative care.

If responses to this survey indicate that the group is coming to a consensus, definitions will be drafted based on survey responses for presentation at the next OPPEN meeting. If consensus is not forming, a second round of this survey will be sent before domain definitions will be drafted for presentation to the group.

Participation in this study is completely voluntary and 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 513-827-7954. 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.

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 homecare 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

Defining Domains

Domain 1: Structure and processes of pediatric home-based hospice and palliative care

As defined by the NCP, the guidelines of this domain include:

- A comprehensive and timely assessment of patient and family forms the basis of care.
- The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for the patient–family decision making. Family is defined by the patient.
- An interdisciplinary team (IDT) provides services to the patient and family consistent with the care plan. In addition to chaplains, nurses, physicians, and social workers, other therapeutic disciplines who provide PC services to patients and families may include: child life specialists, nursing assistants, nutritionists, occupational therapists, recreational therapists, respiratory therapists, pharmacists, physical therapist, massage, art and music therapists, psychologists, and speech and language pathologists.
- The PC program is encouraged to use appropriately trained and supervised volunteers to the extent feasible.
- Support for education, training, and professional development is available to the IDT.
- In its commitment to quality assessment and performance improvement (QAPI), the PC program develops, implements, and maintains an ongoing data-driven process that reflects the complexity of the organization and focuses on PC outcomes.
- The PC program recognizes the emotional impact of the provision of PC on the team providing care to patients with serious or life-threatening illnesses and their families.
- Community resources ensure continuity of the highest quality PC across the care continuum.
- The physical environment in which care is provided meets the preferences, needs, and circumstances of the patient and family, to the extent possible.

Question 1: In considering the Domain ‘‘Structure and Processes of Pediatric Home-Based Hospice and Palliative Care,’’ to what extent do you agree that the above elements completely define this domain?

1 Completely Agree
2 Somewhat Agree
3 Somewhat Disagree
4 Completely Disagree

If you answered 2–4, please describe (a) which of the above elements you think are not applicable to pediatric HBHPC for this domain, (b) what elements you believe are missing from this domain, (c) what elements would better define or refine it for pediatric HBHPC, and (d) any other concerns you may have:

Domain 2: Physical aspects of care

As defined by the NCP, the guidelines of this domain include:

- The IDT assesses and manages pain and/or other physical symptoms and their subsequent effects based on the best available evidence.
- The assessment and management of symptoms and side effects are contextualized to the disease status.

Question 2: In considering the Domain ‘‘Physical Aspects of Pediatric Home-Based Hospice and Palliative Care,’’ to what extent do you agree that the above elements completely define this domain?

1 Completely Agree
2 Somewhat Agree
3 Somewhat Disagree
4 Completely Disagree

If you answered 2–4, please describe (a) which of the above elements you think are not applicable to pediatric HBHPC for this domain, (b) what elements you believe are missing from this domain, (c) what elements would better define or refine it for pediatric HBHPC, and (d) any other concerns you may have:

Domain 3: Psychological and psychiatric aspects of care

As defined by the NCP, this domain includes:

- The IDT assesses and addresses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.
- A core component of the PC program is a grief and bereavement program available to patients and families, based on assessment of need.

Question 3: In considering the Domain ‘‘Psychological and Psychiatric Aspects of Pediatric Home-Based Hospice and Palliative Care,’’ to what extent do you agree that the above elements completely define this domain?

1 Completely Agree
2 Somewhat Agree
3 Somewhat Disagree
4 Completely Disagree

If you answered 2–4, please describe (a) which of the above elements you think are not applicable to pediatric HBHPC for this domain, (b) what elements you believe are missing from this domain, (c) what elements would better define or refine it for pediatric HBHPC, and (d) any other concerns you may have:

Domain 4: Social aspects of care

As defined by the NCP, this domain includes:

- The IDT assesses and addresses the social aspects of care to meet patient–family needs, promote patient–family goals, and maximize patient–family strengths and well-being.
- A comprehensive, person-centered interdisciplinary assessment (as described in Domain 1) identifies the social strengths, needs, and goals of each patient and family.

