

MyPref: An Adaptive Conjoint Analysis-based Communication and Cancer Treatment Decision-Making Tool for Adolescents with Advanced Cancer (RP400)

Presenter: Jennifer Snaman, MD, Dana-Farber Cancer Institute and Boston, Boston, MA
Gabrielle Helton, BA, Dana Farber Cancer Institute, Boston, MA
Eve Wittenberg, PhD, Harvard University, Boston, MA
James Tulsky, MD,FACP,FAAHPM, Dana-Farber Cancer Institute, Boston, MA
Joanne Wolfe, MD,MPH,FAAHPM, Dana-Farber Cancer Institute, Boston, MA

Objectives

1. To describe adaptive conjoint analysis methodology and the use of this methodology in decision making.
2. Recognize the value of use of this novel communication and decision-making tool to engage Adolescent and Young Adult patients with cancer in conversations around preferences for care.
3. To develop prospective ways to utilize MyPref to conduct longitudinal conversations with Adolescent and Young Adult patients to provide high quality, preference-based care in advanced cancer.

Abstract

I. Importance: Adolescents and young adults (AYAs) with cancer receive high intensity care and experience significant symptoms at the end of life. As novel therapies increase, AYAs face multiple treatment options, each with unique risk/benefit profiles.

II. Objective(s): To engage AYAs in decision-making, we developed *MyPref*, an adaptive conjoint analysis-based tool. Following completion of *MyPref*, participants received a summary of their preferences for 9 treatment-related factors identified during pre-testing (such as side effects, quality of life, or route of treatment). We conducted a mixed-methods pilot study to examine the utility and acceptability of *MyPref* in AYAs with advanced cancer, their parents, and oncology providers.

III. Method(s): Patients and their parents independently completed *MyPref*, the *MyPref* Experience Questionnaire (MPEQ), the Preparation for Decision Making (PrepDM) scale, and a semi-structured interview. Providers completed an example *MyPref*, MPEQ, and interviews. MPEQ and PrepDM results were analyzed descriptively. Interviews were audio recorded, transcribed, thematically coded, and analyzed.

IV. Results: Fifteen AYAs, 7 PTPs and 11 providers participated in the pilot. Participant's preferences were varied, however, most participants prioritized quality of life and time until the cancer progresses. All AYA and parent participants agreed or strongly agreed that *MyPref* was easy to understand and complete and would be useful for other AYAs. All agreed that *MyPref* prepared them to make a better decision and talk to their doctor about what matters most to them. No participants experienced stress due to participation. All providers rated *MyPref* as quite a bit (3) or very helpful (8).

V. Conclusion(s): *MyPref* appears to be acceptable to AYA patients, their parents and oncology providers and useful in helping patients prepare for future treatment decisions.

VI. Impact: The *MyPref* tool may be a useful way to engage AYAs with advanced cancer and their parents in longitudinal discussions around preferences for treatment and prepare AYAs for future decision-making.

Identifying the Many Functions of Communication in Pediatric Oncology: Perspectives of Parents (RP401)

Presenter: Bryan Sisk, MD, Washington University School of Medicine in St. Louis, St. Louis, MO

Lindsay Blazin, MD, St. Jude Children's Research Hospital, Memphis, TN

Jennifer Mack, MD MPH, Dana-Farber Cancer Institute, MA

Justin Baker, MD, FAAP, FAAHPM, St Jude Children's Research Hospital, St Jude Children's Research Hospital, TN

Objectives

1.Explain the core functions of communication in pediatric oncology

2.Hypothesize novel interventions that will target the functions of communication in pediatric oncology

Abstract

I. Importance: Communication between clinicians and parents fulfills several important functions, but these functions have not been directly studied in pediatric oncology. A clear understanding of these functions is necessary to better support families now and to develop effective communication interventions in the future. In adult oncology, a National Cancer Institute consortium identified six communication functions: exchanging information, making decisions, responding to emotion, enabling self-management, fostering healing relationships, and managing uncertainty. We hypothesized that communication in pediatric oncology has functions not represented in adult oncology.

II. Objective(s): To identify the functions of communication in pediatric oncology from the parental perspective.

III. Method(s): Semi-structured interviews with 63 parents of children with cancer from 3 institutions (Washington University, St. Jude Children's Research Hospital, Dana-Farber Cancer Institute) at 1 of 3 time points: active treatment, survivorship, bereavement. We analyzed interview transcripts using inductive and deductive coding strategies. Adult communication functions served as an *a priori* framework for codebook development.

IV. Results: We identified 8 distinct functions of communication in pediatric oncology. Six of these functions are similar to previous findings from adult oncology, though these functions manifested differently in pediatrics: (1) building relationships, (2) enabling family self-management, (3) exchanging information, (4) making decisions, (5) managing uncertainty, and (6) responding to emotions. We also identified 2 novel functions not previously described: (7) supporting hope and (8) validation. Supporting hope was operationalized by providing reassurance and redirecting towards hope beyond survival. Validation was operationalized by reinforcing "good parenting" beliefs, empowering parents as partners and advocates, validating concerns, and celebrating successes.

V. Conclusion(s): Parental interviews provided evidence for 8 distinct functions of communication in pediatric oncology.

VI. Impact: Clinicians can use this framework to better understand and fulfill the communication needs of parents. Future interventions should target these communication functions.

Popular Smartphone Apps to Improve Wellness and Reduce Stress: Science or Snake Oil? (RP402)

Presenter: Nancy Lau, PhD, University of Washington School of Medicine/Seattle Children's Hospital, WA

Alison O'Daffer, BA, Seattle Children's Hospital, Seattle, WA

Susannah Colt, MA, Seattle Children's Research Institute, Seattle, WA

Joyce Yi-Frazier, PhD, Seattle Children's Research Institute, Seattle, WA

Tonya Palermo, PhD, University of Washington, Seattle, WA

Abby Rosenberg, MD,MA,MS, Seattle Children's Hospital, Seattle, WA

Objectives

1. Audience participants will be able to: Describe the breadth of popular wellness apps for stress management, understand the relative lack of evidence for efficacy, and identify the few apps with scientific backing.

2. Audience participants will be able to: Identify novel strategies to gauge the merit of the smartphone apps that providers, patients, families, and self-help seekers may be using for stress management and psychosocial coping.

Abstract

I. Importance: In an oversaturated market of commercially available smartphone apps for psychosocial self-care, providers, patients, and consumers interested in mental health-related apps may wonder which, if any, are efficacious. Metrics available to consumers include user popularity and media buzz. When an app purports to be based in science, its “scientific backing” may not reach classical standards of clinical rigor.

II. Objectives/Research Questions: What are the therapeutic content/features of commercially available stress management apps? Do any of these apps have evidence of efficacy?

III. Methods: First, we conducted a systematic review of commercially available apps on Apple and Google Play platforms utilizing conventional self help-seeking search terms related to stress management. Results were limited to free, English-language apps. Apps were independently evaluated for inclusion and discussed to reach 100% consensus. Second, a traditional literature review was conducted on the apps identified for inclusion, in search of studies with original data collection.

IV. Findings: We found 1,009 stress management apps. Content varied widely, from gratitudes to hypnosis. The most common evidence-based strategy was mindfulness/meditation, followed by positive psychology and goal-setting. Most apps were intended to be used as standalone interventions with only 5% targeted at psychological disorders, and <1% for chronic illnesses.

Fewer than 1% (n=19) had original research publications. The most common therapeutic components for this subset were relaxation, cognitive behavioral therapy, positive psychology, mood/symptom monitoring, and mindfulness/meditation. The “Headspace” mindfulness app had the most evidence, including 7 randomized trials. Most other scientifically backed apps were supported by a single feasibility or efficacy study.

V. Conclusions & Impact: Fewer than 1% of commercially available stress management apps that self-help seekers would find on their smartphones have evidence of efficacy. Clinicians and investigators may use these findings to help patients and families navigate the volume of emerging digital health interventions for stress management and wellness.

