



ROLE DELINEATION STUDY
HOSPICE AND PALLIATIVE
CREDENTIALING CENTER (HPCC)
CERTIFIED HOSPICE AND PALLIATIVE
PEDIATRIC NURSE (CHPPN®)

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PSI SERVICES

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SUBMITTED TO



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INTRODUCTION

The Role Delineation Study (RDS) described in this report was conducted during 2018 at the request of the Hospice and Palliative Credentialing Center (HPCC). The purpose of the RDS was to describe the activities of the HPCC Certified Hospice and Palliative Pediatric Nurse (CHPPN®) in sufficient detail to provide a basis to inform future activities of the HPCC related to the CHPPN® role, and especially to provide a basis for updating the examination specifications for the CHPPN® examination.

A Role Delineation Advisory Committee (RDAC) was identified by HPCC to provide content expertise throughout the role delineation study process. The RDAC was composed of nurse subject matter experts (SME) with diverse backgrounds in hospice and palliative pediatric nursing that reflected the specialties within hospice and palliative pediatric nursing throughout the United States. Each member of the RDAC was highly qualified by academic degree, experience, licensing, and/or certification to participate fully as an SME on the Hospice and Palliative Pediatric Nursing RDAC.

In addition to appreciating the efforts of the RDAC, special thanks is given the HPCC staff for helping facilitate this study, including the Director of Certification, Sandra Lee Schafer, MN, RN, AOCN, and Certification Programs Associate, Keisha Davidson, MBA.

METHODOLOGY

Seven major tasks were initiated during a RDAC meeting held in January 2018. A summary of each task follows.

1. Identifying the target practitioner

For the purposes of this study, the RDAC adopted the following target practitioner practice definition of a CHPPN®:

Hospice and palliative pediatric registered nursing practice is the provision of care for perinatal, infant, pediatric, adolescent, or young adult patients and their families with the emphasis on their physical, psychosocial, emotional, and spiritual needs. The care is patient and family-centered with a focus on quality of life through pain and symptom management from the time of diagnosis throughout the trajectory of care. This care is provided in a collaborative, interdisciplinary manner in diverse settings to those experiencing serious or progressive illness through the end of life.

2. Develop a sampling plan

In order to gather role delineation data from nurses who consider themselves to meet the definition of the target practitioner, the RDAC decided to reach out to relevant healthcare organizations and ask them to share links to the RDS survey with their members. A link to the survey was also disseminated to Hospice and Palliative Nurses Association (HPNA) members and to HPCC certificants via an e-newsletter. The sampling plan specified that survey links would be distributed during the first week of April 2018. The published response deadline was May 31, 2018.

3. Identify major classifications of tasks

During the January meeting, the RDAC discussed several different ways in which CHPPN® might view the overall role related to CHPPN® practice. Following discussion, the RDAC agreed that the role of a CHPPN® should be primarily aligned with the texts used to educate nurses in the specialty. In addition, the RDAC acknowledged the importance of several issues brought up in the professional literature. The committee identified seven task-related content domains under which the tasks would be categorized:

1. Serious or Progressive Conditions in Children
2. Pain Management
3. Symptom Management: Neurological, Cardiovascular, Respiratory
4. Symptom Management: Gastrointestinal, Genitourinary, Musculoskeletal, Skin/Mucous Membrane, Nutrition, Immunology, and Hematology Systems
5. Symptom Management: Psychosocial, Emotional, & End of Life
6. Family-Centered Care, Education, and Advocacy
7. Professional Practice

4. Identifying task statements for the survey instrument

In order to develop a comprehensive draft list of tasks performed by the CHPPN® certified nurse, a draft list of task statements was prepared using materials provided by the HPCC and the previous RDS. All of these compiled materials were reviewed and discussed thoroughly by the RDAC at the first meeting. Members of the RDAC were encouraged to suggest additional task statements that could be pertinent to the practice of a CHPPN® certified nurse. A final draft list of task statements was developed for review by the RDAC. After review of the draft list, the RDAC authorized development of the final survey.

5. Determine the rating scales

The committee discussed the advantages and disadvantages of various rating scales which could be used in responding to the tasks. PSI suggested the use of a single significance scale. This single scale is intended to solicit judgments that combine the importance of a task with the frequency with which it is performed, after first considering the extent to which the task is necessary to the performance of the job. The significance scale adopted by the RDAC is shown below.

