Pediatric Hospice and Palliative Medicine: A Career Guide for Pediatric Residents

Developed by the AAP Section on Hospice and Palliative Medicine

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A LETTER FROM THE AUTHORS:

Dear Colleagues,

Welcome! We developed this career guide to help you understand more about pediatric hospice and palliative medicine (PHPM) to answer questions such as— *What is the field of PHPM? What do PHPM doctors do on a day-to-day basis? What characteristics lend themselves to a fulfilling career in PHPM? How does one go about becoming a PHPM doctor?*—so that you can make a more informed choice about whether PHPM would be the "right career path" for you.

We hope you find this guide beneficial and that it provides the guidance you are seeking as you learn more about a challenging yet rewarding field of pediatric medicine.

Sincerely,

Lisa Humphrey, MD, FAAP, FAAHPM
Hemangini Bhakta, MD, FAAP
Erin Rholl, MD, MA, FAAP

AUTHORS:

Lisa Humphrey, MD, FAAP, FAAHPM
Associate Professor, The Ohio State University School of Medicine
Medical Director, Palliative Care
Nationwide Children's Hospital

Hemangini Bhakta, MD, FAAP
Assistant Professor, Cleveland Clinic Lerner College of Medicine/ Case Western Reserve University
Staff Physician, Pediatric Palliative Care
Cleveland Clinic Children's Hospital

Erin Rholl, MD, MA, FAAP
Assistant Professor, Medical College of Wisconsin
Neonatology and Pediatric Palliative Care
Children's Wisconsin

WHAT IS PEDIATRIC PALLIATIVE CARE AND HOSPICE MEDICINE?

What is palliative care?

According to the American Academy of Pediatrics (AAP) endorsed National Consensus Project for Quality Palliative Care Fourth Edition,[1] palliative care "focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing seriously ill people relief from the symptoms and stress of an illness. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family."

The following features characterize the philosophy and delivery of palliative care:[1]

- Appropriate at any stage in serious illness, and it is beneficial when provided along with treatments of curative or life-prolonging intent
- Provided over time to patients based on their needs and not their prognosis
- Offered in all care settings by various organizations
- Focused on what is most important to the patient, family, and caregivers, assessing their goals and preferences and determining how to best achieve them
- Interdisciplinary to attend to the holistic care needs of the patient and their identified family and caregivers

What is hospice care?

Hospice is both a philosophy of care and an insurance benefit covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.[2] Hospice is considered the model for compassionate care for people who have a prognosis of 6-months or less because they are dying from their illness, with a focus on caring, not curing. Hospice care is most commonly provided in the patient's home, but may also be provided in hospitals, nursing homes, and freestanding hospice units. Pediatric hospice care is unique in that patients may continue to receive medical treatments focused on curing an illness while still under the care of hospice providers through "concurrent care." For example, a child could be receiving chemotherapy but also qualify for hospice services. To learn more about Pediatric Concurrent Care, visit https://www.nhpco.org/palliativecare/pediatrics/pediatric-concurrent-care/.

What is pediatric hospice and palliative medicine?

Pediatric hospice and palliative medicine (PHPM) is both a philosophy and an organized method for delivering competent, compassionate and consistent care to children with serious illness as well as to their families.[3] PHPM is provided along with concurrent disease-modifying therapy when disease- modifying therapy is appropriate, or as the main focus of care when disease-modifying therapy is no longer effective and comfort is of the utmost importance.

The AAP released a policy statement on PHPM in 2013 and reaffirmed this policy in 2020,[4] outlining core commitments to the discipline:

- Being patient centered and family engaged
- Respecting and partnering with patients and families
- Pursuing care that is high quality, readily accessible and equitable
- Providing care across the age spectrum and life span, integrated into the continuum of care
- Ensuring that all clinicians can provide basic palliative care and consult pediatric palliative and hospice care specialists in a timely manner
- Improving care through research and quality improvement efforts

WHAT IS A "TYPICAL DAY IN THE LIFE" OF A PHPM PHYSICIAN?

There are many paths to a career in pediatric hospice and palliative medicine, and one physician's day may look very different from another's day. To answer this question, we reached out to the group of our colleagues to comment and share their "typical" day.

