STATE OF THE SCIENCE OF PEDIATRIC PALLIATIVE CARE

Virtual Conference

December 11-12, 2023

DEPARTMENT OF HEALTH & HUMAN SERVICES·USA

NIH *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

Contents

Key Highlights

On December 11 and 12, 2023, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) held a State of the Science of Pediatric Palliative Care Conference. Panelists presented on epidemiology, cross-cutting themes, scientific methodology, challenges in research, ethical considerations, and workforce needs. The panelists identified the following key gaps and challenges that should be prioritized for future research funding and strategic research direction at NICHD. More than 200 attendees joined the conference live each day (249 on December 11 and 218 on December 12). The videocast recording was also made publicly available and attendees continued to access the conference proceedings on-demand.

Epidemiology and Cross-cutting Themes

- There was a need for more qualitative research to capture family and caregiver perspectives across different populations, including historically underserved communities, and the impact of intersectionality.
- Palliative care was complex and human-centered, which should drive research and predictive modeling approaches. More research was needed to address effective communication, person-centered care, and the therapeutic alliance.
- Population epidemiological studies were needed to develop accurate predictive models of outcomes and survival, polysymptomatic patient management, and family bereavement.
- It was important to capture clinician perspectives across different care settings.
- Family and clinical perspectives should be considered together to better understand how to align care practices and expectations, as well as to address structural and systematic biases, discrimination, and racism.
- Longitudinal and multidisciplinary data were needed to better understand the intersection between polysymptomatology and polypharmacy. Research was needed to help providers prioritize which symptoms to act on by using parent report of frequency, severity, and the extent of bother
- Better data collection tools, methods, and common core measures were needed to efficiently capture the data needed to inform meaningful intervention approaches and longitudinal studies.
- Patients, families, siblings, and caregivers should be engaged early in the research process. Language equity and other cultural factors should also be addressed.

Scientific Methodology and Resources

- Administrative data, such as Centers for Medicare & Medicaid (CMS) data, was available to researchers and could support longitudinal, linked data, and national-level studies. However, the use of administrative data can come with financial and time constraints that researchers should consider early in the research process.
- A disproportionate amount of pediatric palliative care research funding supported palliative care for specific conditions, such as cancer and might not generalize across different conditions. There was a need for increased research funding in other areas.
- There were emerging pediatric intensive care unit (PICU) patient populations that required more research to better understand their needs and clinical trials to evaluate appropriate interventions.
- There were differences across patients, conditions, and measures that could impact the power of clinical trials. Population grouping methods should be considered.
- Not enough pediatric palliative care providers were available to meet needs and there was a need for specialized training to bridge this gap.
- Emerging research methods, such as study optimization and digital technologies, were needed. Implementation science approaches were also needed to assess the feasibility of interventions.

Challenges in the Research Field

- There was not enough information about the transition from childhood to adulthood and how to provide the best care. There was a need to consider who had the highest morbidities, what demographics were being reached, and who was receiving services and why.

- There was little information about pregnant women with serious illness and their palliative care needs.

- Very young children are able to give a reliable voice to their experiences and should be considered alongside provider and parent perspectives.

- Qualitative data was needed to support quantitative data to have a holistic understanding.

- The perspectives of nurses, nurse practitioners, social workers, and the child’s community should be captured.

Psychosocial Impact of Palliative Care

- Family health should be a priority in both the NICHD Strategic Plan and in their requests for proposals. There should be a focus on family health equity and the impact of social determinants of health. The interrelatedness of individual family members and the family unit should also be considered.

- Sibling needs were unique and should be addressed. For example, there could be a cost study to determine the value of early sibling intervention versus long term cost of late intervention.

- Innovative methodologies such as indigenous research methods (a research approach that draws from the knowledge and traditions of Indigenous people), qualitative research, and community-based participatory research should be embraced. National, multicenter, longitudinal studies were needed to understand caregiver wellbeing and changes over time. There should be a focus on efficacious interventions that included nontraditional interventions, such as peer support

- There needed to be a better understanding of how caregiver health and wellbeing impacts their child's health.

- There was a need to objectively and psychometrically measured mental health pediatric palliative care.

- Rigorous studies were needed to inform not only how palliative care specialists communicate with primary care, ICU, and specialty care providers.

Ethical Challenges

- Paradigm shifts were needed to advance the ethical decision making process for the use of medical technology in children. For instance, longitudinal process-based approaches to decision making could help improve accountability to advance health equity and regain societal trust. Precision medicine concepts could be applied to decision making and communication.

- There was a need for interdisciplinary research to better understand bio-psycho-social-spiritual needs among non-cancer patients.

- Research was needed on how to communicate about the reasons for and intentions of therapies and transparency about goal concordant care.

- Early ethics training with the next generation of palliative care providers and ethics consultants was needed to help them develop therapeutic relationships and mitigate conflict.
- There was a need to teach providers to be aware of and overcome their biases and moral differences.

Workforce Needs

- There was a need for career training opportunities for mid-career providers and junior investigators, flexible and creative funding mechanisms, and alternate training pathways.

Day One

Welcome and Opening Remarks

Tessie October, M.D., M.P.H. Medical Officer, NICHD
Allison Cernich, Ph.D., ABPP-Cn, Deputy Director, NICHD

Dr. Tessie October and Dr. Allison Cernich welcomed participants to the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) State of the Science of Pediatric Palliative Care Conference. Dr. Cernich talked about the importance of palliative care as a specialized service that aims to provide relief to patients and their families from the symptoms and stress that arise from serious illnesses. Although pediatric palliative care impacts an estimated 74,000 children and their families, peers, and communities the United States, it is a nascent field that offers several research opportunities. The objective of this conference was to review the current state of science in pediatric palliative care and examine the gaps and opportunities that NICHD could explore as future research priorities.

Epidemiology of Pediatric Palliative Care

Chris Feudtner, M.D., Ph.D., M.P.H., Children's Hospital of Philadelphia

Dr. Chris Feudtner defined epidemiology as the study of patterns and associations within a defined population that can help guide research and policy. Epidemiology can be divided into two broad areas: population epidemiology (patients, their families, and communities) and clinical epidemiology (diagnoses, prognoses, and interventions).

Dr. Feudtner noted that there was a dire lack of research in clinical epidemiology and reviewed data from population epidemiology studies. For example, data indicate that the most likely population to require palliative care services are infants from the day they are born (the day a child is most likely to not survive) through the first year of life. Children with genetic congenital conditions and trauma victims are also sizable populations in need of palliative care. Other areas of population epidemiology that require further research include accurate predictive models of outcomes and survival, polysymptomatic patient management, and family bereavement.

Cross-Cutting Themes in Pediatric Palliative Care Research

Moderator: Tracy King, M.D., M.P.H.

Health Equity Research in Pediatric Palliative Care

Khaliah Johnson, M.D., Emory University School of Medicine

Dr. Khaliah Johnson talked about health equity, which is a state in which all people have the opportunity to attain their highest level of health and wellbeing, and the goal of liberation, which is a state in which there is never a barrier to reaching health equity. She highlighted a number of research studies indicating significant disparities in pediatric healthcare, such as higher cancer death rates among Black and Latinx children, higher numbers of pediatric HIV among Black and Latinx children, and lower hospice enrollment among Black pediatric patients and their families. Dr. Johnson noted the impact of social determinants of health, such as poverty, housing instability, geographic location, insurance status, and health literacy, on pediatric health outcomes. She also emphasized the crosscutting effect of structural racism across all social determinants of health

Dr. Johnson said that her research team recently conducted systematic literature review, which identified a lack of qualitative research in pediatric palliative care. To bridge this gap, her research team initiated a series of one-on-one interviews with Black and Indigenous patients and their families to better understand their perspectives. Some emerging themes included experiences of stigma and discrimination, mistrust, the lack of support for family decision-making, a lack of racial concordant care, and a lack of representation in the health care workforce. Additionally, families indicated that their pain experience encompassed not only the physical pain experienced by the patient, but also social, psychological, and spiritual pain. Her research team noted other gaps in qualitative research, such as perspectives from fathers and grandparents, experiences of community health workers, and the impact of intersectionality. Dr. Johnson called for NICHD to fund more qualitative research centered on the experience of historically marginalized communities, systemic and social challenges, and interdisciplinary perspectives.

