

Introduction to the Special Issue on Palliative Care, End-of-Life, and Bereavement: Integrating Psychology Into Pediatric Palliative Care

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Objective: While most pediatric palliative care (PPC) teams do not yet routinely include psychology, roles for pediatric psychologists in PPC are expanding. The goals of this Special Issue are to promote awareness of the breadth and depth of PPC, highlight the diverse and growing roles for psychologists as PPC clinicians, scientists, educators, and advocates, and showcase the latest interdisciplinary PPC research.

Method: The nine articles in this collection describe key PPC concepts and research approaches, the value of the interdisciplinary team in PPC, the impact of child illness and child loss on caregivers, needs of grieving families, ethical challenges in PPC and at end-of-life, and disparities among underrepresented and historically marginalized populations. **Results:** The series of articles curated for this Special Issue illustrate the many contributions psychologists offer to the field of PPC. **Conclusion:** PPC-specific training and development of core competencies are necessary pathways to improve future integration of pediatric psychologists in pediatric care delivery, research, and advocacy.

Implications for Impact Statement

Psychologists are being increasingly recognized as offering unique and valuable contributions to the field of pediatric palliative care (PPC) as clinicians, researchers, educators, and advocates. This Special Issue has been curated to be helpful to trainees, PPC psychologists, and non-PPC psychologists alike, as well as our interdisciplinary PPC team members, as we strive to further establish our discipline as integral to the PPC field.

Keywords: psychology, pediatrics, palliative care, end-of-life, bereavement

Pediatric palliative care (PPC) is an interdisciplinary approach that targets the prevention and relief of suffering in youth with chronic or life-limiting diseases, regardless of prognosis, from the time of diagnosis throughout the illness trajectory (Hauer,

2019). PPC interventions can occur simultaneously with curative treatments, as they aim to improve quality of life, facilitate decision-making, and alleviate distressing symptoms like pain, fatigue, nausea, difficulty sleeping, anxiety, and more. While

Editor's Note. This is an introduction to the special issue "Pediatric Palliative Care, End-of-Life, and Bereavement." Please see the Table of Contents here: <https://psycnet.apa.org/journals/cpp/9/3>.—JVS

None of this article, in whole or part, have been submitted for publication or presented elsewhere.

We would like to acknowledge and extend our gratitude to the reviewers who gave their time and expertise, during a particularly challenging year, and provided thoughtful feedback on the articles in this Special Issue.

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PPC includes end-of-life, hospice, and bereavement care, the American Academy of Pediatrics recommends that PPC interventions start early and are integrated throughout treatment (American Academy of Pediatrics, 2013). The landscape and practice of PPC is unique from adult palliative care (World Health Organization, 2018), as clinical decision making, symptom management, and communication must be tailored to a child's developmental stage, taking into consideration their physical, hormonal, cognitive, and socio-emotional development. PPC also requires a different level of family engagement given the dependence of children on their parents and laws and preferences for caregiver involvement in treatment decision-making.

PPC clinical programs and research first gained prominence in the late 1990s and early 2000s (Feudtner et al., 2019). A series of position statements and reports coming out of national organizations (e.g., American Academy of Pediatrics, 2000; Institute of Medicine, 2003) propelled enthusiasm for PPC (Kang & Feudtner, 2012), with practice and support of PPC rapidly growing over the last 10 years as the medical field increasingly came to recognize PPC as an integral component of, if not a standard of practice for, treating pediatric patients with serious and life-threatening illnesses (Feudtner et al., 2013). While there has been a steady rise in the number of PPC programs in the U.S. over the last several decades, significant variability in program structure, staffing, and services remains (Rogers et al., 2021). PPC, then, is a relatively young and continually evolving field, and psychologists are well positioned to contribute to advances in the care of children living with chronic illness and their families.

Where We Have Been: Psychologists in Palliative Care

Palliative care is, by definition, an interdisciplinary effort, and psychosocial team members are viewed as critical in palliative care. Clinical Practice Guidelines for Quality Palliative Care recommend that social workers and chaplains, specifically, are included as core palliative care team members (National Consensus Project for Quality Palliative Care, 2018). Psychological support of patients and families receiving palliative care, then, is not exclusively assigned to psychologists, as all team members collaborate

to provide care based on individual patient needs, available staff and resources, and the institutional care model. Historically, psychologists have been absent from palliative care practice, delivery, and teams, and psychology's role in palliative care has not been well defined or well understood. In fact, integrating the psychologist into palliative care has been a more recent initiative (Payne & Haines, 2002), perhaps due to increased focus on the biopsychosocial framework in medicine, more psychologists specializing in health/illness (i.e., health psychologists and pediatric psychologists), and a societal push to improve end-of-life care (Haley et al., 2003).

