Full Conference Programme

European Paediatric Psychology Conference 2023

Organized by the European Paediatric Psychology Network (EPPN), in collaboration with the Society for Pediatric Psychology (SPP), Division 54 of the American Psychological Association (APA)

Conference Chair:
Line Caes, Associate Professor of psychology, University of Stirling

Scientific committee Co-Chairs:
Rocio de la Vega
Nicola Scott
Yvonne Vance

Scientific committee members:
Michelle Ernst
Christine Sieberg
Tine Vervoort
Eileen Chaves
Kathleen Lemanek
Kindell Schoffner
Sanita Ley

The Society of Pediatric Psychology is approved by the American Psychological Association to sponsor continuing education for psychologists. The Society of Pediatric Psychology maintains responsibility for this program and its contents.

Sincere thanks to our conference Sponsors and Exhibitors:

PROGRAM WEDNESDAY, 30 August 2023

8.30 – 11.30 **Registration opens**
Pathfoot Crush Hall

9:30-11.00 PRACTICAL WORKSHOPS (INCLUDED IN THE CONFERENCE REGISTRATION FEE!)

Workshop 1: Clinical and Academic mentoring (relevant for both mentees & mentors) (Christine Sieberg & Lauren Heathcote) – *Seminar room PD3*

Workshop 2: Connection, cooperation and adaptability: Using DNA-V and the ProSocial framework to improve outcomes for children & young people, families and staff and teams (Jim Lemon) – *Seminar room PC21*

Workshop 3: Graded exposure treatment for adolescents with chronic pain (GET Living) (Laura Simons & Lauren Harrison) – *Seminar room PD1*

Workshop 4: Leadership in Practice: Supporting developing leaders in Paediatric Psychology (Helen Griffiths & Karen Steinhardt) – *Seminar room PC22*

Workshop 5: Taking a biopsychosocial approach to childhood obesity: how psychology can contribute across the system (Michelle Clark, Kerstin Hunter & Niall Anderson) – *Seminar room PC23*

11.30 - 12.00 **Opening ceremony (Moderator: Line Caes)**
Lecture theatre Pathfoot

12:00 - 13:00 **Lunch**
Pathfoot Eatery

13.00 – 14.00 **Plenary Session 1: Jim Lemon (Moderator: Nicola Scott) (1 CE credit offered)**
'Well, I know who I am, but I'm not sure why I'm up here speaking either...'
Seeing as I'm here now, this is how Paediatric Psychology collaborations are using Contextual Behavioural Science at the individual, team and international levels.
Lecture theatre Pathfoot

Learning Objectives

a. Identify the central ideas of ProSocial and how it is used to improve the functioning of individuals, teams, and systems.
b. Identify some of the tools used in ProSocial following participation in individual and group exercises.
c. Identify application strategies for ProSocial in their own contexts.

14.00 – 15.30 Parallel symposium session 1 (1.5 CE credits offered)

Symposium 1: Managing the Unexpected: Adapting Clinical Trials in the Time of Covid and Beyond (Chair: Marilyn Stern) *– Lecture theatre Pathfoot*

Individual Talks

1. Adaptations to Intervention Delivery of a Family-based Pediatric Weight Management Program Stemming from the COVID-19 Pandemic (Katherine Darling) - ***ONLINE***
2. Lending an Ear during a pandemic: Lessons learned from a pilot randomized control trial of an online self-management programme for adolescents with arthritis in Ireland (Hannah Durand)
3. Protecting HPV PROTECT: Unexpected challenges and adaptations in executing a provider focused HPV vaccine intervention for pediatric cancer survivors during the COVID-19 pandemic (James L Klosky)
4. Changes made to the iAmHealthy Schools Rural Pediatric Obesity Intervention Program at the onset of the COVID-19 Pandemic: Intervention and Measurement (Ann M Davis)