Dr Renee Boss, MD, MHS, FAAP
John Hopkins School of Medicine, Baltimore, MD, 2022

As new faculty in Neonatology and Palliative Care, I spent 4 very busy years doing a Masters in Clinical Research and a Faculty Fellowship in Bioethics. I squeezed my clinical time everywhere in between. Those were challenging years (I also had a newborn) but I saw them as a time-limited investment in my research career.

Since then, I've maintained a balance of clinical work/ research/ education and home life. I like to work intensely and efficiently during business hours M-F, then turn it all off. No emails, meetings, or work on nights/ weekends unless I have clinical duties. I stick to this ~95% of time -- I get plenty done and (mostly) avoid burnout.

My clinical work is in 2-week service blocks. Just before a block, I take notes about my projects and to-do's for when I finish service. I tell everyone—myself included— to expect I will do no scholarly work for 2 weeks. I schedule no meetings my first 1-2 days after service, to regroup and recenter.

My scholarly days are largely a combo of meetings and nudging along 5-10 active projects. I eventually became skilled at mentoring (that took several years) and most of my projects involve both helping mentees do things and doing some myself. The parts of research I don't love (chasing potential study participants, kee ping databases) I enlist mentees/ research assistants to shoulder. I love analyzing qualitative data and writing, so I like to lead those parts of projects. I have a lot of control over my scholarly schedule, and this really improves my quality of life at work.

Dr Jared Rubenstein, MD, FAAP
Texas Children's Hospital, Houston, TX, 2022

I'm a pediatric palliative care doctor and fellowship program director at a large quaternary care children's hospital. Our interdisciplinary palliative care team is a consult service that sees inpatients and outpatients and includes doctors, nurses, nurse practitioners, social workers, a chaplain, research coordinators, and grief/bereavement support. In my roles, I have both clinical and academic responsibilities.

I spend my clinical time on the inpatient consult service. We see patients throughout the hospital and from all different subspecialties. My typical day starts around 8am where I review charts from the patients on our census. Then at 8:30 the rounding team members (attending, social worker and/or chaplain, trainees) huddle and make our plan for the day. We spend the morning seeing patients to assist with pain/symptom management, eliciting goals of care, shared decision making, and quality of life support. I aim to always break for lunch around noon. I strive to normalize that me and my colleagues take a break to eat together, have some camaraderie, and debrief/process the events of the morning. I find it really hard to be a good doctor without food and a bit of time for socializing and processing our challenging work. After lunch is more patient care, often with new consults and family meetings until around 4 where we stop to write notes and sign out. Our team often spends time at the end of each day de briefing/processing some more. This helps us leave some of the emotional weight of our work at work so we can be present at home. When trainees are present, these

debriefings also include time reviewing treatment plans and communication procedures from the day for learning points.

On weeks I'm not on clinical service, I have education and administrative time. I use that time for the administrative work of our fellowship program as well as our elective rotations for residents, medical student, and nursing students. This is also time I can use to read, work on research or publication writing, and to give lectures.

I truly feel like we have the best job in healthcare. We get to help care for amazing people and support them through the most challenging times in life. We get to work with amazing colleagues who make doing this challenging work a joy. And we get to train others to learn more about this amazing field.

Dr Melanie Brown, MD, MSE, FAAP
Johns Hopkins School of Medicine, Baltimore, MD, 2022

I am a Palliative and Integrative Medicine physician. I have a number of different roles and love that each day is different from the next. I am fortunate to be able to combine my passions into a career where I feel that I am truly able to make a difference in the lives of children through both direct patient care and medical education.

My various roles include Medical Director for the Palliative Medicine service at Johns Hopkins Children's Center where I lead the outpatient palliative medicine clinic and collaborate in the Integrative GI Clinic for chronic abdominal pain. When on the inpatient service, my day starts at around 7am with chart review and covering any urgent inpatient needs. We then start rounds at around 9 and discuss both the inpatients and outpatients. The rest of the day is busy seeing new consults, following up on the patients on our services and meetings with the team and the families. In addition to assisting with symptom management, we also help with family decision making, goals of care and staff support. During the inpatient service week, I also cover call on nights and weekends and lead the inpatient team interdisciplinary meetings which consists of psychosocial support staff, providers, and trainees. I also hold a palliative medicine clinic one day a week and an integrative pain clinic with the GI team one half day a week.