Facilitators and Barriers of Advance Care Planning Discussions with Adolescents, Young Adults and Parents of Children with Serious Illness (RP403)

Presenter: Lindsay Partin, BS, Boston Children's Hospital, Boston, MA

Danielle DeCoursey, MD, MPH, Boston Children's Hospital, MA

Anna Revette, PhD, 617-632-2364, Boston, MA

Joanne Wolfe, MD, MPH, Dana-Farber Cancer Institute, Boston, MA

Objectives

1. Describe the advance care planning communication preferences of children, adolescent and young adults with serious illness and their families.
2. Describe multidisciplinary clinicians current approach to advance care planning communication as well perceived facilitators and barriers to initiating advance care planning discussions with adolescents, young adults and parents of children with serious illness.
3. Discuss opportunities for further research to improve advance care planning communication for children and AYAs with serious illness and their families.

Abstract

I. Importance: Parents desire earlier and more opportunities for advance care planning (ACP), however, large scale adoption of ACP for seriously ill children, adolescents, and young adults (AYAs) remains unrealized. Little is known about the perceived facilitators and barriers of ACP discussions.

II. Objective(s): To explore multidisciplinary clinician perceptions about typical approaches and perceived facilitators and barriers to ACP discussions.

III. Method(s): Semi-structured focus groups and individual interviews were conducted with multidisciplinary clinicians at two centers from December 2018-April 2019. An interdisciplinary three-person team then conducted thematic analysis incorporating both prefigured and emergent codes. Through an iterative process, a comprehensive coding structure was created, and each transcript coded independently by two coders with the third serving as an adjudicator, achieving high interrater reliability ($\kappa>0.85$). Utilizing grounded theory and framework analysis, we present findings related to clinician perceptions about current approaches to ACP, and facilitators and barriers to ACP discussions.

IV. Results: The sample included 35 stakeholders including physicians, nurses, psychosocial clinicians, and chaplains. Overall, providers valued facilitating ACP conversations with patients and their families and aimed to do so by supporting, empowering and establishing trust. Providers prioritized understanding family dynamics, establishing goals of care, and delineating the overall disease trajectory in ACP discussions. However, various factors impeded ACP discussions. Primary clinician level barriers included limited communication skills, prognostic uncertainty, competing demands and conflicting messaging associated with multidisciplinary team care, while perceived patient and family level barriers included poor prognostic awareness, avoidance, complex patient/family dynamics and the influence of culture and religion. Clinicians identified alignment with the patient's primary team and normalization as facilitators of ACP discussions.

V. Conclusion(s): Despite ubiquitous recognition of the importance of ACP communication, various clinician and parent level barriers were identified which do not meet the needs of children and AYAs with serious illness and their families.

VI. Impact: Improvement strategies should prioritize serious illness communication interventions to facilitate ACP and ensure care is aligned with patient and family goals and values.

When Cancer Survivors Become Cancer Caregivers: Psychosocial Effects on Couples (RP404)

Presenter: Maija Reblin, PhD, Moffitt Cancer Center, FL
Dana Ketcher, PhD, MPH, CPH, Moffitt Cancer Center, Tampa, FL
Amy Otto, PhD, Moffitt Cancer Center, Tampa, FL

Objectives

1. Describe the psychosocial impact of being a cancer survivor caring for a spouse with an advanced cancer diagnosis
2. Compare the psychosocial outcomes of those experiencing dual roles of cancer survivor and cancer family caregiver.

Abstract

I. Importance: As early detection and treatment improves, more people become cancer survivors, making it increasingly common that survivors eventually care for a spouse also diagnosed with cancer. Understanding these relationships is crucial to understanding patient-caregiver dynamics.

II. Objective: Describe the impact of advanced cancer caregivers' personal history of cancer on their own and the patients' psychosocial outcomes using quantitative and qualitative methods.

III. Method(s): Eighty-eight advanced cancer patients and their spouse caregivers completed questionnaires. Caregivers also completed a brief qualitative interview about coping strategies. Data from dyads including caregivers with and without a personal history of cancer were compared.

IV. Results: Eleven caregivers were cancer survivors. These caregivers were mostly white ($n=10$), 64 years old on average, and married for 30 years ($SD=9.32$). There were no significant differences in demographics, anxiety, or depression between survivors and non-survivors. Survivors reported higher preparedness for caregiving than non-survivors ($t=2.479, p=.01$). Patients whose caregivers were survivors reported higher depression symptoms than patients whose caregivers were not survivors ($B=2.371, SE=1.009, t=2.349, p=.021$). During interviews, only 3 survivor caregivers referenced their own cancer. Survivor caregivers did, however, report drawing upon shared cancer experiences from other family members and support groups as a coping strategy.

V. Conclusion(s): Caregivers' personal cancer history may give them tools to prepare for caring for a spouse with cancer. However, they may prefer to focus on the patient rather than their own past experiences. Patients with a survivor caregiver may report higher levels of depression because of their own prior experience with cancer as a caregiver. Caregivers also reported not speaking with the patient about their own cancer experience, suggesting avoidance and/or a desire to avoid upsetting the patient by bringing up their own concerns.

VI. Impact: Cancer survivorship may impact caregiving for others with a cancer diagnosis. More research is needed to understand this relationship.

Relating physical decline with reevaluating goals of care: a qualitative study of young men with Duchenne Muscular Dystrophy and their caregivers (RP405)

Presenter: Daniel Grossoechme, DMin, MS, Akron Children's Hospital, Akron, OH

Rachel Thienprayoon, MD,FAAHPM, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Hemant Sawnani, MD, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Ian Rossman, MD, PhD, MS, Akron Children's Hospital, Akron, OH

Kathryn Mosher, MD, Akron Children's Hospital, OH

Sarah Friebert, MD,FAAP,FAAHPM, Akron Childrens Hospital, Akron, OH

Objectives

1.Identify at least two barriers to goals of care conversations in this population

2.Articulate the emergent theory of how adolescents/young adults with Duchenne Muscular Dystrophy relate disease progression with reevaluating their goals of care

Abstract

I. Importance: Duchenne Muscular Dystrophy (DMD) is a progressive, life-limiting disease that has evolved into a chronic illness of “unanticipated adults” living into their fourth decade. How these young men appreciate physical changes of disease progression, and whether and how they relate changes to care preferences, is unknown.

II. Objective(s): This knowledge is required in order to design interventions to improve goals of care (GoC) communication.

III. Method(s): We are executing a 2-site grounded theory study of young men with DMD (11 years and older), and their caregivers, using a semi-structured interview guide.

IV. Results: A total of 16 interviews are completed (n=10 caregivers; n=6 patients, median age 26 years, range 11-33). We anticipate completing 32 additional interviews (n=14 caregivers, n=18 patients). The following themes have emerged: (1) reconsideration of GoC is frequently deferred, in part due to extended periods of disease stability; (2) outpatient providers focus on immediate health status and inpatient providers focus on returning patient to baseline status, but neither focus on GoC; (3) lack of experience with autonomous decision making; and (4) patient trust that caregiver will make the best choice for them. Caregivers describe that preparation for physical changes and their implications is derived from DMD support groups. Patients describe that revised GoC focus on improving quality of life by increasing physical comfort and mobility, frequently with improvised devices. The interview guide will be revised to deepen understanding of why patients and caregivers who have GoC conversations believe they are important, and what factors make those conversations successful. Purposeful sampling to include more adolescents is needed.

V. Conclusion(s): Anticipated completion of data collection and analysis is winter, 2020. Community-based support groups may be an underutilized resource to promote reconsideration of GoC due to disease progression.

VI. Impact: We anticipate developing a final theory of how patients and caregivers relate disease progression to GoC, leading to intervention development.