Symposium Abstract

Virtual clinical trials have emerged as an innovative model to accelerate clinical trial engagement. The COVID-19 pandemic served as a catalyst for these efforts and has increased the importance of digital technology in clinical trial implementation. The pandemic also created challenges related to participant recruitment and engagement, data collection and management, and specific COVID-related challenges (e.g., Zoom fatigue). This symposium discusses challenges faced in the implementation of several large scale trials targeting different groups of pediatric patients and describes adaptations made to address these disruptions. Our first presentation focuses on challenges and lessons learned when implementing a group-based pediatric weight management trial, "JOIN for Me," targeting disadvantaged youth that was designed to be delivered in person by community health workers and then transitioned to remote delivery. A second paper reports on a RCT conducted in Ireland targeting adolescents with juvenile idiopathic arthritis that dealt with clinics closing during the pandemic and needing to identify ways to proceed with data collection exclusively using digital technology. Our next paper focuses on a multi-site clinical trial, "HPV PROTECT," evaluates the effectiveness and implementation of a provider intervention in promoting HPV vaccine uptake in young survivors of childhood cancer. Our final paper reports on the "iAmHealthySchools" project delivered via telehealth into rural homes and discusses the feasibility of remote delivery of interventions and measurement that are likely here to stay. The challenges and adaptations in executing these interventions in the context of the COVID-19 pandemic are highlighted. Strategies used are hoped to prove helpful in designing future virtual or hybrid RCTs, including developing trust and rapport with participants, providing support through multiple routes of dissemination, and using data management applications for automating as many tasks as possible, and project management. Consideration of developing new paradigms for data collection are considered.

Learning Objectives

a. Identify the challenges and potential benefits associated with transitioning a pediatric weight management intervention (e.g., JOIN for Me, iAmHealthy) and measurement from in person to remote delivery in response to the COVID-19 pandemic, and how these might apply to one's own work.
b. Explain the importance for virtual or hybrid RCT's and for developing new paradigms for data collection including automating research tasks.
c. Describe the process of adapting an intervention (e.g., HPV PROTECT) in the context of the COVID-19 pandemic, while considering the effect of these changes within an implementation science framework.

Symposium 2: Preparing and Conducting International Pediatric Psychology studies: Ethical Aspects and Guidelines for Good Practice (Chair: Eileen Chaves) *– Seminar room PC21*

Individual Talks

1. It's happening over there, so why should we care? (Gerald Koocher)
2. Current International challenges in peds psych research: results from an international survey (Rocio de la Vega)
3. Recommendations to streamline ethical approval processes for international pediatric studies (Line Caes)
4. Bringing it all together – International Psychology Research Ethics in Action (Eileen Chaves)

Symposium Abstract

The international character of pediatric psychology research is growing, presenting a series of associated ethical challenges. As pediatric psychology expands as a field across the globe, psychologists are in the unique position of working in interdisciplinary research collaborations not only with other psychologists but also with medical providers, occupational therapists, dieticians, physical therapists, educational experts, basic scientists, and others. The international growth and presence of pediatric psychology stimulates important international collaborations, with research projects no longer being limited to one single region or country. Developing an understanding of ethical issues related to international pediatric psychology research is key to creating successful research collaborations and being able to start or continue research across countries. Unfortunately, one of the major obstacles to project fruition is often acquiring ethical approval for research, as children and youth are considered a vulnerable population. While pediatric psychologists are often aware of these requirements in their own countries and institutions, specific information on these requirements across countries is often difficult to assess. Through this symposium, presenters will describe the ethical issues inherent in pediatric psychology generally, as well as describing the findings and recommendations of a study examining relevant ethical issues in international pediatric psychology research. The symposium will be both didactic and experiential, utilizing a case study to help participants think through and apply the recommendations described throughout the presentation in order to create an international pediatric psychology study, focusing on the 'how-to's' of navigating international ethics adherence and approval.