Question 4: In considering the Domain ‘‘Social Aspects of Pediatric Home-Based Hospice and Palliative Care,’’ to what extent do you agree that the above elements completely define this domain?

1 Completely Agree
2 Somewhat Agree
3 Somewhat Disagree
4 Completely Disagree

If you answered 2–4, please describe (a) which of the above elements you think are not applicable to pediatric HBHPC for this domain, (b) what elements you believe are missing from this domain, (c) what elements would better define or refine it for pediatric HBHPC, and (d) any other concerns you may have:

Domain 5: Spiritual, religious, and existential aspects of care

As defined by the NCP, this domain includes:

- The IDT assesses and addresses spiritual, religious, and existential dimensions of care.
- A spiritual assessment process, including a spiritual screening history questions, and full spiritual assessment as indicated, is performed. This assessment identifies religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family, as well as symptoms, such as spiritual distress and/or pain, guilt, resentment, despair, and hopelessness.
- The PC services facilitate religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.

Question 5: In considering the Domain ''Spiritual, Religious, and Existential Aspects of Pediatric Home-Based Hospice and Palliative Care,'' to what extent do you agree that the above elements completely define this domain?

1 Completely Agree
2 Somewhat Agree
3 Somewhat Disagree
4 Completely Disagree

If you answered 2–4, please describe (a) which of the above elements you think are not applicable to pediatric HBHPC for this domain, (b) what elements you believe are missing from this domain, (c) what elements would better define or refine it for pediatric HBHPC, and (d) any other concerns you may have:

Domain 6: Cultural aspects of care

As defined by the NCP, this domain includes:

- The PC program serves each patient, family, and community in a culturally and linguistically appropriate manner.
- The PC program strives to enhance its cultural and linguistic competence.

Question 6: In considering the Domain ''Cultural Aspects of Pediatric Home-Based Hospice and Palliative Care,'' to what extent do you agree that the above elements completely define this domain?

1 Completely Agree
2 Somewhat Agree
3 Somewhat Disagree
4 Completely Disagree

If you answered 2–4, please describe (a) which of the above elements you think are not applicable to pediatric HBHPC for this domain, (b) what elements you believe are missing from this domain, (c) what elements would better define or refine it for pediatric HBHPC, and (d) any other concerns you may have:

Domain 7: Care of the patient at the end of life

As defined by the NCP, this domain includes:

- The IDT identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of patients and families.
- The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential symptoms, patient and family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures.
- Respectful post-death care is delivered in a respectful manner that honors the patient and family culture and religious practices.
- An immediate bereavement plan is activated post-death.

Question 7: In considering the Domain ''Care of the Patient at the End of Life in Pediatric Home-Based Hospice and Palliative Care,'' to what extent do you agree that the above elements completely define this domain?

1 Completely Agree
2 Somewhat Agree
3 Somewhat Disagree
4 Completely Disagree

If you answered 2–4, please describe (a) which of the above elements you think are not applicable to pediatric HBHPC for this domain, (b) what elements you believe are missing from this domain, (c) what elements would better define or refine it for pediatric HBHPC, and (d) any other concerns you may have:

Domain 8: Ethical and legal aspects of care

As defined by the NCP, this domain includes:

- The patient or surrogate's goals, preferences, and choices are respected within the limits of applicable state and federal law, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.
- The PC program identifies, acknowledges, and addresses the complex ethical issues arising in the care of people with serious or life-threatening illness.
- The provision of PC occurs in accordance with professional, state and federal laws, regulations, and current accepted standards of care.

Question 8: In considering the Domain ''Ethical and Legal Aspects of Pediatric Home-Based Hospice and Palliative

Care,'' to what extent do you agree that the above elements completely define this domain?

1 Completely Agree
2 Somewhat Agree
3 Somewhat Disagree
4 Completely Disagree

If you answered 2–4, please describe (a) which of the above elements you think are not applicable to pediatric HBHPC for this domain, (b) what elements you believe are missing from this domain, (c) what elements would better define or refine it for pediatric HBHPC, and (d) any other concerns you may have:

Domain 9: Coordination of care

This domain was added by OPPEN members during our April 2016 meeting. How would you define the domain ''Coordination of Care in Pediatric Home-Based Hospice and Palliative Care''? Please list all elements that you believe are fundamental to include in the definition for this domain.