Navigating autonomy during a vulnerable transition: Examining Patient and Caregiver Experiences of Transitions from the Hospital to the Home within a Palliative Care Program (RP406)

Presenter: Sarina Isenberg, PHD,MA, Sinai Health System, Toronto, ON

Stephanie Saunders, MA, Sinai Health System, Toronto, ON

Tieghan Killackey, MN,RN, University of Toronto PhD Nursing Science and Bioethics, Toronto, ON

Jaymie Varenbut, BSc, University of Toronto, Toronto,

Emily Lovrics, RN, Mount Sinai Hospital, Toronto,

Ramona Mahtani, MD, University of Toronto, Toronto,

Natalie Ernecoff, PhD, MPH, University of Pittsburgh, Pittsburgh, PA

Kerry Kuluski, PHD, Trillium Health Partners, Mississauga, ON

Mark Bernstein, MD, Sinai Health System, Toronto,

Russell Goldman, MD, Temmy Latner Centre, Toronto,

Camilla Zimmermann, MD, University of Toronto, Toronto,

Kirsten Wentlandt, PhD, MD, UHN, Toronto,

Objectives

1. To describe the patient and caregiver experience of the transition from hospital to home in the context of palliative care
2. To explore how the patient and caregiver experience of the transition might differ
3. To compare expectations of the transition experience to the reality of the transition

Abstract

I. Importance: Although transitions from hospital to the community are well-described, little is known about the experience of transitioning from inpatient palliative care (IPC) to home-based palliative care (HPC).

II. Objective(s): To examine patients' and caregivers' experiences during the transition from IPC to HPC.

III. Method(s): Longitudinal, prospective qualitative study with data collection prior to hospital discharge (Visit 1) and 2-3 weeks after discharge home (Visit 2). A constructivist critical theory orientation was used to conduct a grounded theory qualitative study. Adults receiving IPC who were being discharged to HPC, and their caregivers, were recruited from two academic health centres. Data were collected using semi-structured interviews, which were transcribed and coded using an inductive iterative process.

IV. Results: Twenty-four patients/caregivers completed Visit 1, of whom 16 also completed Visit

2. Patients'/caregivers' autonomy, or lack thereof, emerged as the central theoretical concept; this manifested in three ways: (1) Patients/caregivers receiving IPC felt powerless with regard to the timing of discharge, or the care that would be received at home; (2) Patients/caregivers receiving IPC felt they had more control over their home environment; (3) Patients/caregivers receiving IPC and HBC who felt they had limited support took control of their healthcare through trial and error strategies.

V. Conclusion(s): Shifts in autonomy were identified surrounding the transition from IPC to HPC. Patients and caregivers expressed feeling limited autonomy in the process; however, certain factors led to increased autonomy including discharge to home and learning strategies to cope with their illness at home.

VI. Impact: These findings can be used to help future palliative patients/caregivers navigate the changes they may experience on transitioning from IPC to HPC. Further, these results can inform the development of autonomy-enhancing interventions to improve the patient and caregiver experience of this transition.

Palliative Care Principles and Advance Care Planning in Pediatric Oncology: Prospective, Longitudinal Investigation of Communication Across the Illness Trajectory (RP407)

Presenter: Erica Kaye, MD, St. Jude Children's Research Hospital, Memphis, TN

Kendall Kennedy, BS, Morehouse School of Medicine, Atlanta, GA

Melanie Gattas, RN, St. Jude Children's Research Hospital, Memphis, TN

Justin Baker, MD, FAAP, FAAHPM, St Jude Children's Research Hospital, St Jude Children's Research Ho, TN

Objectives

1. Describe the evidence from a growing body of literature demonstrating the benefits derived from earlier integration of palliative care principles and advance care planning in the context of cancer care, as well as the barriers to discussion of these sensitive topics.
2. Discuss the value of studying prognostic communication, including discussion of palliative care principles and advance care planning, through qualitative analysis of conversations between clinicians, patients, and families recorded at high-intensity time points (e.g., disease reevaluation discussions) across the illness trajectory.
3. Describe the timing and content of discussion related to palliative care principles and advance care planning across the illness trajectory for children with high-risk cancer as found in this study, as well as review the commonalities that emerged regarding linguistic style, context, and prompts for discussion of these sensitive topics.

Abstract

I. Importance: In the field of medical oncology, palliative care principles and advance care planning are often discussed late in the illness trajectory, limiting the time available for nuanced discussions to guide goal-concordant care. Presently, the timing, frequency, context, and content of these critical discussions in the setting of pediatric cancer is not well understood.

II. Objective(s): To determine the frequency and timing of pediatric palliative care and advance directive discussions across the progressive illness course for children with progressive cancer and their families; to explore the linguistic styles/strategies used to introduce these sensitive topics and explore the statements that precede or prompt discussion.

III. Method(s): Serial disease reevaluation conversations between pediatric oncologists, children with progressive cancer, and their families were recorded across the illness trajectory. Following codebook development, mixed methods analysis of audio-recorded medical dialogue was conducted using MAXQDA software.

IV. Results: Approximately 38 hours of prognostic communication conversations were recorded for 16 patient-parent dyads across months to years, out of which a total of 44 minutes (2%) involved discussion related to palliative care principles or advance directives. Advance directives were discussed less frequently than palliative care principles, with 7 minutes' worth of coded dialogue (0.3% of total recorded dialogue). The vast majority (98%) of dialogue occurred following significant disease progression while on study. The most frequent codes were: quality of life, palliative chemotherapy, and goals of care. Common linguistic patterns emerged in the conveyance of these topics, along with similar contexts prompting discussion.

V. Conclusion(s): Palliative care principles and advance directives are discussed infrequently across the disease course for children with high-risk cancer. When discussed, patterns emerge regarding linguistic style, context, and prompts.

VI. Impact: These data offer opportunities to develop targeted interventions to encourage earlier discussion of palliative care principles and advance care planning for children with high-risk cancer and their families.

Exploring Parental Decision-Making Regarding Long-term Ventilation for Children With and Without Severe Neurological Impairment (RP408)

Presenter: Vasu Munjapara, BA, Johns Hopkins School of Medicine, Baltimore, MD

Renee Boss, MD, Johns Hopkins School of Medicine, Berman Institute of Bioethics, Baltimore, MD

Benjamin Wilfond, MD, Seattle Children's Hospital, WA

Carrie Henderson, MD, University of Mississippi, MS

Jessica Raisanen, MSPH, Johns Hopkins University, MD

Kelly Shipman, MS, CCRP, Seattle Children's Hospital, Seattle, WA

Nicholas Jabb, MD, Johns Hopkins Berman Institute of Bioethics, Baltimore, MD

Jori Bogetz, MD, Seattle Children's Hospital and Research, Seattle, WA

Objectives

1. Describe what is known about illness trajectory and risk for mortality in children with SNI who have LTV.
2. Analyze the differences between parents' recollection of clinician counseling regarding LTV between parents of children with SNI and without SNI.

Abstract

I. Importance: Decisions around long-term ventilation (LTV) in children should consider the child's illness trajectory. Data suggest that children with severe neurologic impairment (SNI) are at increased risk of LTV being lifelong once placed (permanent) and have increased mortality compared to those without SNI due to their underlying medical complexity.

II. Objective(s): To evaluate whether parents of children with SNI perceive clinician counseling regarding LTV differently than parents of children without SNI.

III. Method(s): We interviewed parents from three academic centers who were faced with a decision about LTV for their child within the last 5 years. Interviews were audio recorded and transcribed. Content analysis was performed within and across groups of parents according to their child's SNI status.

IV. Results: A total of 37 parents were interviewed; 24 with children with SNI and 13 with children without SNI. Among children with SNI, 46% had LTV and 83% were alive. Among children without SNI, 69% had LTV and 85% were alive. Parents of children with SNI perceived less certainty from clinicians regarding LTV permanence than parents of children without SNI. Despite this, mortality related to LTV was discussed with both groups and honesty about risk of death was appreciated by all parents. In contrast to parents of children without SNI, parents of children with SNI more often recalled detailed descriptions or examples provided by clinicians detailing how their child might die. This often caused distress and felt insensitive to parents.

V. Conclusion(s): Parents of children with SNI perceived less clarity from clinicians regarding LTV permanence compared to parents of children without SNI. Parents of children with SNI often experienced insensitive counseling about risk of death.