Efforts have been made to describe psychologists' unique contributions in adult specialist palliative care and adult end-of-life care (Golijani-Moghaddam, 2014; Haley et al., 2003; Payne & Haines, 2002), highlighting roles in direct clinical services to patients and families (e.g., assessment and intervention, including bereavement support), consultation with and support of health care team members, education and teaching, support at the organization level (e.g., program development and evaluation), and design and implementation of psychological research. In 2017, the American Psychological Association's Council of Representatives released its Resolution on Palliative and End-of-Life Issues (APA, 2017), wherein they described the contemporary roles psychologists play (or could play) in palliative care settings (i.e., research, practice, advocacy/policy) and provided recommendations for increasing psychology's visibility in the field and for expanding contributions to patients with life-limiting illness and their families. Most recently, the Psycho-Oncology Cooperative Research Group's (PoCOG) End-of-Life Care Special Interest group from Australia released a professional consensus statement on the need for better integration of psychology in palliative care (Sansom-Daly et al., 2021). They note multiple domains of expertise in which psychologists can contribute to end-of-life care specifically, including end-of-life assessment (e.g., distinguishing between normative distress, maladjustment, and mental illness), end-of-life interventions (e.g., pain management, anticipatory anxiety), and team- and systems-related skills (e.g., staff support, advocacy at systems level).

Less attention has been paid specifically to psychologists within pediatric versus adult palliative care. Survey data from 2013 indicated that almost

95% of PPC programs did not include a psychologist (Feudtner et al., 2013), yet many pediatric psychologists are doing the work of palliative care outside of formal PPC programs (e.g., embedded within disease-specific medical teams or as consultation liaison psychologists; Hildenbrand et al., 2021). As the WHO has identified behavioral health specialists as particularly important in PPC work (World Health Organization, 2018), we must continue to delineate roles for psychologists in palliative care. By demonstrating our specialized training in evidence-based assessment and intervention, child cognitive and socioemotional development, family/ecological systems theory, and research methodology, we can advocate for more systematic inclusion into palliative care teams to help further the standard of care in PPC (Edlynn & Kaur, 2016). Ongoing and increased participation in institutional, local, national, and international PPC committees, special interest groups, task forces, and other advocacy efforts can promote pediatric psychology within the PPC field, as well as facilitate unique cross-discipline collaborative opportunities.

Where We Are: An Introduction to the Special Issue

With only a small minority of PPC programs in U.S. children's hospitals employing dedicated full-time psychologists (Feudtner et al., 2013), non-PPC psychologists often are called upon to fill diverse roles related to evaluation of psychological needs and provision of evidence-based interventions. Further, opportunities for psychologists in palliative care are expanding (Kasl-Godley et al., 2014), and the demand for our expertise will grow as PPC leaders continue to recognize the value of integrating psychology into their care models (Edlynn & Kaur, 2016). Therefore, this Special Issue aims to promote awareness of the breadth and depth of PPC; call attention to the diverse and growing roles for psychologists as PPC clinicians, scientists, and advocates; and showcase the latest interdisciplinary PPC research. We expect this collection of articles to be helpful to trainees, PPC psychologists, and non-PPC psychologists alike—as well as our interdisciplinary collaborators—as it highlights several core themes: (a) attention to individual patient and family differences, be they cultural, spiritual, developmental, or system-driven; (b) necessity of close collaboration with other members of the interdisciplinary team, between

psychosocial and medical providers, as well as among different professionals within the psychosocial discipline; and (c) approaching interventions and programming from an inquisitive and consumer-driven perspective, honoring patient and caregiver expertise derived from their own lived experiences.

This Special Issue begins with classifying how psychologists are involved in PPC across the country, with Hildenbrand et al.'s (2021) important update to the previous data (Feudtner et al., 2013) that expands our understanding of how psychologists are currently practicing PPC. Authors highlight the extent to which pediatric psychologists are involved in PPC, whether formally integrated into the interdisciplinary PPC team or as parallel consultants. A strong case is made for the recognition of pediatric psychologists as core members of PPC teams, with strategic recommendations for improving integration.