Depending on the results of this survey, if the group is not reaching consensus, we may send out an email 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 email if you are willing to be contacted for one additional survey. You will receive the email before the OPPEN meeting in November.

Appendix 2: OPPEN Survey Round 2

Defining Stakeholder-Prioritized Domains of Quality for Home-Based Hospice and Palliative Care: A survey of the Ohio Pediatric Palliative and End-of-Life Network

Background

Before and during the April 2016 meeting of OPPEN, OPPEN members came to a consensus regarding the domains of care, which are appropriate for high-quality pediatric HBHPC. All eight domains previously identified by the NCP for Quality Palliative Care were retained, and one additional domain was added. In November of 2016, a new survey was developed to define these domains. In analyzing those results, a 10th domain was added.

The consensus list of domains of care applicable to pediatric HBHPC now includes:

Domain 1: Structure and Processes of Care
Domain 2: Physical Aspects of Care
Domain 3: Psychological and Psychiatric Aspects of Care
Domain 4: Social Aspects of Care
Domain 5: Spiritual, Religious, and Existential Aspects of Care
Domain 6: Cultural Aspects of Care
Domain 7: Care of the Patient at the End of Life
Domain 8: Ethical and Legal Aspects of Care
Domain 9: Coordination of Care (NEW)
Domain 10: Bereavement Care (NEW)

To map measurable indicators to these domains, domains must be clearly defined. This is a second round of a Delhi study whose purpose is to continue to refine domain definitions and to develop consensus among the group in how each domain is defined.

Participation in this study is completely voluntary and 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 513-827-7954. 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 30 minutes.

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 homecare 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

Refining the List of Domains in High-Quality Pediatric Home-Based Hospice and Palliative Care

How important is it that each of the following domains of care be included in the list of domains of high-quality pediatric HBHPC?

Domain		*Critical*			*Moderate*		*Not important*
Structure and processes of care	1	2	3	4	5	6	7
Physical aspects of care	1	2	3	4	5	6	7
Psychological and psychiatric aspects of care	1	2	3	4	5	6	7
Social aspects of care	1	2	3	4	5	6	7
Spiritual, religious, and existential aspects of care	1	2	3	4	5	6	7
Cultural aspects of care	1	2	3	4	5	6	7
Care of the patient at the end of life							
Ethical and legal aspects of care	1	2	3	4	5	6	7
Coordination of care	1	2	3	4	5	6	7
Bereavement care	1	2	3	4	5	6	7

Refining Domain Definitions in High-Quality Pediatric HBHPC

Domain 1: Structure and processes of care

Defining criteria		*Critical*			*Moderate*		*Not important*
A comprehensive and timely assessment of patient and family forms the basis of care.	1	2	3	4	5	6	7
The IDT will elicit and document preferences of the child or adolescent to the degree possible using developmentally appropriate tools.	1	2	3	4	5	6	7
The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for the patient–family decision making.	1	2	3	4	5	6	7
An IDT provides services to the patient and family consistent with the care plan. In addition to chaplains, nurses, physicians, and social workers, other therapeutic disciplines who provide HBHPC services to patients and families may include: child life specialists, nursing assistants, nutritionists, occupational therapists, recreational therapists, respiratory therapists, pharmacists, physical therapist, complementary/integrative therapies, including but not limited to massage, art and music, and/or aromatherapists, psychologists, and speech and language pathologists.	1	2	3	4	5	6	7
The pediatric HBHPC program is encouraged to use appropriately trained and supervised volunteers to the extent feasible.	1	2	3	4	5	6	7
Support for education, training, and leadership and professional development is available to all members of IDT.	1	2	3	4	5	6	7
In its commitment to QAPI, the HBHPC program develops, implements, and maintains an ongoing data-driven process that reflects the complexity of the organization and focuses on HBHPC outcomes.	1	2	3	4	5	6	7
The HBHPC program recognizes the emotional impact of the provision of HBHPC on the team providing care to patients with serious or life-threatening illnesses and their families and develops strategies to monitor, prevent, and intervene on an ongoing basis.	1	2	3	4	5	6	7
Community resources ensure continuity of the highest quality HBHPC across the care continuum.	1	2	3	4	5	6	7
The physical environmcseent in which care is provided meets the preferences, needs, and circumstances of the patient and family, to the extent possible.	1	2	3	4	5	6	7