VI. Impact: More research and education are needed to improve clinician counseling of parents regarding LTV that meaningfully reflects the child's illness trajectory and provides honest information in a sensitive manner.

Poly-symptomatology in Pediatric Palliative Care Patients: Baseline Evaluation of SHARE Parent Reported Data (RP409)

Presenter: Chris Feudtner, MD,PHD,MPH, The Children's Hospital of Philadelphia, Philadelphia, PA

Ross Hays, MD, Childrens Hospital & Regional Med Ctr, Seattle Childrens Hsopital, WA

Stefan Friedrichsdorf, MD,FAAP, Children's Minnesota, Minneapolis, MN

Emily Johnston, MD, University of Alabama at Birmingham, Birmingham, AL

Sarah Friebert, MD,FAAP,FAAHPM, Akron Childrens Hospital, Akron, OH

Tammy Kang, MD, MSCE, FAAHPM, Texas Children's Hospital, Houston, TX

Joanne Wolfe, MD,MPH,FAAHPM, Dana-Farber Cancer Institute, Boston, MA

Objectives

- 1.Describe the study design of this study
- 2.Specify the 5 most prevalent symptoms in pediatric palliative care
- 3.Describe how symptom count, frequency, and severity contribute to poly-symptomatology

Abstract

I. Importance: Pediatric palliative care (PPC) teams care for patients with a wide variety of conditions, often with substantial medical complexity, making symptom management challenging. Parental report data regarding the frequency and severity of symptoms in these patients has been limited.

II. Objective(s): Characterize the prevalence, frequency, and severity of specific symptoms, as reported by parents of patients receiving PPC.

III. Method(s): Parent-reported data were gathered from baseline questionnaires in a two-year longitudinal study being conducted at 7 children's hospitals in the Pediatric Palliative Care Research Network (PPCRN) SHARE project. Data included child's demographic and clinical characteristics, and 15 symptoms measured via the Memorial Symptom Assessment Scale, which scores symptom frequency (1, almost never; 2, sometimes; 3, a lot; 4, almost always) and severity (1, slight; 2, moderate; 3, severe; 4, very severe).

IV. Results: Of the 501 PPC patients thus far enrolled with completed data, 55% were male, 66% white, mean age of 7.3 years (± 7.3 SD); the most prevalent complex chronic morbidities included neurologic (48%), cardiovascular (47%), and respiratory (34%) conditions; 72% were technology-dependent. Parents reported an average of 4.9 (± 3.3 SD) symptoms per patient. The five most common symptoms were pain (55%); among patients with pain, mean frequency, 2.6; mean severity, 2.3), lack of energy (53%; 2.8; 2.4), irritability (47%; 2.4; 2.1), drowsiness (43%; 2.6; 2.2), and shortness of breath (39%; 2.7; 2.4). 10% of patients had markedly elevated level of symptoms (minimal frequency and severity scores of "a lot" and "severe" for each symptom), with the typical patient in this subgroup having 6 symptoms.

V. Conclusion(s): A majority of children receiving palliative care are experiencing poly-symptomatology. An important sub-group of patients suffer frequently from numerous severe symptoms.

VI. Impact: Assessment and management of poly-symptomatology is a critical aspect of PPC.

Quality of Life of Children and Adolescents Undergoing Hematopoietic Stem Cell Transplantation is Negatively Affected by Psychological Distress Experienced by Their Parents: A Case for Pediatric Palliative Care (RP410)

Presenter: Chelsea Balian, CPNP, Children's Hospital Los Angeles, Los Angeles, CA
Jessica Ward, PhD, MPH, MSN, RN, cPNP, Children's Hospital Los Angeles, Los Angeles, CA
Paula Murray, PhD, Children's Hospital Los Angeles, Los Angeles, CA

Objectives

1. State the elements and trajectory of distress for parents caring for children and adolescents undergoing hematopoietic stem cell transplantation (HSCT) or chimeric antigen receptor (CAR) T-cell therapy.
2. Examine the impact of parent distress on symptoms and quality of life (QoL) experienced by children and adolescents undergoing HSCT or CAR T-cell therapy.

Abstract

I. Importance: Hematopoietic stem cell transplantation (HSCT) is curative for children with life-threatening conditions but can result in compromised quality of life (QoL). Parents provide extensive care for their children and can experience distress, yet the association between parent and child outcomes has not been sufficiently investigated.

II. Objective(s): To examine the impact of parent distress on QoL among children undergoing HSCT or chimeric-antigen receptor (CAR) T cell therapy.

III. Method(s): This multisite study employed a longitudinal, repeated measures design. English or Spanish-speaking children ages 2-18 years, with any diagnosis, and planned HSCT or CAR therapy were eligible. Beck Anxiety and Depression Inventories, the Perceived Stress Scale and the PROMIS Sleep and Fatigue Short Forms were administered to parents pre-HSCT/CAR, and day+30, +60, +90 post-HSCT/CAR. The PedsQL Cancer Module was administered to children (parent-proxy for younger children) at corresponding timepoints. Descriptive statistics and longitudinal parallel process (type of effect modeling) analyses were used to explore relationships between parent distress (a single factor consisting of sleep, fatigue, anxiety, depression and stress) and child outcomes.

IV. Results: To date, 139 child/parent dyads (278 participants) were enrolled across 4 sites. Child mean age was 8.3 years ($SD=4.9$), 57% were male, primarily with an underlying diagnosis of malignancy (68.9%). Most parents were mothers (79.1%), mean age of 38.9 years ($SD=8.1$). Parent anxiety, depression and stress scores were higher than normative means generated from non-psychiatric samples. A significant inverse relationship between parent distress and child QoL was found at baseline and over time post-HSCT. When parent distress was higher at baseline, child QoL was lower. When parent distress increased over time, child QoL decreased.

V. Conclusion(s): Findings suggest that parents experience heightened distress during the acute phase of their child's HSCT or CAR therapy, and this may impact their child's QoL.

VI. Impact: Up front palliative care involvement and integration should be considered for children undergoing HSCT or CAR therapy to address parent and child distress.

Supporting In-Home Caregivers in Symptom Assessment of Frail Older Adults with Serious Illness: A Pilot Study (RP411)

Presenter: Sarah Nouri, MD, MPH, University of California, San Francisco; Primary Care Research Fellowship, CA

Aiesha Volow, MPH, UCSF, San Francisco, CA

Christine Ritchie, MD, FAAHPM, University of California San Francisco, San Francisco, CA

Brookelle Li, BA, University of California, San Francisco, CA

Ismael Tellez, BA, UCSF, CA

Rebecca Sudore, MD, FAAHPM, UCSF & San Francisco VA, CA

Objectives

1. Describe the use of a Symptom Assessment (SA) Toolkit designed to support in-home caregivers of homebound older adults with serious illness.
2. Explore next steps in evaluation and dissemination of the Toolkit.

Abstract

I. Importance: Many older adults with serious illness who depend on others for care have symptoms that are difficult to manage. Supporting in-home caregivers in symptom assessment (SA) may improve suffering among older adults.

II. Objective(s): To test the feasibility of a SA-Toolkit for caregivers to assess and track older adults' symptoms.

III. Method(s): With multi-stakeholder input, we created a SA-Toolkit consisting of illustrations depicting symptoms, a validated 5-faces severity scale, and an easy-to-use tracking system with phone numbers of family/friends/clinicians to contact if symptoms worsened. We recruited English-speaking patients ≥ 65 years old and their caregivers from a home-based geriatrics program in San Francisco. Using validated questionnaires at baseline and 1-week, we assessed patients' symptoms, patients' and clients' self-efficacy with SA (5-point Likert scale), and acceptability (i.e., recommend to others). We used Wilcoxon signed-rank tests.