Vulnerable Populations

Jori Bogetz, M.D., Seattle Children's Hospital

Dr. Jori Bogetz said that children with medical complexity often experience functional limitations, high healthcare resource needs, and severe neurological impairment related to their conditions or complications of their conditions. Families of children with medical complexity must adjust to and navigate not only through their child's comorbid conditions and symptoms, but also complex emotions, extensive new medical information, uncertainty, and anticipatory grief. Parents care for their children 24/7 and are therefore the experts in their child's needs. Yet, parents often feel unheard in the inpatient setting. As a result, parents feel they must be hypervigilant about their child's care and fight for the care their child needs. Research indicates that parents often experience discrimination, feel frustrated, and question the aggressiveness of treatment. Research also indicates that clinicians often lack confidence in providing care for children with medical complexities. Clinicians tend to rely on their set beliefs, leaving parents feeling undervalued.

Dr. Bogetz and her research team developed an intervention to promote a therapeutic alliance between clinicians and parents. They began by exploring both parent and clinician perspectives, which highlighted the need to understand the child's uniqueness, celebrate milestones, and think about the child holistically. Dr. Bogetz and her team developed a photo-narrative intervention, in which parents were asked to provide photos representing stories about their child and family culture and clinicians were asked to reflect on what they learned from these stories. Dr. Bogetz and her research team found that the intervention helped shift the way that clinicians approached families in terms of overcoming assumptions and bias and promoting shared decision-making. Dr. Bogetz called on NICHD to focus on research that addressed effective communication, person-centered care, and the therapeutic alliance.

Symptom Management and Measurement

Jamie Feinstein, M.D., M.P.H., University of Colorado, Denver; Children's Hospital Colorado

Dr. Jamie Feinstein talked about how children with medical complexities often have medical comorbidities that tend to accrue over time and are often addressed using multiple medications. To better understand the level of agreement between parents and clinicians on the importance of different symptoms, Dr. Feinstein and his research team asked parents to report their child's symptoms immediately prior to a primary care visit, then reviewed primary care provider's clinical notes. Although some symptoms, such as seizures, had a high level of agreement, other symptoms, such as fatigue or coughing, had low levels of agreement. This finding highlighted the opportunity to improve systematic collection and presentation of symptom data to inform subsequent care.

Although there are many assessment tools for measuring symptoms, few capture the chronic symptoms experienced by children with medical complexities. Therefore, another opportunity was to define a set of common core measures to help capture high-quality, relevant data for this population. There was also a need to prioritize which symptoms to act on by using parent report of frequency, severity, and the extent of bother. Although there was a need to track symptoms longitudinally to understand changes over time, longitudinal symptom tracking can be very labor intensive. Therefore, there was a need to identify ideal methods for longitudinal data collection. Dr.

Feinstein talked about pairing longitudinal symptom and medication data to identify bi-directional associations. He and his research team paired parent-reported longitudinal symptom, clinical, and pharmacy data and used these data to develop a pharmacist-based intervention to optimize pediatric polypharmacy regimens, which was being evaluated in a randomized controlled trial. He called for NICHD to support the systematic collection of symptom data to support symptom prioritization and changes over time, as well as the longitudinal data needed to generate high-quality interventions.

Panel Discussion and Q&A

Question: What is the concern about predictive models using artificial intelligence (AI)?
Answers: Dr. Feudtner answered that over the last decade, researchers have been using AI to identify people who might be in need of palliative care interventions. This can be a wonderful advance and a potentially useful health services utilization control measure. However, many of the efforts are focused on identifying people who might die. This can be linked to negativism and thoughts that a patient might warrant less intensive interventions. AI data tends to not be as accurate as people assume. AI data can be accurate at a population level by ruling out the people who are very unlikely to die, but the remaining people might have a one in three chance of dying, which was not the same as the likelihood of dying in the next six months. This is a subtle point that is often not acknowledged and suggests that these AI data were not ready for clinical implementation. Dr. Feudtner said that his team will be starting a new study on how structural biases affect estimates of survivorship. He emphasized that AI data was not as straightforward as people wished it to be.

Dr. Johnson agreed and added all of medicine, including palliative care, is a humanistic practice. One-on-one human connection cannot be replaced by AI.

Question: What are the lessons learned that might help the field improve engagement with families in research so that their voices are more representative of the whole population of patients and families?
Answers: Dr. Bogetz answered that the first important thing to consider was the importance of asking families what their priorities are. Often researchers are nervous to engage families because they are already managing so much around their child's care. However, families have said that they want to contribute to help other families who are going through similar experiences. The families do understand the value of research and want to contribute to the narrative and how their stories impact decision-making. Engaging with bereaving families is also important and it can be beneficial for them to share.

Dr. Johnson added that patient-centered care was often talked about in the context of clinical medicine and there was a need to apply that construct to research. There was also a need to be flexible and consider what is practical for parents in terms of when, where, and how to engage with them. This might mean running a research study in the evening and ensuring that a research team has that flexibility.

Dr. Feinstein talked about his team's efforts to engage patient and parent partners from as early as the conception of a research idea and throughout the research process. This provides a practical aspect that makes it easier for patients and families to engage.

Dr. Feudtner added that language equity was an important best practice. It was much easier for an individual to talk to someone who is fluent in their preferred language than an interpreter. It was also important to communicate the "why" or the real-life benefit of the research from a child- and family-centered point-of-view. Families need to know the value of their participation.

Question: What are your thoughts on how to make research findings more translatable and easier to facilitate uptake by providers, especially in the context of time and reimbursement constraints?
Answers: Dr. Bogetz answered that the integration of family and clinician voices across all clinical settings was important, as was understanding areas of potential biases. These perspectives should be baked into systems of care, such as families sharing what was most important, what they need or want to know, or how to get multidisciplinary supports. There could be system changes in the medical record system and other business approaches so that the person-centered approach was embedded in these processes.

Dr. Feinstein talked about his team's work with comprehensive medication reviews, which was time consuming and labor intensive. A primary care physician could not participate in such a labor intensive effort during usual clinical care. Therefore, they had to identify new ways to offload that work to other key people who do behind-the-scenes work with medication reconciliation and regimen work, which could then be shared with the clinician in a meaningful, efficient way during a clinical visit. He emphasized that while family perspectives were important, clinicians were another very important perspective to include.

Dr. Feudtner said that implementation science was a key consideration. He added that a deep relationship between clinicians and families did not necessarily take a long time and, conversely, a shallow relationship could be sustained over a long period of time because the right questions are never asked. One key area of research was relationship development. For instance, how quickly one can establish trust during a primary care visit can impact the rest of the visit.

Dr. Johnson said that it was important to apply what was learned from qualitative studies to the day-to-day clinical practice. This included helping clinicians understand how to use those stories and the value of spending a few more minutes to explore the family narrative. Clinicians can then elevate those stories to leadership or policymakers, who often resonate with real life experiences.