As Medical Director for Gilchrist Kids, a community hospice organization, I cover night and weekend call 1 full week a month and work closely with the nurse manager of the program. My roles in medical education include Assistant Program Director for the Palliative Medicine Fellowship and Course Director for the Medical Student Integrative Medicine Course. I also have the opportunity to participate in collaborations outside of the institution including research projects and advocacy with the American Academy of Pediatrics.

Dr Kara Huncik, MD, FAAP
Hand of Hope, Agape Care, SC, 2022

My path to Pediatric Palliative and Hospice care was not linear, but definitely fruitful. After residency, I began my career in Pediatrics as Medical Director for a start-up, hospital-based, Medicaid funded program for children with special needs and chronic medical conditions. Within this role, I learned a tremendous amount about patient care within an interdisciplinary team, patient and family-centered care, legislation/politics, leadership, and advocacy. When we lost the funding for that program, I turned my sights to private practice in pediatrics, where I eventually became a partner in a large pediatric group. I spent the next 12 years honing my skills in patient care, leadership, practice management and business, all while continuing to care for a sizeable population of children with chronic medical conditions and special needs. Then in 2021, I took on the position that I currently hold, as Medical Director for a private company offering home-based palliative and hospice care to children and families. In taking this position, I believe I have found my calling! It's as if all my passions, interests, values, experiences, and training have converged together, and I have a profound gratitude for

my role, my colleagues, the patients, and their families. On any given day, I have the great honor of direct patient care, mentorship to many different professional disciplines, leadership for my team, coordination of care with my medical colleagues, advocacy for patient rights and access to services, and education through outreach and speaking engagements. Make no mistake, though, I still take call nearly every night, and I have a lot of paperwork! Honestly, though, there is some truth to the adage, "when you find a job you love, you never work a day in your life." It's work, but it doesn't feel like a burden.

The variety in these responses illustrates the breadth and depth of possibility in the field of palliative medicine. Many PHPM physicians divide their time between palliative care and other specialties: general pediatrics, hospital medicine, complex care, hematology-oncology, intensive care, neonatology, anesthesia, and so on. Some physicians divide time based on weeks of one service line versus another, while others integrate palliative care consults into their days serving in other areas.

Many patients cared for in pediatric hospitals are eligible for palliative care, but not all programs care for the same populations of patients. Some teams focus a great deal on pain and symptom management, in addition to other responsibilities, while other teams are not invited to consult for this purpose. Some teams are consulted to assist in evaluating patients for solid organ transplant, others are consulted in all patients receiving bone marrow transplants, and yet others are not involved in caring for children in either population. Many of these differences are reflective of institution-specific practices and structures. Many PHPM teams work with institution leadership to develop department-specific diagnoses and conditions for consults. Most palliative care teams have close relationships with hospice organizations nearby. Some PHPM physicians serve as the medical director of the pediatric arm of a hospice; some pediatric hospitals directly provide pediatric home-based hospice and palliative care through their affiliated homecare organizations. Palliative care teams in those institutions are typically intimately involved in caring for patients who are receiving home-based hospice and palliative care through the institutional program.

There are commonalities to differing palliative care programs; the following are activities a given team may encounter in a day:

- Complicated pain and/or symptom management
- Evaluating goals of care with a family
- Assisting families as they define quality of life
- Evaluating and recognizing the importance of spirituality
- Coordinating care among multiple hospital-based teams, primary care doctors, and home health care
- Improving communication between teams and families
- Leading or participating in care conferences
- End-of-life care, advance directives, Do-not-resuscitate (DNR) orders
- Hospice care
- Bereavement support and follow up

There is some truth to the aphorism, "If you have seen one pediatric palliative care team, you have seen one pediatric palliative care team." But spending time with any PHPM team in an elective rotation can offer you critical insight into how all teams care for a variety of patients. For this reason, we recommend that any resident considering a career in PHPM seek to spend time with a palliative care team, either in their institution or on an away-rotation. If your institution does not offer a palliative care rotation, consider reaching out to adult palliative care teams in your area or to programs with palliative care fellowships. Most programs that offer fellowships also offer elective rotations for residents.

WHAT PERSONALITY CHARACTERISTICS ALIGN WITH PHPM?

All careers require character compatibility to ensure success and longevity; medicine is no different. Even within medicine, subspecialties lend themselves to different personalities. So what are the ideal PHPM characteristics? The obvious one is a high emotional intelligence quotient. Equally important (yet less obvious), PHPM physicians need strong emotional management strategies and cognitive malleability.