IV. Results: Eleven patient-caregiver dyads participated. Patients were 84.7 years old (SD 5.7), 81.8% women, and 27.3% non-white. From baseline to 1-week, the mean number of symptoms decreased (3.7 (1.5) at baseline to 2.6 (1.8) at follow-up, $p=0.03$). Specifically, the number of patients with pain decreased from 63.6% to 36.4%, anxiety 54.6% to 18.2%, depression 45.5% to 27.3%, and loneliness 36.4% to 18.2%. Caregiver self-efficacy increased (4.6 (0.3) to 4.8 (0.3), $p=0.09$). Patients found the symptom illustrations easy-to-use (8.7 on 10-point scale), but the faces scale less so (7.3/10) because it provided "too many choices." Caregivers liked the SA-Toolkit because it was "easy to use"; nearly all (10/11, 90%) would recommend it to others. Suggested improvements included personalizing materials according to patients' symptoms.

V. Conclusion(s): The SA-Toolkit resulted in decreased symptom burden among patients and higher caregiver self-efficacy in symptom assessment. Acceptability of the Toolkit was high among both patients and caregivers.

VI. Impact: A SA-Toolkit is feasible and may help reduce suffering in frail, older patients.

Difficult Conversations: Telling Adolescents about a Parent's Life Limiting Illness and Death (RP412)

Presenter: Mary Mayo, PhD, RN, retired, OH

Denice Sheehan, PhD, RN, Kent State University, Kent, OH

Dana Hansen, PhD, APRN, ACHPN, Kent State University, Kent, OH

Pam Stephenson, PhD, Kent State University, Kent, OH

Objectives

1. Describe two ways parents informed their adolescents of a parent's life limiting illness and death.
2. Identify 1 way healthcare professionals can assist families with disclosure.

Abstract

I. Importance: When a parent is diagnosed with a life limiting illness, one of the most difficult tasks facing the parents is informing their children. This study describes four ways in which parents disclose information about a parent's life limiting illness and death to their adolescent children.

II. Objective(s): To explicate ways in which parents tell their adolescents about a parent's life limiting illness and death.

III. Method(s): Descriptive qualitative methods were used. Data were drawn from and 56 individual pre-death and 15 post death interviews with hospice patients, spouses and their adolescent children; all were part of a larger grounded theory study on strategies to help adolescents with a parent in hospice. The interviews were digitally recorded and transcribed verbatim. The transcripts were coded and analyzed using conventional content analysis techniques.

IV. Results: Parents informed adolescents about a parent's life limiting illness and imminent death in ways that were intended to ease the adolescents' distress. The parents engaged in the process of disclosure in one of four ways: measured telling; skirted telling; matter-of-fact telling; inconsistent telling.

V. Conclusion(s): The findings support a framework that describes the processes of disclosure of a parent's illness, imminent death and death to their adolescent children. Pre death findings about the ways the adolescents were informed were consistent with the post death findings.

VI. Impact: These results can be used to inform the development of interventions in which health care professionals assist families with disclosure pre and post death by tailoring strategies according to the family's communication style.

Provider Views on Integrating Family Caregivers in Clinical Encounters (RP413)

Presenter: Rachel Havyer, MD,FAAHPM, Mayo Clinic, MN

Karen Schaepe, PhD, Mayo Clinic, MN

Joan Griffin, PhD, Mayo Clinic, MN

Objectives

- 1.Critique, from the view of providers, the potential benefits and drawbacks of integrating family caregivers into clinical encounters.
- 2.Describe provider attitudes, beliefs and ethical and clinical considerations that may affect the integration of family caregivers into clinical encounters.

Abstract

I. Importance: Family caregivers frequently accompany patients to clinical encounters, particularly when dealing with serious illnesses. Family caregivers, however, are not often invited to be active participants in clinical encounters. Little is known about provider perceptions on engaging caregivers in clinical encounters.

II. Objective(s): Our aim was to better understand providers' perceptions on engaging caregivers during clinical encounters.

III. Method(s): Twenty providers in primary, specialty, or palliative care from our institution in 3 distinct geographic areas of the United States (southeast, midwest, and southwest) were invited by email to participate in individual interviews (via telephone or in-person). Using a standard interview guide, providers were asked about their previous experiences with caregivers in clinical encounters and their views about integrating caregiver assessment into clinical encounters. Data were inductively analyzed using a thematic approach.

IV. Results: We identified 3 themes among this sample of providers regarding: 1) the appropriate role of caregivers in the clinical encounter; 2) effectively managing the conversation when caregivers are involved; and, 3) the systemic barriers to caregiver integration. Providers chiefly view caregivers as sources of supplemental information or as absorbers or reinforcers of clinical instructions for care at home. Providers voiced concerns about the ethics of assessing caregiver capacity to provide assistance to the patient without having clinical authority to treat the caregiver or the adequate resources to provide help to the caregiver. Finally, providers identified structural barriers, including time constraints, for integrating caregivers into the clinical visit.

V. Conclusion(s): These findings provide insight into provider attitudes on the family caregivers' role in clinical encounters, a perspective that is essential for understanding opportunities and challenges for implementing caregiver interventions in clinical settings.

VI. Impact: Further work is needed to identify the best strategies to overcome barriers to integrating caregivers in clinical encounters in order to improve the holistic care of patient-caregiver units.

Health-Related Quality of Life of Parental Caregivers of Children with Medical Complexity (RP414)

Justin Yu, MD, University of Pittsburgh Clinical and Translational Science Institute, PA
Kristin Ray, MD, MS, University of Pittsburgh School of Medicine, PA

Objectives

1. Recognize that parental caregivers of medically complex children report mental health that is poorer than their physical health.
2. Differentiate which aspects of care coordination support are associated with higher reports of mental health-related quality of life among parental caregivers of children with medical complexity.

Abstract

I. Importance: Caregiver health affects health outcomes of those being cared for. Little is known about the health of parental caregivers of children with medical complexity (CMC) or whether receipt of care coordination support is associated with improved caregiver health.

II. Objective(s): To examine the health-related quality of life (HR-QOL) among CMC parental caregivers and the association of HR-QOL with caregivers' experiences of care coordination.

III. Method(s): Parental caregivers of CMC previously treated in community practices were surveyed from July 2018 to July 2019. The Center for Disease Control's HR-QOL-14 assessed caregivers' HR-QOL. The Family Experiences of Care Coordination survey assessed receipt of care coordination services. We use descriptive statistics and negative binomial regression adjusted for caregiver and child characteristics to report caregiver HR-QOL and examine its association with experiences of care coordination.

IV. Results: Among 136 parental caregivers, the median number of physically and mentally unhealthy days in the preceding month was 2 and 3.5, respectively. Caregivers reported a median of 2 days feeling depressed, 7 days feeling anxious, and 16 days not getting enough sleep. Parents who reported having a "knowledgeable and supportive care coordinator who advocated for their child's needs" had significantly fewer mentally unhealthy (incidence rate ratio [IRR], 0.46; 95% confidence interval [CI], 0.22-0.95), depressed (IRR, 0.44; 95% CI, 0.21-0.91), and anxious (IRR, 0.5; 95% CI, 0.29-0.85) days. "Receiving a shared care plan" was associated with significantly fewer mentally unhealthy (IRR, 0.46; 95% CI, 0.23-0.93) and anxious (IRR, 0.53; 95% CI, 0.31-0.92) days. Other care coordination activities (e.g., assistance with specialist referrals) were not associated with differences in HR-QOL.

V. Conclusion(s): Caregivers of CMC report a mental HR-QOL that is lower than their physical HR-QOL. Having a supportive care coordinator and receiving a shared care plan was associated with fewer days feeling mentally unhealthy, anxious, or depressed.

VI. Impact: Improved parental mental health may be another benefit of care coordination for CMC, however longitudinal data are needed.

Tracheostomy Decision-Making for Children with Medical Complexity: Roles, Factors, Facilitators and Barriers (RP415)

Presenter: Savithri Nageswaran, MD, Wake Forest School of Medicine, NC
Shannon Golden, MA, Wake Forest University Health Sciences, NC
Nancy King, JD, Wake Forest School of Medicine, NC
William Gower, MD, MS, University of NC School of Medicine, NC

Objectives

1. To identify the roles of caregivers and healthcare providers in the decision-making process about tracheostomy for children with medical complexity, and the factors that they take into account when making the decision.
2. To identify facilitators and barriers to the tracheostomy decision-making process at the caregiver and healthcare provider level.