Question: Are there any findings about how diagnostic or developmental grouping might promote research in this field?
Answers: Dr. Feudtner answered that it depended on one's mental model. If one was looking for mechanisms of disease, then looking across diseases makes no sense. Looking at symptomatology as it arises from the underlying disease alone was different than looking at the many consequences of the underlying disease. There could be many underlying conditions related to fatigue, and these could be grouped together. The goal was to consider whether one's thinking is mechanistic or etiologic and then expanded that to the impact on the family. For example, a family with a child with severe neurologic impairment might not care about the exact disease contributing to the impairment, but rather the effect of the impairment on the child and family. The impact might be more similar than different across families, and therefore could be aggregated to see the big picture. If one took a disease-specific perspective, it would be easy to overlook a large part of the forest for very specific trees.

Dr. Bogetz emphasized the importance of broadly disseminating the concepts that apply to everyone across healthcare systems—particularly when the health system is as complex as palliative care.

Question: How can an outpatient setting programmatically support better symptom assessment and medication use to reduce polypharmacy?
Answers: Dr. Feinstein said that it was important to first deliberately and systematically collect symptom data across different care settings. Then, it was important to consider how to use that data to manage polypharmacy across multiple clinical settings and domains. Determining how to do this required a team of different experts. His team was conducting a clinical trial in which a pediatric pharmacist acted as a polypharmacy medication coordinator for children across all domains and also helps clinicians involved in the child's care determine how to consolidate medications and still treat multiple symptoms.

Dr. Feudtner added that patient- and parent-reported outcomes did not need to be done in person and could be collected using a number of formats, such as a phone or wearable device. This would help cross inpatient, outpatient, and home settings.

Scientific Methodology and Resources

Moderator: Karen A. Kehl, Ph.D., R.N., FPCN

Intervention Science and Clinical Trials Research

Lisa Lindley, Ph.D., R.N., FPCN, FAAN

Dr. Lisa Lindley talked about the importance of administrative data, such as insurance claims, death certificates, and census data, as a critical tool for understanding pediatric palliative care. Administrative data was defined as data that was collected for reasons other than research and typically collected by governmental entities. Some administrative data was publicly available to researchers, such as the Healthcare Cost and Utilization Project (HCUP) data or a new social determinants of health dataset—both collected by the Agency for Healthcare Research and Quality (AHRQ). Other administrative data had restricted access, such as data collected in the Pediatric Health Information System (PHIS).

Dr. Lindley focused on Medicaid data from the Centers for Medicare & Medicaid Services (CMS), which was complex and encompassed both public and restricted use datasets. CMS data was both longitudinal and representative of the nation, but could be costly and time intensive to access for research. CMS data had other challenges, such as the amount of time needed to clean and pre-process it, the need to evaluate the quality of both data and measures, and the need for secure data storage solutions. Dr. Lindley added that CMS required researchers to create a Data Management Self-Attestation Plan, which was highly technical and lengthy. However, there had been some advances that made CMS data more accessible to researchers, such as CMS's recent move to allow cloud-based data storage. There was also an opportunity to link CMS data with other datasets such as the National Death Index, which can support multi-level modeling, comparative effectiveness studies, and machine learning or natural language processing. Dr. Lindley encouraged pediatric palliative care researchers to consider a variety of data sources and the potential to link these data to conduct national and longitudinal research.

Intervention Science and Clinical Trial Research

Abby Rosenberg, M.D., M.S., M.A., Dana-Farber Cancer Institute, Massachusetts (pre-recorded)

Dr. Abby Rosenburg reviewed early palliative clinical trials that established a foundation of evidence that palliative care can improve quality of life and increase life expectancy. However, these early studies did not include pediatric palliative care. More recent clinical trials with pediatric cancer patients had shown promising results. For example, a three-step communication intervention improved concordance between teens and parents on care decisions. Dr. Rosenburg noted that results from the PediQUEST clinical trial, which used technology-based patient-reported outcomes to decrease symptom distress and improve quality of life, initially showed no statistically significant difference. However, stratification by age of patient indicated that older children did have statistically significant improvement, emphasizing the importance of embracing negative results in clinical trials as important information to move forward.

Dr. Rosenburg highlighted challenges in pediatric palliative clinical trials. First, most clinical trials had been funded by the National Cancer Institute—a disproportionate representation that may not be generalizable to other conditions. Second, pediatric palliative care was associated with diverse outcomes across populations and conditions, making it difficult to conduct clinical trials with larger populations. There was a need to consider how to group populations to study outcomes. Third, outcome measures also varied across patient-, parent-, and clinician reports. Finally, there were very few early and senior career researchers in the field and funding strategies were needed to bolster the workforce. Dr. Rosenburg talked about other research considerations, such as whether to adapt an intervention or develop a new one, the importance of assessing feasibility and acceptability of interventions, and emerging research methods such as optimization studies and the use of digital technologies.

Research in the Critically Ill

Moderator: Robert “Bob” Tamburro, M.D., M.Sc.

Pediatric Palliative Care in the Pediatric Intensive Care Unit

Sabrina Derrington, M.D., M.A., HEC-C, Children’s Hospital of Los Angeles, California

Dr. Derrington talked about gaps and opportunities for research to improve clinical processes and outcomes in the pediatric intensive care unit (PICU) setting. There had been an emerging need to better understand populations such as children with chronic critical illness, children who leave the PICU but continue to have high at-home critical care needs, and children who arrive at the PICU as a result of firearm or motor vehicle trauma and unintentional drug overdose. Additionally, there was a need to better understand the complex needs of families who must make difficult decisions and experience ongoing social and economic fallout from their child’s PICU stay.

Dr. Derrington reviewed promising interventions that support screening and decision-making in terms of who should receive and likely benefit from palliative care. Although these interventions had shown increased numbers of referrals and consultations, it also identified a crucial question about how to meet the increase in palliative care needs. Palliative care was known to lead to improved care and symptom control, as well as a greater likelihood of avoiding intensive interventions and resuscitation that can lower cost, length of stay, and caregiver stress.

Therefore, there was a need to research ways to integrate palliative care in the PICU workflow, increase the effectiveness of pain management among PICU intensivists, and improve decision-making processes in a dynamic and rapidly changing setting. Training programs, subspecialties in palliative care, and professional courses could help bridge the gap between the workforce and care needs. There was also a need for more education about provider assumptions and biases. Dr. Derrington called on NICHD to increase funding for these emerging populations and in policy and systems of care research to help address workforce gaps.

Perinatal Palliative Care Research Priorities

Renee Boss, M.D., M.H.S., Berman Institute of Bioethics

Dr. Renee Boss outlined four funding categories to advance pediatric palliative care. First, dedicated perinatal palliative care requests for applications (RFAs) could address issues in pregnancy, such as decision-making (e.g., termination or interventions), policy (e.g., the impact of the Dobbs decision), prenatal parenting, ethical complexities (e.g., in terms of termination versus comfort care for infants born with a condition), access to perinatal hospice, and staff skills (e.g., the need for end-of-life skills). These RFAs could also address issues in birth such as decision-making in terms of delivery types, infant symptom management in the delivery room, and staff skills across different settings. Second, maternal and child health RFAs should include a broader view that would include collaboration with non-pediatric physicians and involve research in pregnancy care options, high-risk obstetrics, novel fetal interventions, and maternal mental health.

Third, pediatric palliative care RFAs would generate research into disease-specific issues (e.g., genetic versus cardiac), end-of-life decision-making in the ICU, complex care planning and decision-making, and outcomes among family members. Finally, NICU, PICU, and CICU RFAs could also address disease-specific issues among neonates, ICU treatments and their impact on development, systems of acute versus chronic care, and ethical challenges (e.g., concordance on quality of life, longshot versus fantasy interventions, when a risky treatment becomes obligatory, and provider burnout). Dr. Boss also highlighted cross-cutting research priorities that impacted all the domains of perinatal palliative care including health equity, medical complexity, symptom management, data access, systems of care, family outcomes, bereavement, and ethnical tensions.