Learning Objectives

a. Identify relevant ethical issues related to engaging in international pediatric psychology research.
b. Explain how the recommendations given in the presentation apply to streamline the ethical conduct of international pediatric psychology research studies, as well as how to navigate the international ethics approval process.
c. Apply the recommendations discussed in this symposium to a case study related to creating an international pediatric psychology study.

Symposium 3: The relevance of patient reported outcomes (PROs) in the context of paediatric illnesses (Chair: Amii Steele) *– Seminar room PD1*

Individual Talks

1. Checking IN: The Development of an Electronic Tool in the Pediatric Outpatient Setting to Identify Pediatric Psychosocial Distress Domains that Interfere with Quality of Life (Lori Wiener)

Abstract

Introduction: Children and adolescents diagnosed with cancer and other life-limiting illnesses face significant psychosocial challenges throughout their disease trajectory and treatment. These challenges are often missed in busy pediatric clinics, resulting in lack of preventative and clinically indicated ongoing psychosocial care. Evidence-based Standards recommend routine and ongoing psychosocial screening, yet no tools for electronic, brief, real-time pediatric self- report measure of psychosocial problems with immediate triage capabilities were available.

Methods: The development of Checking IN consisted of 1) identifying the most common distress symptoms from a pediatric distress thermometer (N = 289), 2) using cognitive interviews (N = 47) to test the wording of items assessing these domains in youth ages 8-21 years; 3) developing a child and caregiver proxy measure (Checking IN) within an electronic platform and a clinician summary report with triage recommendations; and 4) conducting semi-structured interviews (N = 134) to assess child, caregiver and researcher perception of the feasibility, acceptability, and barriers of administering Checking IN in addition to provider feedback on the clinician summary report.

Results: Checking IN was found to be “easy” or “very easy” to complete, feasible, and acceptable by most youth and their caregivers. Almost all providers reported Checking IN elicited clinically useful and novel information and over half changed care based on items endorsed. Youth most frequently endorsed symptoms of fatigue, sleep difficulty, attention, and worry, with strong agreement between youth and caregiver-proxy reports regarding psychosocial interference across most domains.

Discussion: Checking IN captured a child’s current psychosocial wellbeing in a systematic, consistent, and informative way, while allowing for psychosocial documentation and the automation of triage referrals during outpatient visits. Future testing of new items and validation is needed along with research that helps determine how accurately Checking IN assesses symptom interference (e.g., pain interfering with quality of life) rather than the presence of a symptom/domain (e.g., having pain). Conclusion: Evidence-based tools are needed to help implement psychosocial Standards of Care. Checking IN can capture a child’s current psychosocial wellbeing in a systematic and clinically meaningful way in the outpatient setting.

Learning Objectives

a. Describe the methodology that led to the development of a distress assessment tool for children with medical conditions, using Checking IN as an example.

2. Health-related quality of life of children and their parents 4 years after admission to PICU (José Hordijk)

Abstract

Introduction: Pediatric intensive care unit (PICU) survivors may be at risk for prolonged morbidities in physical, emotional, and social functioning interfering with daily life, assessed as health-related quality of life (HRQoL). Research into HRQoL in the general PICU cohort, in comparison with healthy controls, and using multi-factorial predictive models is lacking.

Methods: This study included critically ill children who participated in the Pediatric Early versus Late Parenteral Nutrition in Intensive Care Unit (PEPaNIC) multicenter trial. Four years after PICU admission, parents of 684 post-PICU survivors and 369 healthy control children completed the Child Health Questionnaire (CHQ-PF50) regarding their child's HRQoL and Short-Form (SF-12) regarding their own HRQoL. First, HRQoL scores between post-PICU survivors and the healthy control group were compared with multivariable regression analyses, corrected for baseline variables. Second, demographical variables, patient characteristics, and PICU discharge variables were included as predictors for worse HRQoL in post-PICU children, defined as ≤ 1 SD lower than the healthy control group mean, in backward selection logistic regression models.