For the domain ''Structure and Processes of Care,'' to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria		*Critical*			*Moderate*		*Not important*
A comprehensive and timely assessment of patient and family forms the basis of care.	1	2	3	4	5	6	7
The IDT will elicit and document preferences of the child or adolescent to the degree possible using developmentally appropriate tools.	1	2	3	4	5	6	7
The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for the patient–family decision making.	1	2	3	4	5	6	7
An IDT provides services to the patient and family consistent with the care plan. In addition to chaplains, nurses, physicians, and social workers, other therapeutic disciplines who provide HBHPC services to patients and families may include: child life specialists, nursing assistants, nutritionists, occupational therapists, recreational therapists, respiratory therapists, pharmacists, physical therapist, complementary/integrative therapies, including but not limited to massage, art and music, and/or aromatherapists, psychologists, and speech and language pathologists.	1	2	3	4	5	6	7
The pediatric HBHPC program is encouraged to use appropriately trained and supervised volunteers to the extent feasible.	1	2	3	4	5	6	7
Support for education, training, and leadership and professional development is available to all members of IDT.	1	2	3	4	5	6	7
In its commitment to QAPI, the HBHPC program develops, implements, and maintains an ongoing data-driven process that reflects the complexity of the organization and focuses on HBHPC outcomes.	1	2	3	4	5	6	7
The HBHPC program recognizes the emotional impact of the provision of HBHPC on the team providing care to patients with serious or life-threatening illnesses and their families and develops strategies to monitor, prevent, and intervene on an ongoing basis.	1	2	3	4	5	6	7
Community resources ensure continuity of the highest quality HBHPC across the care continuum.	1	2	3	4	5	6	7
The physical environment in which care is provided meets the preferences, needs, and circumstances of the patient and family, to the extent possible.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 2: Physical aspects of care

For the domain ''Physical Aspects of Care,'' to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria		*Critical*			*Moderate*		*Not important*
The IDT assesses and manages pain and/or other physical symptoms in a timely manner and manages their subsequent effects based on the best available evidence.	1	2	3	4	5	6	7
The assessment and management of symptoms and side effects are contextualized to the patient/family's goals and in the context of their disease status, to maximize quality of life.	1	2	3	4	5	6	7
Families are educated in the assessment of pain and other symptoms and in how to manage other physical aspects of care.	1	2	3	4	5	6	7

For the domain ‘‘Physical Aspects of Care,’’ to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT assesses and manages pain and/or other physical symptoms in a timely manner and manages their subsequent effects based on the best available evidence.	1	2	3	4	5	6	7
The assessment and management of symptoms and side effects are contextualized to the patient/family’s goals and in the context of their disease status, to maximize quality of life.	1	2	3	4	5	6	7
Families are educated in the assessment of pain and other symptoms and in how to manage other physical aspects of care.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 3: Psychological and psychiatric aspects of care

For the domain ‘‘Psychological and Psychiatric Aspects of Care,’’ to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT assesses and addresses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.	1	2	3	4	5	6	7
The assessment and management of psychological and psychiatric aspects of care recognize the unique stress on the child living with this illness, and on the family in caring for a child with a life-limiting illness.	1	2	3	4	5	6	7
The assessment and management recognizes that stress can manifest in ways both physical and psychological.	1	2	3	4	5	6	7

For the domain ‘‘Psychological and Psychiatric Aspects of Care,’’ to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT assesses and addresses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.	1	2	3	4	5	6	7
The assessment and management of psychological and psychiatric aspects of care recognize the unique stress on the child living with this illness, and on the family in caring for a child with a life-limiting illness.	1	2	3	4	5	6	7
The assessment and management recognizes that stress can manifest in ways both physical and psychological.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 4: Social aspects of care