Panel Discussion

Dr. October announced that there was not enough time for questions, but reviewed key highlights from the panel presentations.

Day Two

Welcome and Opening Remarks

Tessie October, M.D., M.P.H. Medical Officer, NICHD
Rohan Hazra, M.D., Director, Division of Extramural Research, NICHD

Dr. Tessie October and Dr. Rohan Hazra opened the second day of the conference. Dr. Hazra reviewed the scope of the NICHD research extramural portfolio and other NICHD initiatives such as their different research networks, the Best Pharmaceuticals for Children’s Act, and a new acute pediatric pain network called the HEAL KIDS Pain: Acute Pain Clinical Trials program. They also highlighted the new NICHD Strategic Plan that will launch in 2025.

Expert Panel Discussion: Major Challenges in the Research Field

Moderator: Valerie Maholmes, Ph.D., CAS
Toluwalasé "Lasé" A. Ajayi, M.D., F.A.A.P., Rady Children’s Hospital - San Diego
Danielle Decourcey, M.D., M.P.H., Boston Children's Hospital, MA
Erica C. Kaye M.D., M.P.H., FAAHPM, St. Jude Children’s Research Hospital
Pamela S. Hinds, Ph.D., R.N., FAAN, Children's National Hospital

Question: Advances in medicine have reduced mortality in pediatric populations, yet morbidities persist, with increasing populations of children living with serious illness into adulthood. What is your role in caring for these children and what are the biggest gaps in our knowledge as these children transition into adulthood?

Answer: Dr. Lasé Ajayi answered that the transition from pediatric to adult care is when there are the highest levels of morbidity and mortality, which is true across different conditions. Children are well cared for, but as they transition to adults there is less information about how to provide the best care. Wraparound services are lost. Additionally, the transition period from late adolescence to early adulthood is a period in which people often feel invincible and may not be as compliant with medication and other consistent levels of support and treatment. Palliative care is uniquely positioned to provide that supportive care, both from a psychosocial and symptom management perspective. Palliative care excels in a family-centered, whole-person approach. But, there are disparities and marginalization. For example, the Food and Drug Administration (FDA) recently approved two new treatments for sickle cell disease, but there needed to be an understanding of its cost and accessibility. There was a need to look at who has the highest morbidities, what demographics are being reached, and who was receiving services and why. There are gaps in knowledge that need to be addressed to strengthen the transition gap.

Question: What are some of the biggest challenges among pregnant women with serious illness and what is the impact on their health and the health of their child?

Answers: Dr. Ajayi said that there was a clear lack of data. The lack of data started as a way to address wellbeing of pregnant women by not including them in clinical trials. But this meant that there was a lack of data on what was helpful to pregnant women. For instance, pregnant women were not included in COVID-19 vaccine trials and it was unknown whether the vaccine was safe for them or not. When a certain population is excluded from a clinical trial and other research, there is no information about how to help that population. There was a need to include their voices in research. There was little information about pregnant women with serious illness. For instance, there was a need to understand what is important to a women with cancer undergoing treatment during pregnancy, and what happens to their baby as a result of that treatment. The same was true for women with sickle cell disease who take high doses of opioids because it is unknown how best to treat their pain during pregnancy. Another example is Kate Cox, whose fetus had trisomy 18. She had to leave the state to obtain an abortion. She faced an impossible decision, but she might not have received palliative care to help her during this decision. There were many more women who had a similar stories that did not get told and do not have access to palliative care. It is important to understand who is not accessing palliative care services from a research standpoint. It is also difficult to see providers become a scapegoat for the courts when they are not able to provide the care that is needed and women become afraid to ask for help.

Dr. Pam Hinds added that it was also important to know who paid for care. The National Academies of Sciences had a working group that looked at payers of pediatric palliative care. Payment did occur, but it ended at age 18. There is a paucity of data but the working group used the data available to make recommendations to Social Security. Who pays for care is related to who receives care.

Question: Can you elaborate on the strategies you use to determine eligibility, aside from the age of a child, and for enrolling children in studies to ensure their voices are included in research?

Answer: Dr. Hinds answered that children who had been treated for a long time are often able to give voice at a far younger age than children being treated for the first time. Children as young as 4 years old had been able to provide valid responses about what their bodies were feeling and what they were worried about. There were also clinical anecdotes of children as young as 3 years old who can do the same. In her quality of life research, very young children start out not being able to answer some of the research prompts at the time of diagnosis, but could three months after their diagnosis. They might start out by turning to their mother to get an answer, but a few months later they are answering for themselves. Age was a consideration, as was the seriousness of illness, the impact of their symptoms at the moment of measurement, and whether a child was hesitant or forthcoming. Although there were some who doubted the ability of children to give voice to what their bodies are experiencing, her research team recently completed a survey of 120 clinicians who talked about pediatric cancer patients as young as 4 years old who were able to give voice about their experience. About 12% of these clinicians said they were leery, but the rest indicated that the children's voices were believable enough to make changes in supportive care to meet their needs. When they seek a child's voice, they do it in a way that does not take away from the parent's or clinician's voices. They seek all three voices, which inform a good clinical discussion about the impact of the diagnosis and treatment.

Question: Where does qualitative research fit in terms of having voices heard?

Answer: Dr. Erica Kaye answered that qualitative research was authentic storytelling to elevate the voices of those whose lived experiences were essential to the understanding of how best to support individuals, communities, and healthcare systems. Palliative care was nuanced and person-specific, which can make it very difficult to meaningfully capture and authentically relay through quantitative data. When a person was asked to encapsulate their quality of life using a Likert scale, the data may be true but did not represent the holistic nature of their story. Qualitative data was instrumental to creating the whole story but it does not replace qualitative data. Rather, it supports, supplements, and sometimes leads the understanding and the steps needed to address a challenge.

Question: What are some of the barriers in doing qualitative research? Developmental issues with very young children is one barrier and there is a need to know how accurate their responses reflect what they are feeling. What other barriers are there?

Answer: Dr. Kaye said that some of the barriers she heard about ten years ago were the same that she was hearing about now. There were opportunities to think through legitimate barriers and also to debunk fears that were packaged as barriers. One of the main concerns that people expressed about extensive qualitative research was the potential burden on individuals. Pediatric palliative care providers were acutely concerned about alleviating burden and no one wants to impose even more. But her instinct was that patients and families should be able to say what they feel is a burden or not. It is important to create a pressure-free opportunity to engage or not. She found that, overwhelmingly, patients and families during the highest stress moments of their lives valued an opportunity to share their perspectives. This could be in part because if helps them feel heard, seen, and valued as whole people. This is especially true when talking to bereaved families because it gives them an opportunity to be altruistic by helping other families, as well as an opportunity to honor their child's legacy. While some patients and families opt outed, many more were grateful for the opportunity to participate in qualitative research. She conducted another study in which one question was whether their participation experience was burdensome, painful, or useful. The vast majority of people during the worst moments of their lives said that participating was helpful—even though the goal of the research was not to be helpful but to gain knowledge to help others. Dr. Kaye encouraged researchers to push back when they were told that qualitative studies are burdensome.

Dr. Danielle Decourcey expressed that she had a similar experience. Her team had received a lot of pushback from IRB on a bereaved parent study, which included some open-ended questions about their experience. However, most parents wrote pages and pages of feedback about how sharing their children's stories, although distressing, was far more beneficial for themselves as well as for helping other parents.

Question: How do we bring in all the collective voices to create an environment that is focusing on the whole person, lifting up their values, and honoring the legacy of their child?