Results: Parents reported worse HRQoL on 7 of the 9 subscales in post-PICU survivors compared to healthy control children in multivariable regression analyses. Parents' own mental HRQoL and the impact on the family was worse in 5 of the 6 subscales compared with healthy control parents. Depending on the subscale, 23% to 73% of the post-PICU children obtained a worse HRQoL score. Several baseline factors (higher age, European origin, male sex, syndrome, diagnosis other than cardiac surgery), PICU factors (higher PELOD score, new infection acquirement, longer mechanical ventilatory support, longer length of stay, elective admission), and family factors (lower parental occupational and educational level) were predictive for worse child's HRQoL and parental outcomes with explained variances between 4% and 24%.

Discussion: Several demographical, upon PICU admission, and PICU discharge variables were predictive for worse HRQoL in critically ill children and their parents/family. However, with explained variances up to 24%, research into additional predictor variables for worse HRQoL is needed.

Conclusion: The results support individualized psychosocial care interventions during PICU admission and at follow- up for patients and parents/families to ultimately improve HRQoL outcomes.

Learning Objectives

a. Accurately assess the Health-Related Quality of Life outcomes of pediatric patients and their parents after critical illness of the child.

b. Identify predictors of poor Health-Related Quality of Life outcomes for individuals following PICU stays

3. Psychometric evaluation and inter-rater agreement of the pediatric and parent-proxy Patient-Reported Outcomes Measurement Information System (PROMIS) in children with sickle cell disease (Maud van Muilekom)

Abstract

Introduction: Sickle cell disease (SCD) has a profound impact on the physical, mental and social health of affected children. The primary focus of SCD care is preventive therapy and disease education for which monitoring of symptoms, health and complications that require interventions is necessary. As disease severity varies substantially between individuals, a generic approach to assess health outcomes is required. In this study, we aim to assess the psychometric properties of the generic pediatric and parent-proxy Patient-Reported Outcomes Measurement Information System (PROMIS) measures in children with SCD.

Methods: Between December 1 st 2019 and December 31 st 2020, patients (5-17 years old) and their parents were approached to participate in the study at the Erasmus MC Sophia Children's Hospital and the Amsterdam UMC Emma Children's Hospital in the Netherlands. The following self-report and parent- proxy PROMIS measures were included: Global Health, Cognitive Functioning, Pain Interference, Mobility, Fatigue, Anxiety, Anger, Depressive Symptoms and Peer Relationships. We assessed unidimensionality through confirmatory factory analysis, convergent validity with subscales from the Pediatric Quality of Life Inventory (related domains r > 0.5), discriminant validity (severe vs. less severe disease; Cohen's d), reliability (Cronbach's a and standard error of measurement; SEM) and inter-rater reliability (intra-class correlation coefficients; ICC) of the PROMIS measures.

Results: In total 102 patients and 102 caregivers completed all PROMIS measures, of which 71 were dyads. All measures displayed sufficient unidimensionality and convergent validity. Discriminant validity was found for the expected measures of Global Health and Mobility (d > 0.5), however only parent-reports were able to discriminate on Fatigue (d = 1.02) and Pain Interference (d = 0.49). Reliability was acceptable (Cronbach's a > 0.80, SEM < 0.44) for all PROMIS measures. Inter-rater reliability was moderately-strong for all measures (ICC 0.60 – 0.78) except Peer Relationships (ICC = 0.47, r = 0.31) and Global Health (ICC = 0.26, r = 0.16).

Discussion/conclusion: The PROMIS measures displayed sufficient psychometric properties for use in pediatric SCD care and research. Proxy reports seem viable as alternative to self-report forms of PROMIS.

Learning Objectives

a. Describe the advantages of using Patient Reported Outcome Measurement Information System (PROMIS) parent proxy and self-reports in paediatric sickle cell disease population.

b. Interpret psychometric properties of Patient Reported Outcome Measures (PROMs) developed based on Item Response Theory (IRT).