Emotional management in PHPM is the ability to manage one's own emotions and those around him/her/them. Emotional cognitive processing (the sublimation of emotions into tasks to offset the heavy emotional toll) and healthy boundaries are key characteristics for longevity within PHPM. Concomitantly, PHPM clinicians need to be comfortable with the strong emotions of other healthcare providers, patients, and families. This most commonly includes navigating sadness, anxiety, and anger. Conflict is frequent given these strong emotions so facileness with emotional regulation is key to conflict resolution, job competency, and longevity.

Cognitive malleability is also paramount. Most PHPM jobs will be a blend of acute care and chronic home-based care so physicians need to be knowledgeable and comfortable in both settings. Concomitantly, PHPM physicians must have skill and comfort in a myriad of sub-specialty care domains. While content expertise of a singular subspecialty is never needed, the ability to understand, wield, and deliver the information to parents and converse with consulting physicians is critical. HPM clinicians also need to have the cognitive flexibility to tolerate clinical ambiguity and guide clinician, patient and family decision making despite the uncertainty. Finally, successful HPM physicians possess multiple interactive styles to align with the characteristics of the consulting subspecialty and the clinical scenario at hand. Complex care patients and clinicians facing a life-threatening crisis approach it differently than an intensivist and family facing a sudden life-threatening crisis in previously healthy child. HPM clinicians must have the emotional toolbox, communication skills, and knowledge base to facilitate both scenarios and the myriad of others that reside in the daily practice of HPM.

HOW DO I GET TRAINING TO BECOME A PHPM PHYSICIAN?

The first step is to know that PHPM is the right field for you. This is why we recommend spending time with a PHPM team on an elective rotation, especially if you are considering a PHPM fellowship immediately after a general pediatrics residency.

If your training program does not offer a PHMP rotation, there are other ways that you may learn about the field such as joining the AAP Section on Hospice and Palliative Medicine (SOHPM). The SOHPM hosts a website and two LISTSERVs® that can connect you with others in the field of PHPM. The SOHPM welcomes pediatric trainee members, including medical students, residents, post residency training fellows, and early career physicians (among other member types). The SOHPM engages in various activities to support trainees and early career physicians interested in the field of PHPM. The SOHPM has a formal liaison relationship and subspecialty delegate position with the AAP Section on Pediatric Trainees (SOPT). Trainees interested in PHPM can apply for the SOPT liaison or subspecialty delegate role. The AAP Mentorship Program is another way to get connected to PHPM physicians. This program offers opportunities for mentorship and peer support by matching trainees with mentors based on shared career interests. You may also consider joining the American Academy of Hospice and Palliative Medicine (AAHPM) and attending their annual assembly, if you are able, to make contacts in PHPM and to appreciate the breadth and depth of the field. AAHPM has an active Pediatrics Special Interest Group.

Once you are more certain that PHPM is the career for you, the next step to becoming board-eligible is to complete a fellowship in hospice and palliative medicine. Prior to 2012, practicing physicians who met certain patient care criteria could be "grandfathered" into sitting for the hospice and palliative medicine board exam. Since then, only those physicians who have completed a fellowship are considered board-eligible.

How are typical hospice and palliative medicine fellowships structured?
Hospice and palliative medicine fellowships (HPM) are 12-month, clinical fellowships. The Accreditation Council for Graduate Medical Education (ACGME) Program Requirements include:

- Patient care in the following locations:
    - Inpatient acute care site
        - Inpatient palliative care consultation service
        - Inpatient palliative care or hospice unit
    - Home visits for hospice
        - Long term care experience at a skilled nursing home facility, chronic care hospital, or children's rehabilitation center
        - Ambulatory setting
- Scholarly activity or quality improvement project
- Electives – programs may offer:
    - Acute and chronic pain management service
    - Perinatal Palliative Care
    - Bioethics

HOW DO I FIND OUT ABOUT FELLOWSHIPS?