Answer: Dr. Decourcey said that it was important to include not only families and clinicians, but also nurses, nurse practitioners, social workers, and anyone else who was in the child's life. Palliative care was a very stressful environment and there was a real need to support both providers and researchers who are working in this field. Many clinicians worked in understaffed community hospitals and carry heavy workloads. They did not have time to think about improving quality of care, even if they recognized the need. Utilizing special interest groups through professional societies could be one way to reach sites without palliative care. There was a lot to understand about the different needs, as well as the different approaches that could provide support—such as online forums to discuss difficult cases or to equip clinicians with primary palliative care skills.

Question: What is the American Academy of Hospice and Palliative Medicine (AAHPM) doing to support research and giving voice to these lived experiences?

Answer: Dr. Kaye answered that there had been robust conversations, not just within the AAHPM, but also within the Palliative Care Research Cooperative Group PCRCG) and the National Palliative Care Research Center (NPCRC), focused on how to strengthen and support researchers in pediatric palliative care. AAHPM had a Research Scholars Program, which has funded a number of pediatric palliative care early career investigators. Being a part of this program also came with an invitation to the NPCRC's annual Kathleen Foley Palliative Care Retreat and Research Symposium, which was a stepping stone to the Kornfield Scholars Program Award. AAHPM also coordinated and executed a State of the Science meeting, which was a biennial conference that aimed to be a home for serious illness researchers. There was also a partnership between PCRCG and NPCRC to develop a federally funded consortium to support serious illness researchers and there are plans to prioritize the importance of serious illness research for children and families.

Dr. Kaye said that another new mechanism that was recently approved by AAHPM was the creation of research cores of experts to provide both methodological and grant writing support to early career investigators. They hope this will be a research mentor type of effort that would grow the community of early and mid-career investigators. Bringing people together in this subsidized way showed that their expertise and time had value. Dr. Kaye said that there will be social media and email communications to help recruit for this program. AAHPM had a research committee that did a lot of work to support research voices and goals, and could review investigator-led research concepts and study instruments, as well as white papers and position papers for advocacy efforts. The research committee also reviewed and scored scholarly works, including abstracts for the State of the Science meeting, and helped with the selection of research scholars. AAHPM also partnered with the *Journal of Pain and Symptom Management* on publications and had conducted systematic literature reviews. AAHPM was also putting together advocacy initiatives to support early career investigators in serious illness research. Additionally there had been a lot of discussion about how AAHPM could better support research in pediatrics and recently developed their Pediatric Member Council. Dr. Kaye invited participants to join the AAHPM listserv and other community-centered special interest groups.

Question: What compelled you to do this work and what lessons have you learned?

Answers: Dr. Ajayi said that it can be intimidating to start in research. But, research was only a question that one wanted to have answered and there were others who can help. It was important to not be intimidated because the research question was intended to improve the lives of patients and their families. There were many resources and groups available to help find the best way to answer these questions. Once one realizes that it is just a question to be answered, everything else falls into place.

Dr. Hinds added that there was now an additional resource that was not available 15 years ago, which was the number of national and international groups that have developed research priorities that have been grounded in parent perspectives. There has been consensus from national, international, and professional association on recommendations for pediatric palliative care. Although there were unique topics within each association, there were also commonalities such as communication training for healthcare professionals and decision making.

Dr. DeCourcey talked about the welcoming and friendly experience she had when transitioning into pediatric palliative care research later in her career. She recommended ensuring that one had a wide array of mentors and co-investigators in one’s network. These can be people one meets locally, but one should not be afraid to reach out to anyone in the field. People were welcoming and would help find someone else to help if they cannot.

Dr. Kaye said that there had been many times in her career in which she felt stuck, or she did not know how to navigate a research protocol, grant, or manuscript. What helped more than anything was centering on the storytelling. Ultimately, research was telling a story about why something matters, and people connect most when that story is told authentically and from a place of vulnerability and care. However, the research field does not train or incentivize that vulnerability, but rather rigor and testing. Dr. Kaye encouraged researchers to reset if something does not feel right and ask what the story is support to be and how it can be told in a way that matters to others.

Psychosocial Impact of Pediatric Palliative Care

Moderator: Lori Wiener, Ph.D., DCSW, LCSW-C

Family Impact of Serious Illness

Kim Mooney-Doyle, Ph.D., R.N., CPNP-AC, University of Maryland School of Nursing
Jennifer Siedman, M.Ed., Courageous Parents Network

Dr. Kim Mooney-Doyle talked about the impact that having a medically complex child in the family can have on siblings. Between 60 and 70% of children who receive pediatric palliative care have a sibling. Because of the disruption that serious illness can have on families, well siblings can often experience less parental attention, altered relationships with parents and siblings, poor communication, guilt, perfectionism, neglect, and invisibility. Parents were also impacted by the effects of having a medically complex child can have on all of their children, often experiencing guilt, distress, and uncertainty about how to support their well children.

Ms. Jennifer Siedman talked about her experience as a parent of three children, one of whom had a serious illness, and the difference that pediatric palliative care had on helping the family share in difficult decision making. She reflected on how their experience with pediatric palliative care came later in their journey, suggesting that early intervention might have had an even greater impact.

Dr. Mooney reviewed a number of recommendations for research that aligned with NICHD’s priorities. First, families and family health should be a priority in both the NICHD Strategic Plan and in their requests for proposals. Second, there should be a focus on family health equity and the impact of social determinants of health. Third, the interrelatedness of individual family members and the family unit should be considered, such as amplifying all youth affected by serious illness, and the impact on different developmental stages. Fourth, partnerships with families and communities living with serious illness should be encouraged and supported. Finally, innovative methodologies such as indigenous research methods, qualitative research, and community-based participatory research should be embraced.

Caregiver Impact of Serious Illness

Justin Yu, M.D., M.S., University of Pittsburgh, Pennsylvania

Dr. Justin Yu talked about the different impacts of caring for a medically complex child can have on a caregiver, such as financial and employment implications, uncertainty about the future, complex decision-making processes, and poor mental health outcomes. Additionally, both inpatient and outpatient care facilities are often understaffed and over capacity, exacerbating the burden on caregivers. Dr. Yu highlighted that the trajectory of a medically complex child was very unpredictable, which can hamper the ability to develop evidence-based interventions, strategies, and best practices for supporting family caregivers. Further, Black and other communities that experience poor social determinants of health were overrepresented among families with medically complex children.

Dr. Yu reviewed some of his research team's studies on caregiver mental health, which found that caregivers experienced high levels of anxiety, reduced ability to control emotions, and increased fatigue and sleep impairments. He offered future research directions that NICHD could considering going forward. First, descriptive and observational work should continue. Second, national, multicenter, longitudinal studies are needed to understand caregiver wellbeing and changes over time. Third, there needs to be a better understanding of how caregiver health and wellbeing impacts their child's health. Fourth, there needs to be better strategies for engaging families in research. Finally, there should be a focus on efficacious interventions that include nontraditional interventions such as peer support.

Panel Discussion

Question: If there was an efficacious intervention for parents or siblings, when would be the right time to implement it? Many would suggest that it should be as soon as possible, yet the first year or two often has so many other things going on.

Answer: Ms. Siedman said that it depended on the disease the medically complex child has. For example, her son was diagnosed with a rare disease at 15 months old but seemed very much like a typical child at that point. Her family needed interventions early on because she did not know how to explain what was going on to her other children. It would have also been helpful to have a mental health intervention early on. Families have to cultivate their own "palliative voice," which she and her husband did on their own. But that did not come naturally to many families, who need consistent support to help build that voice. She had not been referred to palliative care until they were facing a crisis. But in a crisis situation, a parent is often focused on so many things that they have diminished capacity to absorb anything right in front of them.