4. Quality of Life for Youth with Critical Congenital Heart Disease (cCHD): Impact of Income Disparities and Facilitative Parenting Practices (Ana Valentina Garcia Villasana): ***ONLINE***

Abstract

Introduction: Improved survival for youth with cCHD heightens interest in predictors of quality-of-life (QoL) and patient-reported outcomes. Information on social-ecological factors that predict QoL can inform interventions to promote positive outcomes. Our research tests whether family income and facilitative parenting (FP) practices predict physical or psychosocial QoL. FP practices that provide support while encouraging independence in children, show promise as a target for interventions to promote positive peer interactions and reduce internalizing symptoms for school-aged children. We hypothesized that lower QoL in both domains would be associated with lower family income and less parent engagement in FP practices.

Methods: Children with cCHD (e.g., Tetralogy of Fallot, dTGA) attending 4th or 5th grade mainstream classrooms (N=101, Mage=10.59, 38%female) completed the Pediatric Cardiac Quality of Life Inventory (Disease Impact and Psychosocial QoL domains); Social Experiences Questionnaire (total score, assessing physical/relational aggression from peers); Youth Self Report (Social Problems and Internalizing Problems subscales); Social Anxiety Scale for Children-Revised (total score); and Self Perception Profile for Children (General Self-Worth subscale). Mothers (N=96) and fathers (N=65) completed the Facilitative Parenting Questionnaire (total score) and reported annual family income. Analyses included hierarchical multiple regression and correlations of these measures with FP practices.

Results: Family income predicted Disease Impact QoL (B=1.667,p=.004), Psychosocial QoL (B=1.610,p=.026), and negative peer interactions (B=-2.414,p=.001). Several measures were associated with FP practices for mothers, but not for fathers, including Disease Impact QoL (B=.093, p=0.034), Psychosocial Impact QoL (B=0.191, p=.000), negative peer interactions (B=-0.142,p=.010), social anxiety (B=-0.212,p=.016), Global Self-Worth (B=0.007, p=.026), and Social Problems (B=-0.046,p=0.03). In each instance, greater use of FP practice was associated with more favorable outcomes.

Discussion: Results suggest that QoL and patient-reported outcomes may be poorer for survivors of cCHD affected by economic disparities, but the utilization of FP practices, particularly by mothers, may foster resilience.

Conclusion: Future research is needed to better understand the impact of fathers' parenting strategies as well as the importance of other structural and functional characteristics of families in youth challenged by cCHD.

Learning Objectives

a. Identify the practical applications of alterable and inalterable variables affecting quality of life for children with Critical Congenital Heart Disease.

Symposium 4: Beyond pain intensity - measuring, assessing, and communicating about paediatric pain (Chair: Daniela Ghio) *– Seminar room PD3*

Individual Talks

1. Adolescents and young people's pain perceptions of their pain related to Juvenile Idiopathic Arthritis (Daniela Ghio)
2. Children's pain is frequently ignored, for Black children with sickle cell disease it is even worse: improving understanding of their pain experience (Anna Hood)
3. Pain communication in children and young people with chronic musculoskeletal pain: Key stakeholder perspectives and potential for intervention (Rebecca Lee)
4. Development and Validation of a Paediatric Breakthrough Pain Assessment Tool (Christina Liossi): ***ONLINE***

Symposium Abstract

To move beyond just measuring pain intensity, information on a wide range of relevant dimensions (i.e., biological, psychological, and sociocultural factors) using multiple assessment methods is needed to capture the paediatric patients' specific experiences and understand the causes, contributors, and effects of pain. Although the biopsychosocial model of pain has expanded our understanding of chronic pain and is frequently cited, in our research, interventions, and clinical settings, the commonly used pain assessment is a numerical rating scale or visual analogue scale. Given the interplay between biological, psychological, and social factors in the transition from acute to chronic pain, symptom management, and treatment outcomes, assessing pain using a unidimensional approach fails to capture the pain experience accurately. The developmental changes which occur during childhood and adolescence make utilising only one unidimensional measurement of paediatric pain particularly challenging.