Abstract

I. Importance: Children with medical complexity (CMC) receive life-sustaining treatments (LST) such as tracheostomy for survival. Although guiding caregivers about LST is an important aspect of pediatric palliative care, very little is known about decision making process about LST.

II. Objective(s): To describe the tracheostomy decision-making process (TDM) for CMC, and to identify the roles of caregivers and healthcare providers (HCP) in TDM, and facilitators and barriers to the process.

III. Method(s): This qualitative study consisted of semi-structured interviews with 56 caregivers of 41 CMC who had received tracheostomies in the prior 5 years, and 5 focus groups of 33 HCP at a tertiary care children's hospital who have been involved in TDM for CMC. Participants were asked about their perspectives on the TDM process. Interviews and focus groups were transcribed, coded, and organized into discrete themes. We performed thematic content analysis of the TDM process.

IV. Results: Although HCP played an important role in guiding families, caregivers felt that the decision about tracheostomy was ultimately theirs to make. Caregivers took into consideration many factors before deciding on tracheostomy; preserving their children's life was the most important. Among HCP, physicians initiated TDM, but nurses played an important role in guiding caregivers. HCPs considered many child-level factors when recommending tracheostomy. Recommending tracheostomy for CMC with limited survival, perceived poor functioning and quality of life, and progressive conditions was ethically difficult for HCP. Caregiver-level facilitators were: being knowledgeable about their child's illness, doing their own research about their child's illness and tracheostomy, and connecting with other parents of children with tracheostomy. Caregiver-level barriers were overwhelmed emotional state, lack of understanding of illness/ tracheostomy, and not comprehending the ramifications of their decisions. At the HCP-level, good communication practices were the facilitators; variability among HCP in clinical care was a barrier.

V. Conclusion(s): The TDM process for CMC is a complex involving many inter-related factors.

VI. Impact: We identified opportunities to improve the TDM process and areas of further research.

Rural/urban differences in clinical care task learning (RP416)

Presenter: Erin Kent, PhD, University of North Carolina, Chapel Hill, Chapel Hill, NC
Eliza Park, MD, University of North Carolina, NC
Michelle Mollica, PhD, MPH, RN, OCN, National Cancer Institute, MD
James Dionne-Odom, PhD,RN,ACHPN, University of Alabama at Birmingham, AL

Objectives

1. Describe preferred learning modalities for clinical care task assistance among general adults and family caregivers.
2. Report differences by rural/urban residence in learning modalities for clinical care task assistance among general adults and family caregivers.

Abstract

I. Importance: Rural family caregivers for patients with serious illness receive minimal formal training but often perform clinical care tasks far from clinical settings. Evidence-based strategies to prepare caregivers for these tasks are needed.

II. Objective(s): We examined acceptability of clinical care task learning modalities among the general population and family caregivers.

III. Method(s): Data from the population-based National Cancer Institute's 2018 Health Information National Trends were analyzed. Caregivers were those currently providing unpaid care/ making healthcare decisions for someone with a health condition. Main outcomes were learning modalities for clinical care tasks: in-person instruction, phone number/hotline, reading materials, online video instruction, or virtual (live instruction over the internet). Rural/urban residence was defined by Rural/Urban Commuting Area Codes: urban=1-3, rural=4-9. Multivariable logistic regression models predicting endorsement (yes/no) of learning modalities were regressed on rural/urban status for the general adult and caregiver populations. Models used sampling weights and adjusted for sociodemographics, and for the caregiver models included duration and hours/week caregiving and caregiver-patient relationship.

IV. Results: Analyses included 2847 adults (51% female, 64% White, 15% rural) and 378 caregivers (66% female, 66% White, 16% rural). In both the general and caregiver population, the most preferred modality for training was in-person (73%, 69% respectively) and the least endorsed were hotlines (13%, 18%). Rural general adult respondents reported 45% lower odds of preferring online/video instruction than urban respondents (adjusted OR: 0.55, 95% CI 0.39-0.78). No other associations were significant in the general adult population and none were significant among caregivers.

V. Conclusion(s): No differences in training preferences for clinical care task instruction between rural and urban family caregivers were found. However, among the general population, rural individuals were less likely to prefer online/video instruction.

VI. Impact: Future research to replicate these findings should be conducted to determine whether telehealth supportive care modalities are acceptable for rural populations.

"We Feel Like We Are in the Dark:" A Population Level Qualitative Study of the Training and Support Needs of Hospice Nurses Caring for Children and Families in the Community (RP417)

Presenter: Amy Porter, MD, PHD, Fellow, Pediatric Complex Care, Rainbow Babies and Children's Hospital, Cleveland, OH

Ashley Kiefer, MD, Children's Hospital New Orleans, LA

Melanie Gattas, RN, St. Jude Children's Research Hospital, Memphis, TN

Justin Baker, MD,FAAP,FAAHPM, St Jude Children's Research Hospital, St Jude Children's Research Ho, TN

Erica Kaye, MD, St. Jude Children's Research Hospital, Memphis, TN

Objectives

1. Describe the evidence from a growing body of literature demonstrating the dearth of pediatric-focused training and resources for community hospice nurses, as well as the lack of comfort of community hospice nurses with providing pediatric care.
2. Characterize the pediatric-specific training and support needs of hospice nurses who provide care to children and families in the community.
3. Describe the innovative ideas proposed by study participants for development of pediatric-specific resources and training opportunities for community hospice nurses.

Abstract

I. Importance: Approximately 500,000 children suffer from serious illness annually, with 50,000 children dying each year. Many of these children and families are eligible for provision of community-based hospice care, yet few organizations offer formal pediatric services. Recent population level data demonstrate that hospice nurses lack training, experience, and comfort in provision of care to children in the community; however, the specific educational preferences and supportive needs of hospice nurses is not well understood.

II. Objective(s): To investigate and describe the pediatric-specific training and support needs of hospice nurses providing care to children and families in the community.

III. Method(s): From a population-level cohort of 551 hospice nurses who completed a comprehensive quantitative survey, an exploratory cohort of 40 hospice nurses were selected using purposive sampling to stratify participants into sub-cohorts based on prior self-reported levels of comfort with pediatric hospice provision. Semi-structured interviews were conducted, with subsequent inductive codebook development. Constant comparative analysis was performed across transcripts using MAXQDA software.

IV. Results: The majority of hospice nurses described insufficient training to care for children with serious illness. Nurses imagine an ideal training experience to involve in-person learning with prioritization of specific topics, including symptom management, medications/dosing, pediatric-specific equipment, concurrent care, anticipatory guidance on disease trajectories and end of life, supporting families, and staff resilience. Barriers to realizing training experiences include lack of awareness of available resources, training opportunities, and mentorship/networking across the pediatric palliative care landscape, as well as stigma against pediatric hospice and palliative care.

V. Conclusion(s): Community hospice nurses express an urgent need for improvements in pediatric-specific resources and training opportunities. Importantly, they offer robust visions for improving training paradigms and available resources.

VI. Impact: These data offer opportunities for collaborative development and investigation of educational programs and policies to improve the provision of community-based pediatric hospice for children, families, and nurses.

An exploration of questions from informal family caregivers of cancer patients in home hospice (RP418)

Presenter: Katherine Doyon, PhD, MS, RN, University of Colorado, CO

Maija Reblin, PhD, Moffitt Cancer Center, FL

Lee Ellington, PhD, University of Utah, Salt Lake City, UT

Objectives

1. identify the domains of care as outlined by the National Consensus Panel Clinical Practice Guidelines for Quality Palliative Care caregivers ask the majority of questions in a home hospice visit.
2. recognize and discuss how to use questions from the informal caregiver in the home hospice environment to reveal caregiver misunderstandings and level of comprehension about the patient's plan of care.
3. determine which domains of care caregivers state uncertainty and confusion yet caregivers do not ask questions in these areas.