- 0 = Not necessary for my job
- 1 = Minimally significant
- 2 = Significant
- 3 = Critically significant

One additional task-related survey question asks respondents to list any important tasks that were not covered by the survey. Another question asks the nurse what percentage of the examination should be allocated each of seven content areas.

6. Determine the relevant demographic variables of interest

The RDAC developed demographic questions for the survey to gather information concerning the background characteristics of the respondents. There were demographic questions concerned professional characteristics such as education, certifications held, experience, percent of time spent in various activities, and current role. Additional demographic questions concerned employer support of the certification and general demographics, such as age, gender, and ethnicity. Responses to demographic items provide the RDAC with a description of the sample of respondents, and enabled subgroup analyses of task statement ratings.

7. Integrate demographics, rating scales, and tasks into a survey instrument

After correspondence with the RDAC, all components of the survey (demographics, rating scales, and tasks) were combined and designed into a draft survey instrument by PSI. As a pilot test, this draft was distributed to the RDAC. After reviewing the RDAC comments, the final online survey was prepared and disseminated in accordance with the sampling plan. The invitation message (including a link to the online survey) was requested to be disseminated by the participating organizations to potentially qualified individuals in accordance with the survey sampling plan.

RESULTS

The sampling plan was implemented and the links to the online RDS survey were distributed. The sampling plan specified that survey links would be distributed during the first week of April, 2018, and the published response deadline was May 31, 2018. The response deadline was extended, however, to June 14th to gather additional responses.

A total of 220 individuals responded to the survey links. Fourteen respondents were eliminated from the survey because they reported that the CHPPN® definition did not describe them. Three more were eliminated due to apparent duplication. (Responses were identified as duplicates if they had the same IP address of another response and also had identical demographics, education, experience, role, etc.) Fifty-seven more were eliminated because, although they had clicked on the survey link and may have responded to demographic items, they did not respond to any of the task statements. Thus, the final number of respondents retained for the sample was 146.

DEMOGRAPHIC INFORMATION

Responses to key demographic questions are depicted in the following graph and tables.

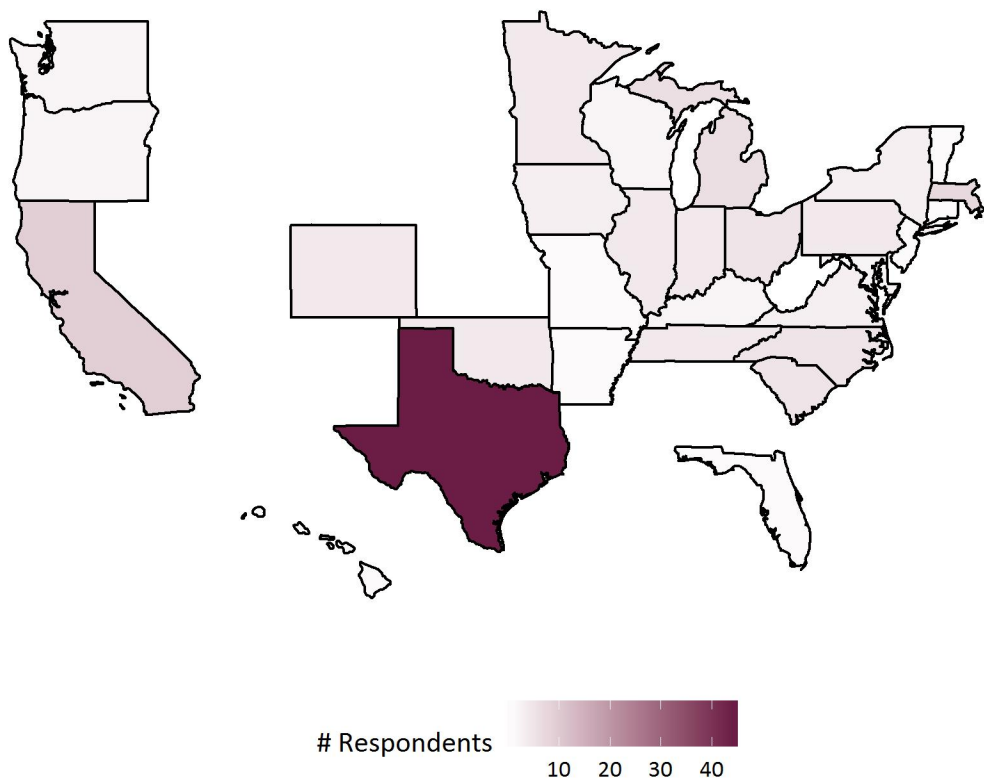


Figure 1. Number of Respondents by State

Table 1. What is the highest degree in nursing you have completed?