Therefore, in this symposia, we aim to discuss approaches to measure and understand the paediatric pain experience using multiple tools (e.g., pain diaries, digital apps) across affected populations (i.e., sickle cell disease, juvenile idiopathic arthritis, musculoskeletal pain, children with cancer) from research utilising qualitative and quantitative methods, and in observational and clinical trial studies. Through our interactive panel discussion, we hope to share and discuss ways to monitor, track, and understand paediatric pain through multidimensional approaches. Specifically, speakers will discuss the importance of understanding pain burden, coping, emotional representation, and pain beliefs. Knowledge gained from our symposium will reinforce that as paediatric psychologists, we can promote, facilitate, and advocate for multidimensional pain measurement for children living with pain in our multidisciplinary teams in clinics and when developing evidence-based treatments in clinical trials. Further, speakers will share lessons learned about the role of healthcare professionals' capabilities, opportunities, and motivations in understanding the paediatric pain experience.

Learning Objectives

a. Identify measures and tools beyond the use of pain intensity that are reflective of the multidimensional nature of pain.
b. Explain the importance of developmental considerations when communicating about pain.
c. Identify and discuss the need for improved communication between healthcare professionals and children about their pain experience.

15.30 – 16.30 **Coffee break + poster session 1**

Pathfoot Crush Hall

1. **Childhood in the hospital: children's perspectives on play during**
   Kelsey Graber

   Introduction: All children have a right to play during childhood. When childhood is experienced in a hospital environment, what is it like to play then? It is understood that children's perspectives should factor into matters affecting childhood, including their healthcare. As children perceive play as related to health and wellbeing, their perspectives on play must also be valued.

   Methods: This qualitative research study utilised ethnographic observations and semi-structured interviews to gain insight into children's own views and experiences of what it is like to play during hospitalisation. Observations occurred over a period of five months on a paediatric oncology ward, and fifteen children participated in interviews.

   Results: Play is a natural aspect of childhood, but not a natural aspect of hospitals. Children need to feel safe and welcome to engage in play. Though play in hospitals can sometimes be physically tiring, challenging, or inaccessible for young patients, children demonstrated how they are active in determining for themselves when play is helpful or good. Hospitalised children emphasise desired objectives and outcomes for play that are similar to children experiencing childhood outside of the hospital: to explore and understand, to have fun and to be happy, to relax and to escape. Play is a way that children reclaim a sense of childhood normalcy in an otherwise atypical, serious environment – a way of feeling like a child and not only a patient.

   Discussion: For a child facing health adversity, medical care takes precedent. However, paediatric patients express that play is an integral aspect of their lives, affecting their perspectives of experiencing childhood in a hospital. The dynamism of play to both cultivate and enhance children's wellbeing in a hospital should not be overlooked.

   Conclusion: Children provide valuable perspectives on the role and importance of play in their childhoods and their health care. As care providers, perhaps there is an opportunity to engage in children's play worlds to better explore and respect their views of what it means to be a child receiving care for their health.

2. **A mixed-methods approach towards understanding the relationship between chronic pain and suicidal distress in adolescence**

Verena Hinze

Introduction: Chronic pain (persistent/recurrent pain for ≥3 months) affects up to 38% of young people and is amongst the leading causes of disability in adolescents worldwide. It often co-occurs with mental health problems and suicidality (self-harm thoughts and acts, irrespective of suicidal intent). As suicidality is a serious concern in adolescence, affecting between 10-30%, the early identification of suicidal risk and prevention is vital. Chronic pain may be a highly prevalent, easily identifiable, and manageable clinical target for suicide prevention efforts in adolescence. However, little is known about which aspects of the pain experience are associated with suicidal distress. This study aims to explore: a) Whether adolescents with chronic pain report suicidal distress. b) Which aspects of the pain experience are associated with suicidal distress? c) How adolescents describe the impact of their pain experience on their feelings?