Abstract

I. Importance: With a growing number of people choosing home hospice care after a terminal cancer diagnosis, communication between the hospice nurse and the informal caregiver is at the forefront of hospice care. Expert communication is vital to convey not only how to carry out the plan of care but also how assess family caregiver's understanding that plan.

II. Objective(s): The aim of this project was to explore the scope of questions from caregivers of cancer patients in home hospice by categorizing caregiver questions using the National Consensus Panel Clinical Practice Guidelines for Quality Palliative Care (NCP) as a template with the addition of the domain Relationship Building to be inclusive of all therapeutic communication.

III. Method: This was a secondary analysis of audio recordings of home hospice nurse visits (N= 32 visits). Coding was conducted in two waves using Nvivo 11 software; first a deductive content analytic process was applied to caregiver questions to identify the NCP care domain; next questions were inductively coded into emerging subcategories.

IV. Results: Questions (N = 224) from caregivers were found in four domains; Physical Aspect of Care (149), Care of the Imminently Dying (37), Relationship Building (36), and Cultural (1). In the domain, Physical Aspect of Care, Medication Management (43%) was the most common subcategory. In Relationship Building, 92% of questions focused on Personal Information about the nurse. In the domain, Care of the Imminently Dying, questions about Symptoms to Recognize (that death was imminent) (57%) were the most common.

V. Conclusions: Results suggest caregivers struggle with basic information acquisition and retention concerning the care of patient and what to expect as the patient deteriorates.

VI. Impact: Caregivers have unmet educational needs in areas of medication management and need further explanation of what future care of the patient entails as the patient deteriorates. Future research is needed to explore how to elicit questions from domains caregivers have stated uncertainty in, yet tend to avoid, such as cultural and spiritual aspects of care.

Disparities in End-of-Life Care in Children Dying of Cancer in Alabama (RP419)

Presenter: Elizabeth Davis, BS, University of Alabama at Birmingham, MSPH in Applied Epidemiology, AL
Isaac Martinez, BA, University of Alabama At Birmingham, Birmingham, AL
Smita Bhatia, MD, MPH, University of Alabama At Birmingham, Birmingham, AL
Emily Johnston, MD, University of Alabama at Birmingham, Birmingham, AL

Objectives

1. To inform attendees on rates and trends in pediatric end-of-life care in Alabama
2. To demonstrate health disparities in end-of-life care in pediatric cancer in Alabama

Abstract

I. BACKGROUND: Nearly 2,800 children die from cancer annually, yet gaps remain in our understanding of their end-of-life (EOL) care. Racial disparities exist in medical intensity (e.g. mechanical ventilation, hemodialysis) of adult EOL care that do not reflect patient preference. It is unknown if the same racial disparities exist in pediatric oncology EOL, especially among African-Americans.

II. OBJECTIVE: To determine rates of and disparities in EOL care for Alabamian children dying of cancer.

III. METHODS: We conducted a retrospective electronically medical record review of pediatric cancer patients who received their oncology care at Children's of Alabama and died between 2012 and 2018. We collected sociodemographics and clinical and EOL care details. We calculated rates 1) hospital death, 2) receiving medically intense interventions in the last 30d of life, 3) having ≥ 2 intensity indicators, 4) palliative care consultation. We constructed multivariable regression models to determine the association between clinical and sociodemographic variables and the above outcomes.

IV. RESULTS: Of the 150 patients, the average death age was 11y (STD: 6.8), 40% had a primary diagnosis of non-CNS solid tumor, and 35% were African-American. Forty-six percent died in the hospital, 57% received medically intense care, 79 % ≥ 2 intensity indicators, and 58% a palliative care consultation. Non-white individuals (primarily African-American) were more likely to receive medically intense EOL care (AOR: 2.6, 95% CI: 1.1-5.9) than non-Hispanic white patients. Patients with hematologic malignancies had greater odds of receiving medically intense EOL care (3.1, 1.1-8.8) and dying in the hospital (3.7, 1.2-11.0) than patients with central nervous system (CNS) tumors.

V. CONCLUSION: This is the first study to examine patterns of care and disparities of EOL care for children with cancer in the Deep South. It is critical to determine if the racial disparities found are goal concordant or due to systemic issues such as lack of hospice access.

Despite Prognostic Awareness and Advance Care Planning Parents Feel Unprepared at End-of-Life for Children with Complex Chronic Conditions (RP420)

Presenter: Jori Bogetz, MD, Seattle Children's Hospital and Research, Seattle, WA

Anna Revette, PhD, 617-632-2364, Boston, MA

Abby Rosenberg, MD,MA,MS, Seattle Children's Hospital, Seattle, WA

Joanne Wolfe, MD,MPH,FAAHPM, Dana-Farber Cancer Institute, Boston, MA

Danielle DeCourcey, MD, MPH, Boston Children's Hospital, MA

Objectives

1. To describe the unique end-of-life medical care needs of children with complex chronic conditions.
2. To elucidate bereaved parent perspectives about preparedness at end-of-life for children with complex chronic conditions.
3. To discuss opportunities for further research to improve parent preparedness at end-of-life for children with complex chronic conditions.

Abstract

I. Importance: Children with complex chronic conditions (CCC) have lifelong, life-threatening health problems with high mortality. With increasing pediatric palliative care availability and advance care planning, little is known about how access to these services influences parental preparedness for their child's end-of-life (EOL).

II. Objective(s): To understand bereaved parent perspectives about preparedness at EOL for children with CCC.

III. Method(s): Thematic content analysis was used to analyze 21 open-response items from a cross-sectional survey of bereaved parents of children with noncancer, noncardiac CCC who received care at Boston Children's Hospital and died between 2006-2015. The interdisciplinary research team iteratively created a coding structure that incorporated prefigured and emergent codes to identify key themes across response sets; including preparedness. All response items were independently coded by two researchers, with a qualitative research expert providing adjudication and ensuring interpretive consistency. Comprehensive analysis focused on the identification of key concepts and patterns around EOL experiences. This abstract includes a subset of themes related to preparedness at EOL.

IV. Results: 110 bereaved parents surveyed also responded to open-response items (110/114, 96%) a mean of 3.88 years (IQR 2.15-6.7) after their child's death. Median duration of illness was 7.54 years (IQR 0.78-18.1) with 90% (100/110) of children having a central nervous system, congenital/chromosomal or neuromuscular CCC. Over 70% (78/110) had subspecialty palliative care involvement and 65% (69/106) endorsed advance care planning. Parents reported understanding their child's prognosis (79%, 86/109) and felt decisions at EOL were made with sufficient parental input (92%, 95/103). Despite this, parents reported being unprepared for the symptoms and/or circumstances surrounding their child's EOL and endorsed feelings of disbelief, surprise, and being overwhelmed.

V. Conclusion(s): Despite high rates of prognostic awareness and advance care planning, the majority of bereaved parents of children with CCC in this large retrospective study felt unprepared for their child's death.

VI. Impact: This study indicates that more research is needed to identify elements which may improve parental preparedness for EOL.

Family Caregiver Burden among Advanced Cancer Patients: Findings from the CONNECT Trial (RP421)

Presenter: Wagahta Semere, MD,MHS, University of California San Francisco, San Francisco, CA

Andrew Althouse, PhD, University of Pittsburgh, Pittsburgh, PA

Douglas White, MD, MAS, University of Pittsburgh School of Medicine, PITTSBURGH, PA

Robert Arnold, MD,FACP,FAAHPM, University of Pittsburgh, Pittsburgh, PA

Thomas Smith, MD,FAAHPM, Johns Hopkins Medical Institutions, Baltimore, MD

Margaret Rosenzweig, PhD, FNP-BC,AOCNP,FAAN, University of Pittsburgh, PA

Kenneth Smith, MD, MS, University of Pittsburgh, Pittsburgh, PA

Yael Schenker, MD, University of Pittsburgh, Pittsburgh, PA

Objectives

1.Compare the experiences of burden for family caregivers in general to that of caregivers for patients with advanced cancer.