For the domain ‘‘Social Aspects of Care,’’ to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria	*Critical*			*Moderate*			*Not important*
A comprehensive, person-centered interdisciplinary assessment (as described in ‘‘Structures and Processes of Care’’) identifies the social strengths, needs, and goals of each patient and family to maximize patient–family strengths and well-being.	1	2	3	4	5	6	7
The specific needs of the sibling(s) are assessed and addressed.	1	2	3	4	5	6	7
The plan of care addresses the school environment and considers advance care planning, which may include but not be limited to DNR orders in a school setting; interacting with school nurses, educators, and classmates; durable medical equipment (DME) at school; transportation.	1	2	3	4	5	6	7

For the domain ‘‘Social Aspects of Care,’’ to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria	*Critical*			*Moderate*			*Not important*
A comprehensive, person-centered interdisciplinary assessment (as described in ‘‘Structures and Processes of Care’’) identifies the social strengths, needs, and goals of each patient and family to maximize patient–family strengths and well-being.	1	2	3	4	5	6	7
The specific needs of the sibling(s) are assessed and addressed.	1	2	3	4	5	6	7
The plan of care addresses the school environment and considers advance care planning, which may include but not be limited to DNR orders in a school setting; interacting with school nurses, educators, and classmates; DME at school; transportation.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 5: Spiritual, religious, and existential aspects of care

For the domain ‘‘Spiritual, Religious, and Existential Aspects of Care,’’ to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT ensures that spiritual, religious, and existential dimensions of care for both the patient and parent(s), are assessed and addressed, recognizing that there may be significant differences.	1	2	3	4	5	6	7
A spiritual screening for spiritual struggle, distress, or spiritual needs of the patient and parent(s) is performed, and, when indicated, a spiritual assessment is performed. This assessment identifies religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family, spiritual distress and/or pain, guilt, resentment, despair, and hopelessness, as well as spiritual resources, including hope, meaning, faith, and connectedness with others.	1	2	3	4	5	6	7
Clinically trained, board-certified chaplains with pediatric expertise and ideally with palliative care/hospice subspecialty certification, conduct spiritual assessments, participate in determining use of spiritual screening tools, and mediate conflicts involving spirituality/religiosity and medical decision making.	1	2	3	4	5	6	7
The IDT facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.	1	2	3	4	5	6	7

For the domain ‘‘Spiritual, Religious, and Existential Aspects of Care,’’ to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT ensures that spiritual, religious, and existential dimensions of care for both the patient and parent(s), are assessed and addressed, recognizing that there may be significant differences.	1	2	3	4	5	6	7
A spiritual screening for spiritual struggle, distress, or spiritual needs of the patient and parent(s) is performed, and, when indicated, a spiritual assessment is performed. This assessment identifies religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family, spiritual distress and/or pain, guilt, resentment, despair, and hopelessness, as well as spiritual resources, including hope, meaning, faith, and connectedness with others.	1	2	3	4	5	6	7
Clinically trained, board-certified chaplains with pediatric expertise and ideally with palliative care/hospice subspecialty certification, conduct spiritual assessments, participate in determining use of spiritual screening tools, and mediate conflicts involving spirituality/religiosity and medical decision making.	1	2	3	4	5	6	7
The IDT facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 6: Cultural aspects of care

For the domain ‘‘Cultural Aspects of Care,’’ to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT provides care to each patient, family, and community in a culturally and linguistically appropriate manner.	1	2	3	4	5	6	7
The HBHPC program supports patients and families in approaching medical decisions in ways that are respectful of the patient’s and family’s culture and values.	1	2	3	4	5	6	7
The HBHPC program is a resource to other medical providers in navigating cultural practices as they relate to patient care.	1	2	3	4	5	6	7
The HBHPC program strives to enhance its cultural and linguistic competence.	1	2	3	4	5	6	7