Degree	Freq	% of Responses (N = 145)	% of Total (N = 146)
Diploma	7	4.83	4.79
Associate Degree	20	13.79	13.70
Bachelor's Degree	58	40.00	39.73
Master's Degree	47	32.41	32.19
Doctoral Degree	13	8.97	8.90
Total	145	100.00	99.32

Table 2. Which of the following best describes your primary setting?

Primary Setting	Freq	% of Responses (N = 146)	% of Total (N = 146)
Ambulatory/Outpatient care clinic	6	4.11	4.11
Freestanding hospice facility	3	2.05	2.05
Hospital: internal palliative care consultative service	28	19.18	19.18
Hospital: NICU, PICU, or ICU	26	17.81	17.81
Hospital: other unit (e.g., scattered beds)	13	8.90	8.90
Hospital: palliative care unit	1	0.68	0.68
I do not routinely see patients	2	1.37	1.37
Nursing home, assisted living, or extended care facility	1	0.68	0.68
Private home	46	31.51	31.51
Other	20	13.70	13.70
Total	146	100.00	100.00

The RDAC determined that the number of responses was adequate and that the respondents were demographically representative for the purposes of evaluating task statement ratings and performing the demographic-based subgroup analyses.

ADEQUACY OF THE INSTRUMENT

There were no tasks that had a mean significance rating below 1.7. A total of 47 (30.7%) of the 153 task statements on the survey had a mean rating between 2.50 and 3.00, therefore could be considered, on average, critically significant to the role of the hospice and palliative pediatric nurse. None of the mean task ratings were in the “minimally significant range”, so the initial task selection process appears to have been efficient in selecting significant tasks for the survey.

After review of the task significance rating results, the RDAC concluded that the tasks selected for inclusion on the task inventory adequately represented the role, and provided a sound basis for defining the activities contained within the CHPPN® role.

Inter-rater reliability was also calculated using Intraclass Correlation Coefficient (ICC) for the task significance ratings on the survey. The overall ICC was found to be .841, and thus the survey task ratings were found to be highly reliable.

CHPPN® NURSE CORE COMPETENCIES

The purpose of the RDS was to describe the activities of the HPCC Certified Hospice and Palliative Pediatric Nurse (CHPPN®) in sufficient detail to provide a basis to inform future activities of the HPCC related to the CHPPN® role, and especially to provide a basis for updating the examination specifications for the CHPPN® examination.

EXAMINATION SPECIFICATIONS

In developing the Examination Specifications, the judgments of the RDAC SME were used in interpreting the data gathered through the role delineation survey. The Detailed Content Outline (DCO), Appendix A, is a summary version of the Examination Specifications. It is a public document that presents, in outline form, a detailed listing of examination content for distribution to candidates, educators, and item writers. For the purposes of this summary report, the DCO can be used as a guide to the content of the exam that is based directly upon the Examination Specifications that were applied during the examination development process. Every examination item was linked to the Examination Specifications/DCO as a first step in implementing the specifications during the examination development process.

Of particular importance to a national certification examination program is that the examination specifications must appropriately reflect the responsibilities of all groups who will participate in the certification program. Therefore, when the decision is made to proceed with a national certification program, it is important to ensure that neither the specifications nor the resulting examinations include task statements that are not considered important responsibilities of the individuals for whom the examination is intended.

In interpreting and using the results of the role delineation survey, several statistical decision rules were proposed for use by the RDAC. These decision rules are statistical criteria that are used to evaluate each task statement to determine whether it ought to be included in or excluded from the Examination Specifications/DCO. The decision rules served as a series of standards that the task must satisfy in order to be included. If a task does not satisfy any of the standards, it is excluded.