Building upon Hildenbrand et al.'s (2021) characterization of the multifaceted roles of pediatric psychologists in PPC, Kentor et al. (2021) then present a clinical case report that highlights some of the barriers and facilitators of interdisciplinary PPC services. Authors illustrate the complexities of treating a patient at the intersection of culture and spirituality, trauma, and disease progression. They highlight the role of pediatric psychology in promoting resilience, decreasing overall suffering despite progressive physical deterioration and disability, and providing culturally syntonic care in collaboration with an interdisciplinary team of medical and psychosocial providers.

We then move to a set of articles focused on parent outcomes and the parent voice, reminding us of the impact of life-limiting diseases on the family unit and the importance of supporting the family's well-being as part of comprehensive PPC. First, Fisher et al. (2021) present data on the relationship between parent's perception of their child's physical symptoms and elevated parent distress, through parent's increased rumination. In identifying this mediator, authors offer pediatric psychologists a unique and seemingly modifiable intervention target. In addition to supporting parents in the context of their children's suffering, a core tenet of PPC is supporting families leading up to, during, and after their child's death. To that end, Clark et al. (2021) use a qualitative design to elicit themes related to coping with infant loss, highlighting the importance of family-centered communication and continuity of support before,

during, and after a child's death. Representation of fathers within the study sample offers insight into differential support practices and needs between mothers and fathers following the death of their children. Authors' observations that parental response to the death of an infant is largely equivalent to the death of an older child emphasizes the importance of psychological and supportive presence across the spectrum of PPC patients regardless of age or disease. [Dias et al. \(2021\)](#) build upon Clark's call for continuity of PPC support in bereavement, as they address the physical toll of child loss on bereaved parents' health. Findings underscore the potential role of pediatric psychologists as family advocates, aiming to minimize the familial and societal implications of physical, cognitive, and psychological morbidities parents experience in the face of loss. Finally, [Henning et al. \(2021\)](#) synthesize qualitative findings from two avenues of support for bereaved parents: a weekend family camp focused on grief education and social support, and a postintervention focus group from a wait-list controlled randomized trial of a group-based intervention for bereaved parents. Authors share insights on families' expressed needs related to bereavement care and follow-up.

Ethical issues are common in PPC, particularly with respect to end-of-life and prognostic communication with children and adolescents. PPC psychologists are often called upon to help reconcile divergent perspectives between medical providers and caregivers about disclosures of illness-related information. In their contribution to the Special Issue, [Brown et al. \(2021\)](#) utilize a case example to propose a unified model that uses an ecological systems framework to guide pediatric psychologists in navigating these challenges. Guiding principles and conversational prompts for facilitating disclosure-related discussions are outlined.

Finally, our issue ends with two articles focused on health disparities within PPC. [Lyon et al. \(2021\)](#) describe community-based research efforts to adapt an advance care planning document for Spanish-speaking adolescents. They describe challenges and lessons learned from the community and barriers faced during COVID. Broader sociopolitical circumstances are also explored, exemplifying cultural humility in the characterization and prioritization of a community's needs. Closing the Special Issue is a topical review by [Sample et al. \(2021\)](#) that reports on the experience of PPC among Black, Indigenous, and persons of color (BIPOC), highlighting the limited research in this area and providing

specific guidance to PPC clinicians for culturally sensitive and humble clinical care.

Overall, the articles in this Special Issue demonstrate the broad scope of PPC (i.e., diversity across disease groups, prognoses, and ages), the contributions of pediatric psychologists in PPC, and the value of the interdisciplinary team in high quality PPC care and research. Authors emphasize clinical implications and offer concrete recommendations for PPC clinicians, which we anticipate will be of the highest value to readers. These include conversational prompts and concrete strategies for intervening in cases where caregivers request non-disclosure ([Brown et al., 2021](#)), parent-driven recommendations for programming and direct support for bereaved parents ([Clark et al., 2021](#); [Dias et al., 2021](#); [Henning et al., 2021](#)), clinical intervention targets for parents during active treatment ([Fisher et al., 2021](#)), and guidance for providing culturally sensitive clinical services ([Kentor et al., 2021](#); [Lyon et al., 2021](#); [Sample et al., 2021](#)).