For the domain ‘‘Cultural Aspects of Care,’’ to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT provides care to each patient, family, and community in a culturally and linguistically appropriate manner.	1	2	3	4	5	6	7
The HBHPC program supports patients and families in approaching medical decisions in ways that are respectful of the patient’s and family’s culture and values.	1	2	3	4	5	6	7
The HBHPC program is a resource to other medical providers in navigating cultural practices as they relate to patient care.	1	2	3	4	5	6	7
The HBHPC program strives to enhance its cultural and linguistic competence.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 7: Care of the patient at the end of life

For the domain ‘‘Care of the Patient at the End of Life,’’ to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT educates families on the expectations and the process of dying and normalizes the experience when appropriate.	1	2	3	4	5	6	7
The IDT identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of patients and families.	1	2	3	4	5	6	7
The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential signs and symptoms, patient and family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures.	1	2	3	4	5	6	7
Post-death care is delivered in a respectful manner that honors the patient and family culture and religious practices.	1	2	3	4	5	6	7
In the context of the patient’s end of life, the specific needs of the sibling(s) are assessed and addressed.	1	2	3	4	5	6	7

For the domain ‘‘Care of the Patient at the End of Life,’’ to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria	*Critical*			*Moderate*			*Not important*
The IDT educates families on the expectations and the process of dying and normalizes the experience when appropriate.	1	2	3	4	5	6	7
The IDT identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of patients and families.	1	2	3	4	5	6	7
The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential signs and symptoms, patient and family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures.	1	2	3	4	5	6	7
Post-death care is delivered in a respectful manner that honors the patient and family culture and religious practices.	1	2	3	4	5	6	7
In the context of the patient’s end of life, the specific needs of the sibling(s) are assessed and addressed.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 8: Ethical and legal aspects of care

For the domain ‘‘Ethical and Legal Aspects of Care,’’ to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria	*Critical*			*Moderate*			*Not important*
The patient or parent’s/legal guardian’s goals, preferences, and choices are respected within the limits of applicable state and federal law, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.	1	2	3	4	5	6	7
The patient’s assent to the care plan will be elicited and documented.	1	2	3	4	5	6	7
In the event of unresolved conflict between child and parent goals, or if the child withholds assent, the IDT may act in consultation with a local or institutional bioethics committee, and the outcome of that consultation will be documented.	1	2	3	4	5	6	7
The HBHPC program identifies, acknowledges, and addresses the complex ethical issues arising in the care of people with serious or life-threatening illness.	1	2	3	4	5	6	7
The provision of HBHPC occurs in accordance with professional, state and federal laws, regulations, and current accepted standards of care.	1	2	3	4	5	6	7

For the domain ‘‘Ethical and Legal Aspects of Care,’’ to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria	*Critical*			*Moderate*			*Not important*
The patient or parent’s/legal guardian’s goals, preferences, and choices are respected within the limits of applicable state and federal law, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.	1	2	3	4	5	6	7
The patient’s assent to the care plan will be elicited and documented.	1	2	3	4	5	6	7
In the event of unresolved conflict between child and parent goals, or if the child withholds assent, the IDT may act in consultation with a local or institutional bioethics committee, and the outcome of that consultation will be documented.	1	2	3	4	5	6	7
The HBHPC program identifies, acknowledges, and addresses the complex ethical issues arising in the care of people with serious or life-threatening illness.	1	2	3	4	5	6	7
The provision of HBHPC occurs in accordance with professional, state and federal laws, regulations, and current accepted standards of care.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 9: Coordination of care

For the domain ''Coordination of Care,'' to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria		*Critical*			*Moderate*		*Not important*
The provision of care for the patient and family is developed, documented, regularly reviewed, and revised by the IDT, with the wishes of the patient and family and outcome goals clearly defined and consensually agreed upon.	1	2	3	4	5	6	7
The IDT provides continuity of care and helps to join other medical providers in delivering the best care for each patient and family, with emphasis on maximizing patient's goals and advocating for the patient's/family's well-being in context of complex medical systems.	1	2	3	4	5	6	7
The IDT coordinates all services that the patient and family need during the HBHPC experience, which may include coordination of DME, medications, school needs, private duty nursing, etc.	1	2	3	4	5	6	7
The IDT will maintain regular high-quality communication among medical providers and assist in interpretation of multiple consultant perspectives.	1	2	3	4	5	6	7