2.Evaluate patient-related factors that contribute to burden among caregivers for advanced cancer patients.

3.Assess how the relationship between patient-related factors and caregiver burden is affected by time spent caregiving.

Abstract

I. Importance: Family caregivers for patients with advanced cancer spend significant time caregiving and experience burden that has been associated with poor outcomes. Patient-related factors associated with caregiver burden in this population are not well understood.

II. Objective(s): (1) Identify patient-related factors associated with caregiver burden and (2) examine how this relationship is modified by time spent caregiving.

III. Method(s): This cross-sectional study draws from baseline data collected as part of a cluster randomized trial of an oncology nurse-led primary palliative care intervention (CONNECT). Patients with advanced cancer and their family caregivers were enrolled from 17 oncology practices in Western Pennsylvania. Caregiver burden was measured using the Zarit Burden Interview (ZBI-12; range 0-48, higher scores indicating more burden). Patient-related factors included functional status (ECOG), depression and anxiety symptoms (HADS), and quality of life (FACIT-Pal). Oncologists assessed functional status, while patients reported mood symptoms and QOL. Using multivariable regression with interaction terms, we analyzed (1) independent associations between patient-related factors and caregiver burden and (2) the effect modification of hours spent caregiving on these relationships.

IV. Results: Among 430 patient-caregiver dyads, the mean patient age was 69.8 ± 10.2 and the mean caregiver age was 61.4 ± 13.3 . Over 70% of caregivers were women, spending an average 43.9 ± 52.7 hrs per week caregiving. Caregivers' mean ZBI-12 scores were 10.4 ± 7.3 , indicating low burden. Worse patient functional status ($p<0.001$), poorer patient QOL ($p<0.001$), and higher levels of patient anxiety ($p<0.001$) and depression ($p<0.001$) were significantly associated with higher caregiver burden; the number of caregiving hours per week did not affect these relationships.

V. Conclusion(s): Among patients with advanced cancer, patient-related factors are associated with higher caregiver burden regardless of hours spent caregiving.

VI. Impact: Targeting interventions to support caregivers for patients with worse functional status, QOL, and mental health, may alleviate caregiver burden.

Personal Spirituality and Perceived Importance of Discussing Spirituality Among Parents of Children with Cancer, Pediatric Oncologists, and Psychosocial Clinicians (RP422)

Presenter: Angela Feraco, MD, Dana-Farber Cancer Institute, Harvard Medical School, MA

Sarah McCarthy, PhD MPH LP, Mayo Clinic, Rochester, MN

Sarah Stevens, BA, Dana-Farber Cancer Institute, Boston, MA

Joanne Wolfe, MD, MPH, FAAP, Dana-Farber Cancer Institute, Boston, MA

Objectives

1. Compare parents' perceptions regarding importance of discussing spirituality with pediatric oncologists versus psychosocial clinicians
2. Contrast oncologist versus psychosocial clinician perceptions regarding importance of discussing spirituality with parents of children with cancer

Abstract

I. Importance: Spiritual meaning-making impacts parents' experiences of childhood cancer care. A recent systematic review (Robert et al, *Pediatr Blood Cancer*, 2019) advocated spiritual needs assessments throughout the illness trajectory. However, families of children with newly diagnosed cancer may lack immediate and routine access to chaplaincy. Thus, we sought to understand parent, oncologist, and psychosocial clinician preferences for discussing spirituality.

II. Objective(s): To test the hypotheses that 1. Parents value discussing spirituality with psychosocial clinicians, and more so than with pediatric oncologists; 2. Psychosocial clinicians value discussing spirituality with parents, and more than do pediatric oncologists.

III. Method(s): The overall design was a pilot feasibility study of an interprofessional communication intervention. Parents were eligible if their child had received <14 weeks of cancer treatment upon approach. Pediatric oncologists (fellows and nurse practitioners) and psychosocial clinicians who provided continuity care to children with cancer were eligible. Surveys querying communication attitudes and preferences, self-reported spirituality, and demographic attributes were distributed to parents of children with cancer upon enrollment, and to providers immediately prior to communication training. All participants were queried on degree of personal spirituality (not at all/slightly/moderately/very) and importance of discussing spirituality (not at all/a little/somewhat/very/extremely).

IV. Results: Thirty-one parents (94%), 14 oncologists (100%), and 13 psychosocial clinicians (100%) returned surveys. Overall, 65% of parents, 46% of oncologists, and 50% of psychosocial clinicians self-described as moderately or very spiritual. More parents tended to indicate discussing spirituality with psychosocial clinicians was extremely/very important as compared to discussing spirituality with pediatric oncologists (55% vs. 32%, p=0.07). All psychosocial clinicians versus 35% of pediatric oncologists described discussing spirituality with parents as extremely/very important (p<0.0004).

V. Conclusion(s): Most parents indicated discussing spirituality with psychosocial clinicians was extremely/very important. Parents may place greater importance on discussing spirituality with psychosocial clinicians than with pediatric oncologists, which appears concordant with professionals' views.

VI. Impact: Beyond chaplains, psychosocial clinicians may play an important role in discussing spirituality with parents of children with cancer.

Intersectionality of Gender and Poverty on Symptom Suffering Among Adolescents with Cancer (RP423)

Presenter: Sarah Friebert, MD,FAAP,FAAHPM, Akron Childrens Hospital, Akron, OH

Jennifer Needle, MD,MPH, University of Minnesota, Minneapolis, MN

Jessica Thompkins, BSN, RN, Children's National Health System, Washington, DC

Justin Baker, MD,FAAP,FAAHPM, St Jude Children's Research Hospital, St Jude Children's Research Ho, TN

Yao Cheng, MS, Children's National Health System, Washington, DC

Jichuan Wang, PhD, Childrens National Health System, Washington, DC

Maureen Lyon, PhD, FABPP, Children's National Medical Center & George Washington School of Medicine and Health Sciences, Washington, DC

Objectives

1. Describe the need for attending to gender and poverty in assessing symptom suffering among adolescents with cancer.
2. Explain the importance of intersectionality of gender-poverty combinations for patient-reported outcomes.
3. Discuss baseline finding from a pediatric Advance Care Planning trial.

Abstract

I. Importance: Cancer survival has improved far less for adolescents than it has for older patients. Bona and colleagues identified adverse effects of poverty on relapse and survival for children with cancer.

II. Objective(s): Our objective was to explore potential latent classes/subpopulations in the AYA cancer population with respect to cancer-related symptoms at baseline and to test for gender differences in regard to cancer-related symptoms. Hypothesis 1: Distinctive latent classes/groups exist in the AYA cancer population with respect to cancer-related symptoms. Hypothesis 2: The likelihood of being classified into specific symptom classes will vary in different gender-poverty combinations.

III. Method(s): Four PROMIS® (Patient-Reported Outcomes Measurement Information System) person-centered measures evaluated Anxiety, Depression, Pain Interference, and Fatigue. The PROMIS scores were dichotomized.

IV. Results: AYAs with cancer (N=126) were aged 14 to 21 years, 57% female, 80% white, 26% income equal to or below the Federal poverty level. Latent class analysis (LCA) showed that AYAs were classified into three a priori unknown groups. Class 1, 59%, were in the Low suffering group (lower probabilities of having high scores on all 4 PROMIS measures); Class 2, 28%, were in the High suffering group (higher probabilities of having high scores on all 4 PROMIS measures); and Class 3, 13%, Pain interference/fatigue suffering group (high probabilities of having high scores on only pain interference and fatigue with low scores on anxiety and depression). Multinomial logit model indicated no significant differences in symptoms by gender, age, race or income. Rather, female adolescents in poverty were more likely to be in the High Suffering group ($3.41, p=0.0366$).

V. Conclusion(s): Palliative care referrals should be prioritized for female adolescents with cancer and living in poverty, thereby directing limited resources to those most in need in a timely manner.

VI. Impact: The intersection of female gender and poverty will be critical to accurate interpretation, validation and generalization of longitudinal studies.