By applying the decision rules the RDAC ensured that the resulting examination will reflect the responsibilities of the CHPPN® as rated by a demographically representative group of hospice and palliative pediatric nurses on the survey, and as interpreted by a group of highly qualified SME on the RDAC. Application of the decision rules also assured that the included tasks are applicable across the demographic characteristics of hospice and palliative pediatric nurses as revealed by the survey data.


Once the survey results were collected and organized, the RDAC met twice to evaluate and interpret the results and to develop the Exam Specifications. The general areas for discussion by the RDAC during the meetings (held in July 2018) were centered on overall ratings from the respondents, and the finalization and application of the decision rules. The RDAC took care to review the results of the decision rules in order to assure that no significant but underrated tasks were inadvertently excluded, and to assure that no overrated or unmeasurable tasks were included.


During their analysis of the survey results, the RDAC also decided to revise the original major classifications of tasks, revising the names of the categories and reducing the number of categories from seven to six. The changes are reflected in the DCO.


Based on their analysis and findings, the RDAC constructed and agreed upon the Examination Specification that would be used by item writers and managers to manage and construct the examination.


APPENDIX A


CHPPN® DETAILED CONTENT OUTLINE


 Certified Hospice and Palliative Pediatric Nurse (CHPPN®) Detailed Content Outline		% of Items
1. Management of Conditions and Symptoms: Neurological, Cardiovascular, Respiratory		19%
A. Identify specific patterns of progression, complications, and provide treatment for:		
<ol style="list-style-type: none"> 1. neurological conditions (e.g., encephalopathy, seizure disorders) 2. neuromuscular conditions (e.g., SMA, muscular dystrophy, myopathies) 3. cardiac conditions (i.e., congenital or acquired) 4. pulmonary conditions (e.g., cystic fibrosis, chronic ventilator dependency) 5. congenital anomalies (e.g., chromosomal disorders, genetic disorders, brain malformations) 6. sequelae of complications of birth (e.g., prematurity, anoxia) 		
B. Apply the nursing process to the following actual or potential neurological symptoms or conditions:		
<ol style="list-style-type: none"> 1. dysphagia (difficulty swallowing) 2. myoclonus (spasms of a muscle or group of muscles) 3. dystonia (persistent rigidity of muscles) 4. paraesthesia or neuropathies 5. seizures 6. changes in intracranial pressure 7. paralysis 8. spinal cord compression 9. mental status changes (e.g., agitation, restlessness, irritability, level of consciousness) 		
C. Apply the nursing process to the following actual or potential cardiovascular symptoms or conditions:		
<ol style="list-style-type: none"> 1. coagulation problems 2. edema 3. hemorrhage 		
D. Apply the nursing process to the following actual or potential respiratory symptoms or conditions:		
<ol style="list-style-type: none"> 1. congestion 2. cough 3. dyspnea 		


 Certified Hospice and Palliative Pediatric Nurse (CHPPN®) Detailed Content Outline		% of Items
<ol style="list-style-type: none"> 4. pleural effusions 5. pneumothorax 6. apnea 7. respiratory distress 8. secretions 9. pneumonia 		
2. Management of Conditions and Symptoms: Gastrointestinal, Genitourinary, Musculoskeletal, Skin/Mucous Membrane, Nutrition, Immunology and Hematology Systems		16%
A. Identify specific patterns of progression, complications, and provide treatment for:		
<ol style="list-style-type: none"> 1. hematologic, oncologic, and paraneoplastic conditions (e.g., disorders of the immune system, cancer and associated complications) 2. gastrointestinal and hepatic conditions (e.g., short gut, TPN-dependent) 3. metabolic disorders (e.g., leukodystrophy, Tay-Sachs disease, severe mitochondrial disorders) 		
B. Apply the nursing process to the following actual or potential gastrointestinal symptoms or conditions:		
<ol style="list-style-type: none"> 1. constipation 2. diarrhea 3. ascites 4. nausea or vomiting 5. bowel obstruction 6. bleeding 7. dysmotility 8. reflux 		
C. Apply the nursing process to the following actual or potential genitourinary symptoms or conditions:		
<ol style="list-style-type: none"> 1. urinary incontinence 2. urinary retention 		
D. Apply the nursing process to the following actual or potential musculoskeletal symptoms or conditions:		
<ol style="list-style-type: none"> 1. impaired mobility or complications of immobility 2. deconditioning (e.g., increased weakness, decreased function, activity intolerance) 3. spasticity 		