For the domain ''Coordination of Care,'' to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria		*Critical*			*Moderate*		*Not important*
The provision of care for the patient and family is developed, documented, regularly reviewed, and revised by the IDT, with the wishes of the patient and family and outcome goals clearly defined and consensually agreed upon.	1	2	3	4	5	6	7
The IDT provides continuity of care and helps to join other medical providers in delivering the best care for each patient and family, with emphasis on maximizing patient's goals and advocating for the patient's/family's well-being in context of complex medical systems.	1	2	3	4	5	6	7
The IDT coordinates all services that the patient and family need during the HBHPC experience, which may include coordination of DME, medications, school needs, private duty nursing, etc.	1	2	3	4	5	6	7
The IDT will maintain regular high-quality communication among medical providers and assist in interpretation of multiple consultant perspectives.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Domain 10: Bereavement care

For the domain ''Bereavement Care,'' to what extent do you believe that it is necessary for each of the defining criteria statements to be included as part of the domain definition?

Defining criteria		*Critical*			*Moderate*		*Not important*
A core component of the HBHPC program is a grief and bereavement program available to patients and families, based on assessment of need.	1	2	3	4	5	6	7
An immediate bereavement plan is activated post-death.	1	2	3	4	5	6	7
The qualifications of bereavement providers include understanding the developmental and psychological needs of the individual sibling, patient, parent, family, or classmate/friend.	1	2	3	4	5	6	7

For the domain ''Coordination of Care,'' to what extent do you believe that each of the defining criteria associated appropriately defines the domain *as worded*?

Defining criteria		*Critical*			*Moderate*		*Not important*
A core component of the HBHPC program is a grief and bereavement program available to patients and families, based on assessment of need.	1	2	3	4	5	6	7
An immediate bereavement plan is activated post-death.	1	2	3	4	5	6	7
The qualifications of bereavement providers include understanding the developmental and psychological needs of the individual sibling, patient, parent, family, or classmate/friend.	1	2	3	4	5	6	7

If you chose moderate to, does not define at all, what would you change about this criterion?

Appendix 3: Median and Interquartile Range for Domain Importance and the Necessity of Defining Criteria and Appropriateness of Criteria as Worded

		Round 1				*Round 2*			
		Importance		*As worded*		*Importance*		*As worded*	
Domain	*Defining criteria*	*Median*	*IQR*	*Median*	*IQR*	*Median*	*IQR*	*Median*	*IQR*
Structure and processes of care		2	1.5			2	1.5		
	An assessment forms the basis of care.	1	2	2	0.5	1	2	2	0.5
	The IDT documents preferences of patient and family.	2	1.5	2	1	2	1.5	2	1
	The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family.	1	1	2	1.5	1	1	2	1.5
	An IDT provides services consistent with the care plan.	1	1	2	1	1	1	2	1
	The HBHPC program is encouraged to use volunteers.	3	2	3	1	3	2	3	1
	Education, training, and leadership and professional development are available to the IDT.	2	1	2	1	2	1	2	1
	The HBHPC program develops, implements, and maintains a data-driven quality improvement process.	2	1	2	1	2	1	2	1
	The HBHPC program recognizes the emotional impact on the team.	2	1	2	1	2	1	2	1
	Community resources ensure continuity or care.	3	1	3	1.5	3	1	3	1.5
	The physical environment meets the patient/family's preferences, needs, and circumstances.	2	1	2	0.5	2	1	2	0.5
Physical aspects of care		1	1			1	1		
	The IDT assesses and manages pain and/or other physical symptoms.	1	0	2	1.5	1	0	2	1
	Assessment and management of symptoms and side effects are contextualized to maximize quality of life.	1	0.5	2	1.5	1	0.5	2	1.5
	Families are educated in the assessment of pain and other symptoms and physical care management.	1	1	2	1	1	1	2	2
Psychological and psychiatric aspects of care		2	1			2	1		
	The IDT assesses and addresses psychological and psychiatric aspects of care.	1	0.5	2	1.5	1	0.5	2	1.5
	Assessment and management of psychological and psychiatric aspects of care recognize the unique stress on the child.	1	1.5	2	1.5	1	1.5	2	1.5
	The assessment and management recognizes that stress can manifest in multiple ways.	2	2.0	3	1.0	2	2	3	1
Social aspects of care		1	1			1	1		
	An assessment identifies patient/family social strengths, needs, and goals.	1	1.5	2	2	1	1.5	2	2
	Sibling-specific needs are assessed and addressed.	1	1	2	2	1	1	2	2
	The plan of care addresses the school environment.	2	2	3	2	1	2	3	2