Question: Is there any research on the different inflection points that a family might experience, including any anticipatory changes in mental health?

Answer: Dr. Yu answered that there was no specific research he was aware of that objectively and psychometrically measured mental health in this context. There were qualitative studies, but nothing he was aware of that demonstrated changes in mental health over time. He stressed that it was a huge, important research area to address. For instance, there was a need to consider communication research in adult palliative care to determine whether it could be adapted. But the context was different and rigorous studies could inform not only how palliative care specialists communicate with families but also the primary care, ICU, and specialty care providers communicate.

Question: It can be difficult to get reimbursed or funded to support caregivers and siblings. Can research trials and interventions provide a bridge to that support?

Answers: Dr. Mooney-Doyle said that it was a great question because it interrogated the whole system. The payment system was made up by people and therefore could be questioned. She was part of a sibling research summit earlier in the year and the same question was brought up. There could be ways to offer services and support in places where siblings most reside. This could be community resources such as integrated mental health in the primary care setting or school nurses in the school environment. It was a challenge but that did not mean the topic should be put off for another time. Partnering with families and community organizations that work closely with families was important to identify the best ways to support siblings. A bedside nurse might not be the person providing the support, but could ask right questions and open up a conversation with a parent to connect them with community resources. The topic should be discussed and reimagined in terms of what was practical and possible.

Dr. Yu added that there was a need to weigh the pros and cons of conducting very rigorous clinical trials versus more pragmatic implementation research. There would likely always be a dearth of palliative care specialists. A future clinical trial should be focused on interventions that are basic skills for any clinician who might provide primary pediatric palliative care. They could integrate those skills into their routine practice. However, this did not solve the issue of reimbursement and time. But, there was a need to further expand and formalize education protocols for pediatric palliative care specifically.

Question: What can be done to improve bereavement care?

Answers: Ms. Siedman said that her experience with bereavement was that there was a short period of support after the death of a child. The family is launched into wondering how to cope and what to do next. A parent has to consider the entire family and pick themselves up to ensure that the rest of the family gets the care they need. It should be studied. In terms of financial reimbursement, the question could be about how much less is spend investing in interventions now versus waiting to see what might cost more later. Her family was a large consumers of therapy—both individually and as a group. Some of the therapy was related to her other children’s lived experience, but some was also about bereavement and different ways they process. There was a need to study anticipatory bereavement from the sibling perspective and consideration for changes in their identity. For example, a child can suddenly become an only child. It also differed between children—for example, her son’s identity change was very different than her daughter’s. Some of these changes did not manifest until five years after the death of her child. It is not a succinct timeline.

Dr. Mooney-Doyle added that bereavement intervention and support across the child’s life course fit very well with NICHD’s emphasis on preventative care. It could cross disease states and family members.

Ethical Challenges of Pediatric Palliative Care Research

Moderator: Mihaela Stefa, M.D., Ph.D.

Ethical Decision-Making ECMO, PICU, NICU

Katie Noynihan, M.B.B.S., Boston Children's Hospital

Dr. Katie Noynihan reviewed challenges in ethical decision making processes to sustain the lives of children with life-limiting diseases. Medical advances, such as the ExtraCorporeal Membrane Oxygenation (ECMO), had become normalized through the media as an effective means of survival. However, ECMO was highly invasive, resource intensive, and associated with high levels of morbidity and mortality. While technology had advanced, ethical decision making processes in the use of these technologies had not. As a result, death had become medicalized and framed as avoidable rather than normalized as a social event that everyone will experience. The legacy of structural discrimination and mistrust added another layer of challenge, and studies had shown that there was an association between social determinants of health and ECMO utilization.

Dr. Noynihan said that paradigm shifts were needed to advance the ethical decision making process for the use of medical technology in children. First, there was a need to collaboratively construct ethically-supported definition of beneficial therapy use around a goals. Second, there was a need to implement longitudinal process-based approaches to decision making that prioritizes accountability to advance health equity and regain societal trust. Third, precision medicine concepts could be applied to decision making and communication. Finally, novel approaches were needed to manage conflict.

For instance, decision making approaches should be immune to barriers such as cognitive and implicit biases and group think. Decisions with documented rationales could help discussions with families and hold institutions accountable. Health equity dashboards could offer a way to regain societal trust in medical decision making. High quality data were needed to identify disparities, prioritize targeted interventions, and advance health equity. Tailored communication strategies with balancing parameters to avoid bias could help families with difficult decisions. The next generation of clinicians needed tools and education to prepare them for ethical and shared decision making. Novel, accessible, and practical solutions were also needed to manage conflict.

Adolescent Decision-Making

Cindy Bell, Ph.D., R.N., Corewell Health

Dr. Cindy Bell talked about end of life communications among adolescents and young adults with serious illness. Adolescents and young adults tended to have a higher understanding about the finality of death and the emotional toll that it could take on themselves and their families. Often these individuals experienced a lot of social isolation and *mutual pretense* as a way to make others feel more comfortable about their end of life. Additionally, adolescents and young adults experienced physical, psychological, social, and spiritual changes as they grew up, which were compounded by their advanced disease. It was therefore important to understand their unique developmental needs, their priorities for palliative care, and ways to support their communication and decision making.

Dr. Bell reviewed research on adolescents and young adults with palliative care needs, which showed racial and ethnic disparities, intensified experiences due to psychosocial processes, and barriers to early advanced care planning. Research also provided evidence for effective interventions such as psychosocial stress management, mindfulness, legacy interventions, dignity therapy, and meaning-based therapy. The construct of readiness was another important topic, which was a dynamic process that spanned three main components: awareness (cognitive domain), acceptance (emotional domain), and willingness (behavioral domain). Dr. Bell said that NICHD could focus on finding a care home for this population, trust-building, expanding reach to non-malignant patients, interdisciplinary research for bio-psycho-social-spiritual needs, longitudinal and prospective studies, early intervention, and the need for psychosocial supports.

Panel Discussion

Question: Is there research on coping strategies for moral distress that providers experience related to prolonged patient suffering among professionals? What can help minimize this suffering?

Answer: Dr. Moynihan said that it was a challenging area. One of the key drivers of the moral distress was related to a lack of interdisciplinary communication about the reasons for and intentions of therapies and transparency about goal concordant care. It becomes challenging when there is no easy, accessible, or applicable recourse for challenging parental difference. However, goal concordant care and framing with staff could be one step to address and prevent moral distress. There was a difference between moral difference and moral distress. One way to make that more explicit was by increasing ethics and palliative care literacy among staff. Increasing interdisciplinary communication and transparency across the team was important, as was being transparent with families about realistically framing the feasibility of achieving goals.

Question: How far can ethics go in terms of managing conflict and when does one think about non-ethics dominated approaches about how to adjudicate and manage conflict?

Answer: Dr. Moynihan answered that high quality communication and mediation strategies could go a long way toward preventing conflict. Personalizing an approach, holding the patient at the center, and having preemptive conversations for anticipatory guidance—in combination with a process-based approach—can be very helpful. Framing decisions as more legitimate because they had followed these approaches can seem more robust, which can impact group think and cognitive biases. There needed to be a more accessible and practical path for providers. Early training with the next generation of palliative care providers and ethics consultants will bring the skills needed to develop therapeutic relationships and mitigate conflict so that what is in the best interest of the child can be defined. But conflict can happen even with great communication and sometimes an institution will face a very sticky ethical decision. Using the same language about goal concordant care across the medical and palliative care communities was a key step.

Question: Given the insights from the literature, how can the field move into implementation and better practices?