 Certified Hospice and Palliative Pediatric Nurse (CHPPN®) Detailed Content Outline		% of Items
E. Apply the nursing process to the following actual or potential skin and mucous membrane symptoms or conditions:		
<ol style="list-style-type: none"> 1. dry mouth 2. oral lesions 3. pruritis (i.e. itching) 4. impaired skin integrity (e.g., wounds, pressure ulcers) 5. rash 6. infection (e.g., fungal, cellulitis) 		
F. Apply the nursing process to the following actual or potential nutrition-related symptoms or conditions:		
<ol style="list-style-type: none"> 1. Anorexia 2. cachexia or wasting 3. dehydration 4. electrolyte imbalance (e.g., hypercalcemia, hyperkalemia, acidosis) 5. fatigue 6. feeding intolerance (e.g., oral aversion, increased residuals, pain) 7. failure to thrive 		
G. Apply the nursing process to the following actual or potential immunology and hematology systems symptoms or conditions:		
<ol style="list-style-type: none"> 1. infection or fever 2. myelosuppression (e.g., anemia, neutropenia, thrombocytopenia) 		
3. Management of Conditions and Symptoms: Psychosocial, Emotional, & End of Life		16%
A. Apply the nursing process to the following actual or potential psychosocial and emotional symptoms or conditions:		
<ol style="list-style-type: none"> 1. anger 2. anxiety 3. denial 4. depression 5. fear 6. grief 7. guilt 8. loss of hope or meaning 9. sleep disturbances 10. suicidal or homicidal ideation 11. identity issues (e.g., sexuality) 12. relationship issues (e.g., friendship, intimacy, sex) 13. abandonment 		

		
Certified Hospice and Palliative Pediatric Nurse (CHPPN®) Detailed Content Outline		% of Items
B. End of Life		
<ol style="list-style-type: none"> 1. Identify symptoms the child is entering the terminal phase of condition 2. Identify and respond to: <ol style="list-style-type: none"> a. physical indicators of imminent death (e.g., mottling, changes in breathing, decreased consciousness, decreased urinary output, changes in vital signs) b. psychological indicators of imminent death (e.g., letting go, near death awareness, reassurance of love and allowance to let go) c. pain and symptoms at the end of life (e.g., terminal restlessness, work of breathing, palliative sedation) 3. Honor cultural and spiritual beliefs at the end of life (e.g., care of the body, rituals, faith traditions) 4. Provide comfort and dignity at time of death 		
4. Management of Pain		16%
A. Assessment		
<ol style="list-style-type: none"> 1. Perform comprehensive assessment of pain 2. Identify etiology of pain 3. Identify types of pain or pain syndromes 4. Identify factors that may influence the child's experience of pain (e.g., fear, depression, cultural issues, spirituality, socioeconomic status, developmental level, family issues) 		
B. Pharmacologic Interventions		
<ol style="list-style-type: none"> 1. Identify medications appropriate to severity and specific type of pain (e.g., routes, initiation, scheduling) 2. Verify titration of medication to effect using baseline and breakthrough doses 3. Identify dosage equivalents when changing analgesics or route of administration 4. Identify the risk/benefit of adjuvant medications (e.g., NSAIDs, corticosteroids, anticonvulsants, antidepressants, CNS stimulants, neuroleptics, antispasmodics) 5. Respond to medication side effects, interactions, or complications 		
C. Nonpharmacologic and Complementary Interventions		
<ol style="list-style-type: none"> 1. Respond to psychosocial, cultural, and spiritual issues related to pain 2. Implement nonpharmacologic interventions (e.g., ice, heat, positioning) 		