Where We Are Going: Future Directions

Opportunities for Growth

While the articles in this Special Issue highlight the value of including pediatric psychology as part of the PPC team, limitations of the collected works also reflect larger gaps in real-world PPC practice and help to identify opportunities for future growth. Although multiple studies solicited the parent voice, inclusion of pediatric patients' own perspectives in future studies will be key. Longitudinal, prospective work will complement the growing body of retrospective, qualitative literature, and broadening focus on PPC topics beyond end-of-life and bereavement care (e.g., symptom management, quality of life) will foster awareness of and attention to the full scope of PPC services. Systematic assessment using validated measures is also largely missing across studies, which is a pronounced gap in extant PPC research. Empirical investigation of the theoretical models proposed, employing validated instruments to measure constructs of interest, and clearly articulating a priori outcomes and hypotheses will bolster the quality and meaningfulness of PPC research. Such work can then directly inform clinical practice (e.g., development and empirical validation of a measure of total pain can then be used by bedside clinicians to measure treatment

response). Finally, future studies and efforts need to emphasize greater inclusion of BIPOC voices, investigate how to adapt PPC clinical practices to be culturally syntonetic, and ensure that historically marginalized groups receive equitable care throughout the illness trajectory.

Demonstrating Added Value

While recognition of the value of psychologists in PPC has continued to increase over time, psychologists remain underrepresented in PPC care models, national guidelines, and training curricula. Though reasons for this have not been formally assessed, this may be due in part to a perceived overlap in psychosocial roles and uncertainty regarding value of an additional psychosocial team member, and/or potential lack of clarity within the PPC community about psychology training in concepts relevant to palliative care. It may also be the case that PPC programs and teams struggle to sustain, much less grow, their service. Further, with most PPC programs not currently meeting existing practice standards for program staffing (Rogers et al., 2021), it's challenging to argue for expansion of care teams to include psychology. For these reasons, demonstrating the added value of a psychologist to the PPC team is critical. While recent efforts to analyze the financial costs and benefits of pediatric psychology services have demonstrated that psychology involvement can lead to improved health outcomes and decreased hospital and insurance expenditures (McGrady, 2016), this has yet to be explored specifically within PPC. Pediatric psychologists are well positioned to participate in research efforts focused on how specific PPC staffing and care delivery models impact clinical demand, workload, quality, and patient and family outcomes.

Formalized Training

Another likely culprit in the slow transition from recommendation to reality is the limited training available for psychologists, particularly pediatric psychologists, in palliative care. Palliative, end-of-life, and bereavement care are not routinely incorporated into undergraduate, graduate, or even postgraduate curricula. As a result, most trainees learn by doing, in the moment, and supplement independently with readings, conference workshops, and, once licensed, available continuing education

opportunities. There are currently a number of formal training opportunities (e.g., certificate programs, topic-specific webinars) in PPC available for mixed-discipline audiences as well as discipline-specific programs (see <https://www.nationalcoalitionhpc.org/wp-content/uploads/2021http://03/PPC-Trainings-Resources-Curricula-Guide.pdf> for list of such opportunities). None, however, are developed specifically for psychologists in pediatric settings. Incorporating palliative care, end-of-life, and bereavement course work in graduate curricula, augmented by exposure to formalized PPC-specific clinical opportunities, is a critical next step in order to both ensure delivery of highest quality clinical services and to further establish psychology's role, reputation, and credibility in the PPC field. Further, this is the best way to cultivate a robust network of skillful PPC psychologists upon whom to call when successful advocacy efforts lead to increased job openings.

The World Health Assembly (2014) resolution on PPC outlined three levels of PPC training: routine basic training and continuing education for all health care professionals, intermediate training for providers working with populations with life-threatening conditions (e.g., oncology), and specialized training for those working with seriously ill patients for more than "routine symptom management needs." An equivalent training trajectory for psychologists working in PPC might include: (a) a doctoral degree in clinical psychology as means of routine basic training; (b) intermediate training in pediatric psychology, such as through externships or a predoctoral internship, with significant focus on populations with chronic and life-limiting illness and therefore high PPC needs; and (c) specialized training in PPC during postdoctoral fellowship or as a postgraduate certification, with specific PPC clinical training, research opportunities, and other didactic offerings (e.g., rounds, case conferences, journal clubs, seminars). However, there are currently few pediatric psychology fellowships that are formally focused on PPC. Given this, and the wide variability in education and training experiences for those holding a clinical psychology degree, identifying specific professional competencies appears to be a necessary first step in growing a PPC-informed workforce.