Answer: Dr. Bell said that asking permission to talk about an approach was a wonderful way to start a conversation and give the patient a voice for their needs. One might ask ‘is it okay if I talk to you about this concern?’ or ‘can you tell me more about that?”. This sought permission to create a space in the clinical setting that opened this conversation. Equally, providers needed to look honestly at when they shut down these conversations and to not be too quick to move to chance of a cure.. There was a need to teach providers to be flexible, how to recognize open awareness, and recognize where and with whom a patient wants to process some of their emotions. It was a hard space for a provider to be in. It was important to recognize when they felt the need to shut down because it the conversation was too hard and to recognize that this was an opportunity and a place to process. Pulling in other people who are experts can also help with some of the psychological challenges.

Question: Can you further address how to have a conversation about ECMO in a palliative care discussion in terms of the use of time-limited trials and approaches to comfort care when ECMO fails? Should a palliative care consultation occur before ECMO is started?

Answer: Dr. Moynihan answered that there was often not an opportunity to have that conversation because it used an emergency-instituted therapy. While it would be ideal to have a preemptive conversation, there was a need for a communication path once it has already started. Clear and early introduction about what ECMO is and its risks was very important. ECMO was a bridge to a goal, and it was important to define those goals with the family early on. Using time-limited trials is another way to frame ECMO. Talking to families about ECMO as a therapy with a specific purpose instead of an indefinite machine was very important. Primary palliative care skills should be a core competency for all intensive care clinicians. The next generation of pediatric critical care trainees should have these skills.

Question: Can you speak more about moral difference versus moral distress?

Answer: Moral difference was related to goal concordant care, in which providers align with the patient's and family's values. While something might not be what a provider would do for their loved one, there was a need for providers to acknowledge that these are moral differences and not specifically related to a moral distress. The definition of moral distress was when a provider is forced to provide care that is not aligned with moral compass. There were some extreme circumstances in which professional integrity and responsibility to the child comes into conflict. That can be a grey area and can be better articulated with ethics and palliative care literacy about goal concordant care.

Building the Field of Pediatric Palliative Care

Moderator: Tessie October, M.D., M.P.H.

Workforce Needs

Tammy Kang, M.D., MSCE, FAAHPM, Baylor College of Medicine, Texas Children's Hospital

Dr. Tammy Kang talked about challenges in the pediatric palliative care workforce, including the inability to meet the high need, lack of training, lack of funding, racial and ethnic disparities, and workforce burnout. There was an ongoing need for early intervention, including automatic, mandatory, or trigger consults, spanning a wide scope of serious illnesses. There was also a need to integrate families and siblings into the process and support for providers to navigate those the distrust and other intricacies involved in taking care of a child with serious illness. Pediatric palliative care should be available across different settings, such as the home, the community, community-based hospitals, and academic medical centers, as well as incorporate different languages and cultures. Although the majority of hospitals reported having a pediatric palliative care program, less than half had a full-time staff member. Further, less than half of the programs meet national guidelines and standards.

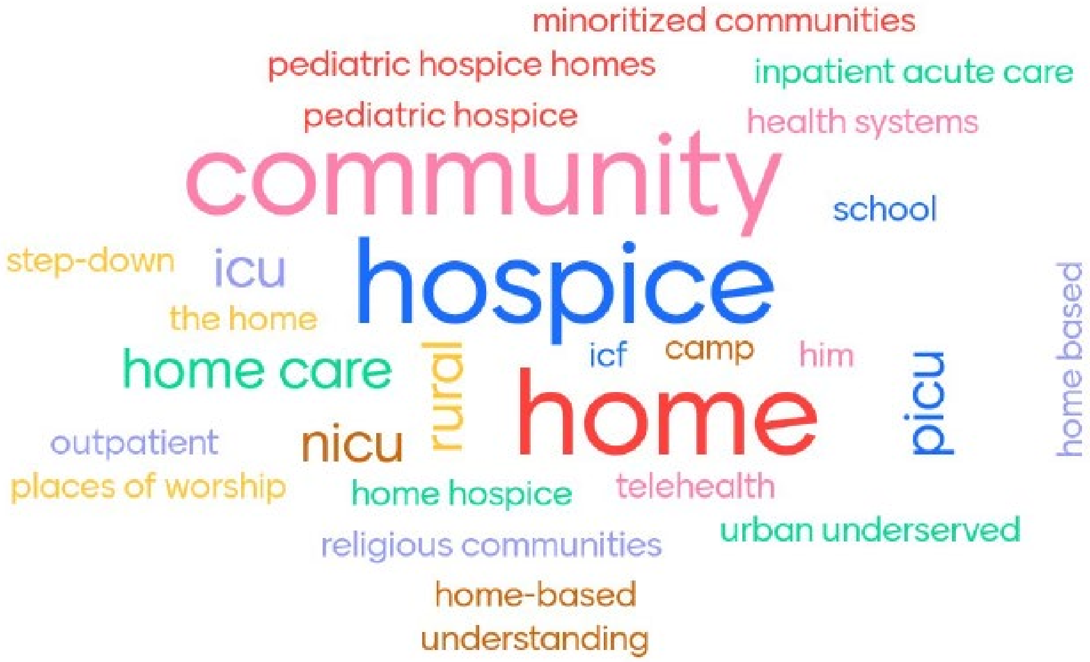
Dr. Kang reviewed the training gaps needed to build the next generation of pediatric palliative care providers. Only 30 of the 185 accredited training programs support pediatricians in hospice and palliative care. Many of those who do enter palliative care training do so as a dual track, with the intend to spend only a portion of their time dedicated to palliative care. Funding for training programs was variable and limited, and there is also limited funding for research in pediatric palliative care. As a result, the number of pediatric palliative care specialists is shrinking while the demand continues to grow—resulting in workforce burnout. There was a need for career training opportunities for mid-career providers and junior investigators, flexible and creative funding mechanisms, and alternate training pathways.

Top 5 Research Questions: Speed Round

Tammy Kang, M.D., MSCE, Baylor College of Medicine, Texas Children's Hospital
Chris Feudtner, M.D., Ph.D., M.P.H., Children's Hospital of Philadelphia
Abby Rosenberg, M.D., M.S., M.A., Dana-Farber Cancer Institute, Massachusetts
Renee Boss, M.D., M.H.S., Berman Institute of Bioethics
Erica C. Kaye M.D., M.P.H., FAAHPM, St. Jude Children's Research Hospital
Jori Bogetz, M.D., Seattle Children's Hospital

Dr. October invited the panelists to discuss their top research questions and asked the audience to participate..

The first question was, “Using one word or a short phrase, what population has the most pressing need for research investigation?” The responses of 62 participants were represented in the following word cloud.