		
Certified Hospice and Palliative Pediatric Nurse (CHPPN®) Detailed Content Outline		% of Items
3.	Facilitate complementary therapies (e.g., massage, therapeutic touch, guided imagery, acupressure, play, art, music, pet, aroma, bibliotherapy)	
D. Evaluation		
1.	Assess for side effects, interactions, or complications of pain management	
2.	Evaluate efficacy of pain relief interventions	
3.	Evaluate family comprehension and participation in the pain management plan	
5.	Family Centered Care, Education and Advocacy	23%
A. Family Support		
1.	Assess and respond to psychosocial, spiritual, and cultural needs	
2.	Assess and respond to family systems and dynamics (e.g., financial concerns, coping skills, physical and mental health of family caregivers)	
3.	Facilitate effective communication among the team and between family members	
4.	Facilitate opportunities for memory making or legacy building	
5.	Promote family self-care activities	
B. Patient Support		
1.	Assess developmental level of the child	
2.	Identify child's awareness of the diagnosis, prognosis, and plan of care	
3.	Identify the family's desire for disclosure of diagnosis, prognosis, and plan of care to the child	
4.	Facilitate communication strategies according to the child's cognitive, verbal, and social abilities	
C. Sibling Support		
1.	Identify the needs of siblings (e.g., psychosocial, emotional, physical)	
2.	Facilitate access to resources to meet the needs of siblings	
D. Education of Child and Family		
1.	Assess developmental level, knowledge base, and learning preferences	
2.	Identify and respond to barriers to ability to learn	
3.	Teach and evaluate primary caregivers' specific skills for care of the child	
4.	Assess and recommend adaptations to reduce safety risks (e.g., medication storage and disposal, infection prevention)	

 Certified Hospice and Palliative Pediatric Nurse (CHPPN®) Detailed Content Outline		% of Items
<ol style="list-style-type: none"> 5. Teach pain and symptom management, including medication administration and side effects 6. Discuss benefit versus burden of treatment options 7. Prepare child and family for transitions between care setting (e.g., hospital, outpatient, home, and community) 8. Teach end-stage disease process including signs and symptoms of imminent death 9. Inform family of community supportive services 		
E. Advocacy for the Child and Family		
<ol style="list-style-type: none"> 1. Monitor care for potential neglect and abuse 2. Assess and respond to barriers to communication 3. Assess and respond to spiritual and cultural needs 4. Facilitate child/family participation in interdisciplinary team (IDT) discussions and the individualized plan of care 5. Facilitate communication and advocate for shared decision making between child, family, and care providers 6. Determine child's and family's hopes, wishes, and preferences throughout the trajectory of care 7. Support advance care planning (e.g., birth plans, advance directives, resuscitation status, redirection of non-beneficial medical interventions) 		
F. Grief and Bereavement		
<ol style="list-style-type: none"> 1. Evaluate the need for anticipatory grief support throughout the trajectory of care 2. Counsel or provide emotional support for the unique grief needs of all affected by the child's condition (e.g., parents, siblings, grandparents, schoolmates, teams, church communities) 3. Provide information regarding funeral practices/preparation 4. Provide information on bereavement resources 5. Participate in bereavement follow-up support activities 		
6. Professional Practice		10%
A. Practice Issues		
<ol style="list-style-type: none"> 1. Incorporate national hospice and palliative standards into nursing practice 2. Incorporate guidelines into practice (e.g., NHPCO) 3. Incorporate legal regulations into practice (e.g., CMS) 4. Educate the public on hospice and palliative care 5. Evaluate educational materials for children and family 		

 Certified Hospice and Palliative Pediatric Nurse (CHPPN®) Detailed Content Outline		% of Items
<ul style="list-style-type: none"> 6. Identify ethical concerns and integrate resources to resolve (e.g., ethics committee, consultation, care conferencing) 7. Participate in continuous quality improvement activities 		
B. Professional Development		
<ul style="list-style-type: none"> 1. Contribute to professional development of peers, colleagues, students, and others as preceptor, educator, or mentor 2. Participate in peer review 3. Maintain professional boundaries 4. Participate in professional nursing activities 5. Maintain knowledge of trends in legislation, policy, health care delivery, and reimbursement as they impact pediatric hospice and palliative care 		
C. Self Care		
<ul style="list-style-type: none"> 1. Identify and implement strategies for dealing with: <ul style="list-style-type: none"> a. nursing grief b. moral distress c. compassion fatigue d. personal beliefs and values 2. Identify and participate in stress management activities 		
Total		100%