Professional Competencies

While professional competencies in pediatric psychology have been established (Palermo et al.,

Table 1*Competency-Informed Roles for Psychologists Practicing in Pediatric Palliative Care (PPC)*

Domains of pediatric psychology competency ¹	Domains of adult PC-specific knowledge competency ²	Competency-informed roles for pediatric psychologists in PPC, end-of-life, and bereavement
Assessment	<ul style="list-style-type: none"> • Biological aspects of illness and dying process • Psychological, sociocultural, spiritual, and interpersonal factors in chronic and life-limiting illness • Normal and abnormal grief and bereavement • Assessment of common physical and mental health conditions • Assessment of families 	<ul style="list-style-type: none"> • Differentiating between normative coping, maladjustment, and mental illness using comprehensive interview, standardized screening with valid measures, etc. • Distinguishing between normative and pathological symptomatology within the context of normative child development • Assessing cognitive functioning and decision-making abilities • Screening/assessing for complicated grief and posttraumatic stress in surviving family members • Evaluating impact of developmental, sociocultural, spiritual, and demographic factors on patient and family adjustment to illness, hospitalization, death, and loss
Intervention	<ul style="list-style-type: none"> • Biological aspects of illness and dying process • Psychological, sociocultural, spiritual, and interpersonal factors in chronic and life-limiting illness • Normal and abnormal grief and bereavement • Communication and facilitation of advance care planning • Psychotherapy for patients with chronic or life-limiting illness • Treatment of families 	<ul style="list-style-type: none"> • Supporting adjustment to illness, treatment, hospitalization, side effects, changes, and limitations • Delivering evidence-based interventions to address emotional and behavioral symptoms (e.g., CBT, behavioral therapy, parent management training, ACT, etc.) • Promoting nonpharmacological pain and symptom management (e.g., fatigue, sleep disturbance, nausea) • Supporting patients and families in decision making • Advocating for, supporting, and amplifying pediatric patients' voices in their medical care • Providing emotional support to caregivers and siblings • Facilitating advance care planning • Addressing anticipatory anxiety about dying and anticipatory grief • Fostering end-of-life opportunities for meaning-making • Providing bereavement care, including psychoeducation and support for normative grief, evidence-based interventions for surviving caregivers and siblings, and approaches for complicated grief
Consultation	<ul style="list-style-type: none"> • Interdisciplinary teams, consultation, and professional self-care 	<ul style="list-style-type: none"> • Facilitating communication between patients, families, and the interdisciplinary healthcare teams • Consulting and collaborating with various care teams involved in the care of complex patients (e.g., primary teams, palliative care, ICU, ethics, and more)
Research	<ul style="list-style-type: none"> • Not addressed in adult PC competencies 	<ul style="list-style-type: none"> • Designing, conducting, and disseminating research on PPC (e.g., QoL, evaluating outcomes of mental health interventions in PPC patients, added value of psychology to PPC teams and patients)

(table continues)

Table 1 (continued)

Domains of pediatric psychology competency ¹	Domains of adult PC-specific knowledge competency ²	Competency-informed roles for pediatric psychologists in PPC, end-of-life, and bereavement
Teaching	<ul style="list-style-type: none"> • Not addressed in adult PC competencies 	<ul style="list-style-type: none"> • Conducting program evaluation and quality improvement projects to improve care delivery • Providing lectures, in-services, and presentations on psychosocial PPC concepts to medical and psychosocial staff • Incorporating appropriate palliative, end-of-life, and bereavement content into graduate curricula • Expanding teaching and supervision of externs, interns, and postdocs through specific PPC clinical training opportunities, research programs, coursework, and other didactic offerings (e.g. rounds, case conferences, journal clubs, seminars)
Systems	<ul style="list-style-type: none"> • Interdisciplinary teams, consultation, and professional self-care 	<ul style="list-style-type: none"> • Supporting team members through staff resiliency, self-care, and well-being efforts • Advocating for psychology services in PPC through demonstrating worth, securing buy-out or funding for position(s)
Leadership	<ul style="list-style-type: none"> • Not addressed in adult PC competencies 	<ul style="list-style-type: none"> • Participating in institutional, local, national, and international PPC committees, task forces, and other efforts to promote pediatric psychology within the specialty • Participating in institutional, local, national, and international pediatric psychology committees, task forces, and other efforts to promote PPC as a subspecialty
Advocacy	<ul style="list-style-type: none"> • Not addressed in adult PC competencies 	<ul style="list-style-type: none"> • Developing and delivering accessible community and public-facing psychoeducation around palliative care, end-of-life, advance care planning, and death • Contributing to advocacy efforts at the federal level to improve patient and family access to PPC