(*continued*)

		Round 1				*Round 2*			
		Importance		*As worded*		*Importance*		*As worded*	
Domain	*Defining criteria*	*Median*	*IQR*	*Median*	*IQR*	*Median*	*IQR*	*Median*	*IQR*
Spiritual, religious, and existential aspects of care		1	1.5			1	1.5		
	The IDT ensures that spiritual, religious, and existential dimensions of care are assessed and addressed.	1	0.5	2	2	1	0.5	2	2
	A spiritual screening for spiritual struggle, distress or spiritual needs of the patient and parent(s) is performed.	1	1	3	1.5	1	1	3	1.5
	Chaplains with pediatric expertise conduct spiritual assessments.	1	2	3	1	1	2	3	1
	IDT facilitates religious, spiritual, and cultural rituals or practices.	1	1	1	2	1	1	1	2
Cultural aspects of care		2	1.5			2	1.5		
	The IDT provides culturally and linguistically appropriate care	1	1	1	2	1	1	1	2
	The HBHPC program supports the patient's and family's culture and values in medical decision making.	1	1	2	2	1	1	2	2
	The HBHPC is a resource to other medical providers.	2	2	1	2	2	2	1	2
	The HBHPC strives to enhance cultural and linguistic competence.	1	1	1	2	1	1	1	2
Care of the patient at the end of life		1	1			1	1		
	The IDT educates families on the expectations and the process of dying.	1	0	1	2	1	0	1	2
	The IDT identifies, communicates, and manages the signs and symptoms at the end of life.	1	1	1	2	1	1	1	2
	The IDT develops care plan to address treatment of signs and symptoms, patient and family care preferences.	1	1	3	1.5	1	1	3	1.5
	Post-death care is delivered in a respectful manner.	1	1	1	2	1	1	1	2
	In the context of the patient's end of life, the sibling-specific needs are addressed.	1	1	2	2	1	1	1	2
Ethical and legal aspects of care		1	2			1	2		
	The patient or parent's/legal guardian's goals, preferences, and choices are respected within the law, accepted medical and professional standards.	1	1	2	2	1	2	2	2
	The patient's assent to the care plan will be documented.	1	1	2	2.5	1	2.5	2	2.5
	In the event of unresolved conflict IDT may consult a bioethics committee.	2	1	2	2	1	2	2	2
	The HBHPC addresses the complex ethical issues.	2	1.5	2	2	1.5	2	2	2
	HBHPC care provision occurs in accordance with laws, regulations, and accepted care standards.	2	1	1	1.5	1	1.5	1	1.5
Coordination of care		1	1.5			1	1.5		
	The plan of care is reviewed and revised by the IDT.	1	2	2	1	1	2	2	1
	The IDT provides continuity of care.	1	1.5	2	1.5	1	1.5	2	1.5
	The IDT coordinates all services that the patient and family need during the HBHPC experience.	2	2	2	1	2	2	2	1
	The IDT maintains regular high-quality communication.	2	2	2	1	2	2	2	1

(*continued*)

Appendix 3 . (Continued)

		Round 1				*Round 2*			
		Importance		*As worded*		*Importance*		*As worded*	
Domain	*Defining criteria*	*Median*	*IQR*	*Median*	*IQR*	*Median*	*IQR*	*Median*	*IQR*
Bereavement care						1	1		
	A grief and bereavement program is available.	1	0	2	2	1	0	2	2
	An immediate bereavement plan is activated post-death.	1	1	1	2	1	1	1	2
	The bereavement provider understands the developmental and psychological needs of the individual.	1	1.5	1	1.75	1	1.5	1	1.75