The official list of all HPM fellowship programs can be found on the ACGME website, and the AAHPM supports a list of Pediatric Hospice and Palliative Medicine Fellowship Training Opportunities at the following link: http://aahpm.org/uploads/Pediatric_Palliative_Care_Fellowships_and_Pediatric_Tracks_Update_07_11_2022.pdf

For those who are interested in pediatric-adult combined fellowships or pediatric-specific fellowships, it is important to note that HPM fellowships come in a number of different forms:

- Adult HPM fellowship with additional pediatric time possible
- Pediatric fellowships
    - Free-standing pediatric fellowship programs
    - Pediatric track embedded within an adult HPM fellowship program

Stand-alone pediatric HPM training programs

These programs are at Children's Hospitals and are run entirely by pediatric HPM faculty and staff. Some may include adult palliative care or hospice rotations for 4-10 weeks or more during the academic year, the experience is otherwise pediatric focused.

Pediatric tracks within adult HPM training programs

These programs vary significantly in the amount of pediatric training offered, from as little as 4-15 weeks of pediatric time to as much as 9-10 months or more of pediatric time – equivalent to what is offered in the stand-alone pediatric HPM training programs. Some pediatric tracks have positions reserved for pediatricians and a rank list that is separate from the adult programs. Other pediatric tracks have a single rank list for all candidates and the pediatric track is utilized if a pediatrician matches into that program. Be sure to look up details of the pediatric experience for each program individually.

Adult training programs

ACGME Hospice Palliative Medicine program requirements include two weeks of pediatrics minimum for all trainees. Some adult HPM training programs are willing to train pedestrians and may be willing to develop or have developed additional pediatric training experience (beyond the required 2 weeks). Each program will be different and should be contacted directly for details.

The difference between these three types of programs (stand-alone pediatric programs, pediatric tracks within adult programs, and adult programs) is not easily identified within the Electronic Residency Application Service (ERAS). Be sure to view the program website or reach out to program directors if you have specific questions. Questions to ask may include:

- How much time do your pediatric fellows spend in pediatrics vs. adult medicine?
- Do you rank your pediatric applicants separately or are they part of you general rank list?
- What is your experience in training pediatricians? Have you had other pediatric fellows?
- How many of your faculty or staff are pediatric-trained?

How do I apply for fellowship?

Applications are submitted via ERAS, which opens July for fellowships starting in July of the following year. Typically fellowship interviews run August through October, with rank lists due in November for the December match. These dates may vary based on the type of training program. Applicants must register with both ERAS and the National Residency Matching Program (NRMP)/ MSMP for the fellowship match.

Combined Fellowship Options

Experts have recently suggested an alternative pathway for combined HPM training with fields such as Hematology/Oncology, Critical Care and Neonatology.[5] However, at this time, the majority of programs require the completion of one fellowship training program before beginning another. If you are interested in a combined fellowship option, we recommend you contact program directors directly to see what options may be available at specific sites.

Mid-Career Pathways

At this time, no fellowships offer specific mid-career pathways. However, programs may be willing to work with candidates to design a program that allows mid-career physicians to spread their fellowship training over two years in order to allow continued clinical practice during training. We recommend that you contact program directors directly to see what options may be available at specific sites.

How do I find the right fellowship for me?

Contact program directors directly and ask questions about how the program will match your individual career interests and goals. You can even request to connect with their current or recently graduated fellows. The interview day will be very informative. Some questions to consider asking are:

- What is the program's history, current focus, and goals for growth?
- What current scholarly projects/quality improvement efforts is the program working on?
- How does the program support the job seeking process including interview preparation, contract negotiation, etc.?
- How does the program support fellows during an emotionally heavy year?

In addition, consider what factors are important to your individual goals:

- Potential for mentorship
- Program size
- Exposure to hospice (adult or pediatric)
- Geography
- Ability to moonlight in prior board certified or board eligible specialty

What makes a good applicant for PHPM? Applicants for HPM fellowship come from diverse clinical backgrounds and all training and career stages. Applicants that are more competitive typically demonstrate:

- A longitudinal interest in PHPM - Use your cover letter to highlight what experiences formed and maintained your interest in the field
- Desire to incorporate PHPM into their post-fellowship career
- Application with a letter from HPM faculty
- Demonstrate the appreciation for and ability to work in multidisciplinary teams

FINAL THOUGHTS:

The PHPM community is growing but remains well-connected and supportive of one another. Many PHPM physicians are willing to provide mentorship and guidance to trainees considering a career in this field. Please feel free to contact the AAP SOHPM (ppc@aap.org) with any questions you may have during this process.

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