¹ Palermo et al. (2014). ² Based on current guidance in adult palliative care (Kasl-Godley et al., 2014).

2014), we currently know little about what makes a competent psychologist practicing in PPC. It is likely, then, that there is wide variability in the knowledge, experience, and training of providers delivering such care. Further, several palliative care organizations have defined hospice and palliative care competencies and/or standards specific for physicians, nurses, and social workers, yet psychology has lagged behind and no such competencies have been developed. The American Psychological Association (Kasl-Godley et al., 2014) and the European Association for Palliative Care's Task

Force on Education for Psychologists in Palliative Care (Jünger et al., 2010; Payne & Jünger, 2011) have provided initial guidance on the specific knowledge, skills, and attitudes (i.e., competencies) needed for psychologists working in adult palliative care. In contrast, however, there has been very limited attention paid to the role of psychologists in *pediatric* palliative care.

Identifying competencies for psychologists practicing in pediatric palliative care settings is critical at this time in order to keep pace with the field of professional psychology and with other health

professionals (Hildenbrand et al., 2021). We have a unique opportunity, if not an obligation, to enhance understanding of the unique contributions of psychologists in pediatric palliative care, allowing for increased integration of psychology within palliative care teams and for more targeted services for children and families. Furthermore, developing competencies is the first step toward improved training opportunities in palliative care, creation of a competency-based educational curriculum, and growth of a well-prepared and skilled psychology workforce.

Table 1 combines select domains of pediatric psychology expertise/competency (i.e., assessment, intervention, consultation, research, teaching, systems, leadership, advocacy; Palermo et al., 2014), broad knowledge and skill competencies previously suggested for psychologists in adult palliative care settings (Kasl-Godley et al., 2014), and specific examples of how those skills may apply to PPC practice. While this table is not intended to be exhaustive or comprehensive, nor is it intended to overlook the interdisciplinary collaboration and contribution of other psychosocial PPC team members, it provides a starting point to understand the scope of activities pediatric psychologists involved in PPC are currently providing or are well-equipped to provide, and from which training competencies for PPC may be initially established. Pediatric psychologists in PPC are encouraged to look to specialities like pain psychology (Wandner et al., 2019), primary care psychology (McDaniel et al., 2014), and clinical health psychology (France et al., 2008), among others, for methods of competency development and gaining consensus.

Concluding Remarks

The field of pediatric palliative care is still in its youth, with psychology integration into the specialty being younger still. As illustrated throughout this Special Issue, pediatric psychologists possess a knowledge base and skill set that position us to be an invaluable part of interdisciplinary PPC teams. Our roles are vast and varied and may range from screening for complicated grief in surviving caregivers after the death of an infant to providing evidence-based interventions for nonpharmacological pain management for a child with treatment-related neuropathy; from discussing treatment goals and advance care plans with an adolescent prior to organ transplant to facilitating an ethics consult in

the context of high moral distress among multiple consulting teams; from initiating a research study on improving quality of life among youth with spina bifida to teaching medical residents about children's understanding of death and dying from a developmental perspective; from leading a wellness debriefing with staff after a difficult death on the inpatient unit to advocating for increased federal funding for PPC through coordinated efforts of national PPC organizations. As we mature as a subspecialty, pediatric psychologists in PPC will be challenged to demonstrate their added value, advocate for inclusion as routine members of the interdisciplinary team, develop a training infrastructure to support workforce expansion, and engage in clinical research that helps us better understand and treat all of the patients and families we serve.

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Received July 12, 2021

Accepted July 13, 2021 ■

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