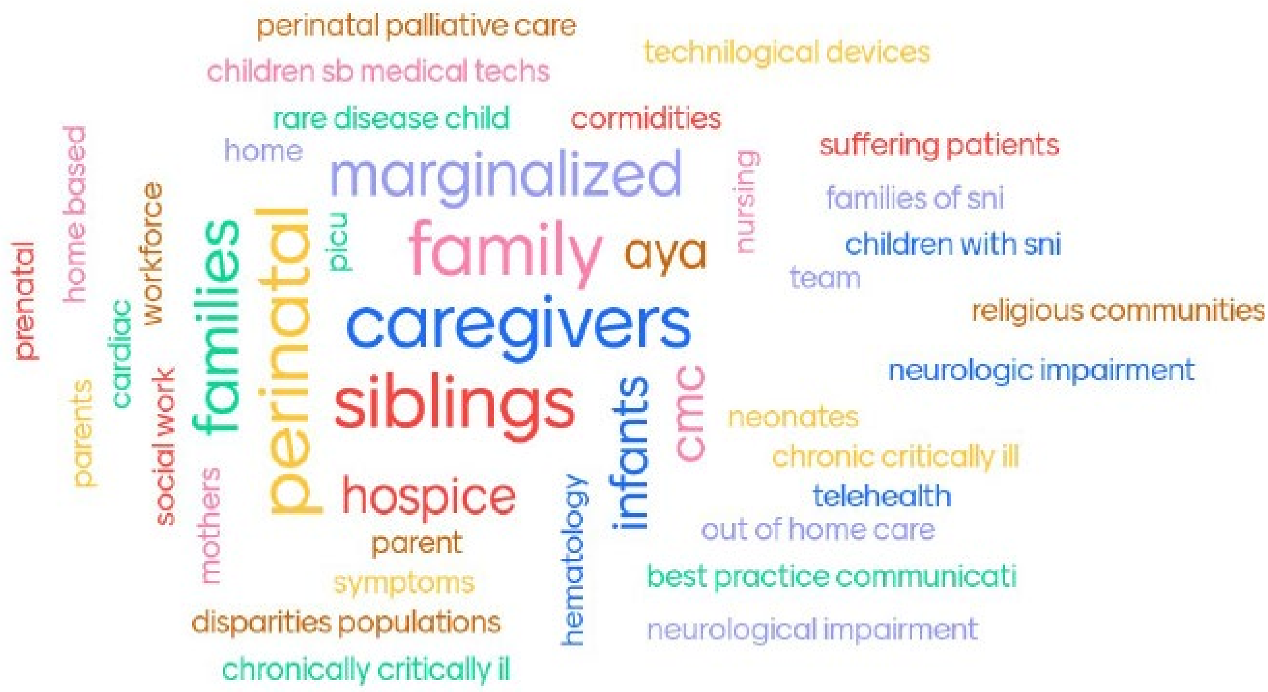
The panelists responded to the word cloud results. Dr. Boss said that she had found it curious how little research there was in perinatal palliative care because infants were so likely to die in the first few days of life. There were a lot of research opportunities and opportunities to collaborate with fetal interventionists, obstetricians, and maternal-fetal medicine specialists.

Dr. Kang said there was a lack of a trained workforce in perinatal palliative care.

Dr. Feudtner said that, from an epidemiological perspective, patients suffering from physical distress was a population that transcended any particular group. But providers often make educated guesses about how to mitigate their symptoms. Symptom management was a broad problem for many children with real repercussions on the family, but there were inadequate strategies.

Dr. Bogetz added that marginalized populations was one focus area, as well as ensuring that lived experiences of the child, family, siblings, and caregivers was captured.

The second question was, “Using one word or a short phrase, what setting is currently missing or needs more attention?” The responses of 63 participants were represented in the following word cloud.



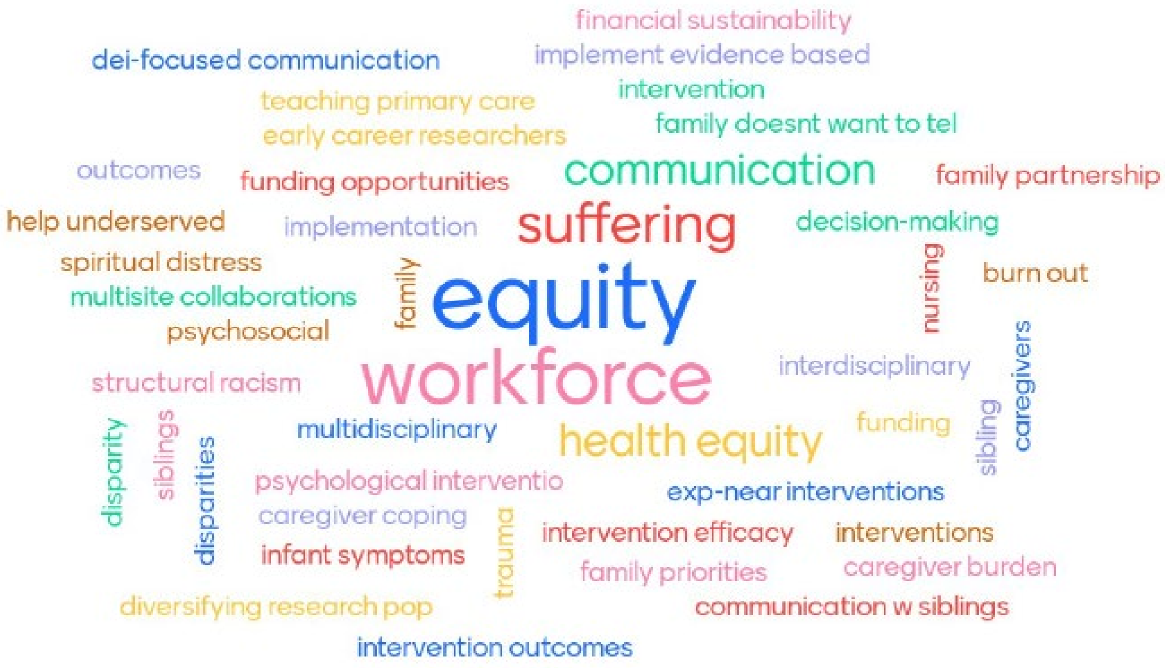
The panelists responded to the second word cloud. Dr. Bogetz commented on the variety of areas that need more research and highlighted the work of Jackelyn Boyden on what families need in the home, hospice, and community settings.

Dr. Kang agreed there was a need to better understand what was happening in the home, hospice, and community. She added that families and siblings were already stretched thin and that compensation for their participation in research would be helpful. Families were often challenged to find even five minutes to participate in a qualitative study. Underrepresented families were another consideration. Often, surveys were sent via email, and a family might not have a computer or a phone, or they could not complete a survey because it is not in their preferred language. It was important to understand what families consider most important and valuable, while also respecting their time and all of the challenges they were facing.

Dr. Boss said that it was also a challenge to collect data from the workforce. Staff providing palliative care services at the home, hospice, or community settings were already stretched thin. It can be easier to find time with an ICU provider than a general pediatrician who only has seven minutes to obtain their perspectives about what was working or not.

Dr. Feudtner said that, epidemiologically, it was known that most deaths in children, and almost all deaths in infants, occurred in hospital settings. Even among children with complex chronic conditions who received care at home, most of their key events occurred at a hospital during a crisis. It would therefore be important to not miss what was happening in hospital settings. He agreed that the home setting was also important because studies show most children spend the year before their death at home. In addition, there was a national crisis in the home nursing system that was having incredible repercussions on the types of care families could receive for their child at home.

The third question was, “Using one word or a short phrase, what is the most urgent topic for pediatric palliative care research?” The responses from 63 participants were represented in the following word cloud.



The panelists responded to the third word cloud. Dr. Kang said that illness often occurred over several years and family bereavement could also continue over a decade or more. It would be difficult to prioritize limited research funding to answer questions that might not have answers for more than ten years. The priority should be the questions that can actually be answered and that could make some headway.

Dr. Bogetz commented on the importance of centering equity in the word cloud, which was a strong direction to focus on. Much of this research would be rooted in community-based approaches and co-development of interventions. She emphasized the need to invest in career development awards to ensure there were researchers available to work in this field.

Dr. Boss commented that suffering was a priority. When a child was suffering, nothing else mattered to the family and it had to be resolved before anything else can be addressed. Symptom management and polypharmacy were also important areas to understand.

Dr. Feudtner said that intervention efficacy and effectiveness was a priority in terms of symptom management. It was important to understand what could relieve suffering in very clearly defined populations with a defined source of suffering. It was also important to ensure that interventions were applied equitably. He expressed concern that there were no means to improve outcomes in terms of equity and that equity and suggested that effectiveness should always be addressed together. He added that implementation science and dissemination of research was important in terms of doing things better and doing them better across multiple settings.