Methods: This mixed-methods, observational study focusses on the cross-sectional relationship between chronic pain and suicidal distress in 77 adolescents (12-19 years) with chronic pain, recruited from the Oxford Centre for Children and Young People in Pain. Participants completed questionnaires on their pain experience and suicidal distress (perceived burdensomeness, hopelessness, and self-harm thoughts and acts), as one emotional distress pathway leading to suicidal outcomes. In an optional interview, participants described their pain experience and how it affects their feelings. Data will be analysed using regression and reflective thematic analyses.

Results: Data collection will be completed in April 2023 (nearly 80% completed the optional interview). So far, participants (12-18 years, largely female) most frequently report persistent pain with pain attacks, often in multiple locations. Preliminary results suggest that feelings of perceived burdensomeness, hopelessness, and self-harm thoughts and acts are very common, which allows us to explore and discuss relationships between aspects of the pain experience and suicidal distress.

Discussion/ Conclusion: Findings show the extent to which adolescents with chronic pain report suicidal distress and which aspects of the pain experience might be associated with suicidal distress. By identifying vulnerable youth these findings may have direct clinical implications.

3. **A qualitative approach to select patient reported outcomes within pediatric physical therapy**
   Dorinde L. Korteling

   Introduction: The patient's and parent's perspective is important in healthcare. Patient reported outcomes (PROs) should therefore be used throughout the healthcare process. Pediatric physical therapy currently lacks an overview of relevant PROs. Therefore, this study aims to uncover relevant PROs within pediatric physical therapy.

   Methods: Separate focus groups will be held with adolescents (12-18 years) treated by pediatric physical therapists, their parents (of children 4-18 years) and pediatric physical therapists in March-May 2023. Adolescents and parents will be asked about the effects of the condition or illness (of their child) has on their lives and what topics they want to discuss with the pediatric physical therapist. Pediatric physical therapists are asked about PROs that would benefit their tailored interventions. During focus groups with adolescents a patient engagement game (All Voices Count game) will be used. In focus groups with parents and pediatric physical therapists positive and negative experiences from the daily life of their children/patients will be collected and ranked by the participants. For each subgroup, a minimum of two focus groups will take place. According to existing literature, four to ten individuals will participate in each focus group. In total, 24-60 participants are expected to participate. Participants from all over the Netherlands are invited to join. Data will be analysed using MaxQDA.

   Results: We will present the results from the focus groups at the conference.

   Discussion and Conclusion: This study aims to provide a set of core PROs for pediatric physical therapy, as part of a larger research project. In the next steps PRO measurements (PROMs) corresponding to the selected set of core PROs will be identified. These PROMs will be validated for use within pediatric physical therapy, after which they will be implemented via the KLIK PROM portal (www.hetklikt.nu) in 15 primary pediatric physical therapy practices throughout the Netherlands. In these practices, children will be monitored with the use of PROMs. The implementation of these PROMs can aid in identifying potential healthcare-related problems early on and facilitate communication between patients, parents and pediatric physical therapists.

4. **Are we meeting the needs of families? Community and social resource needs of parents differ based on sociodemographic characteristics**

Breana L. Bryant

Introduction: Spina bifida (SB) is a common congenital birth defect that impacts quality of life, yet little is known about the adequacy of available community resources. This study examines associations between the extent to which community resource needs are met and parent sociodemographic characteristics (age, race, socioeconomic status).

Methods: 130 mothers of youth with SB (Mage = 40.9±6.9 years; 56.4% non-Hispanic White [NHW]) completed the Social and Community Support Questionnaire, derived from the ACCESS Needs Assessment for Parents Scale. For each item, mothers rated the extent to which the resource is being met (referred to as "extent" below; scale ranged from 1 to 5, higher extent score = resource more taken care of). Sociodemographic characteristics were self-reported and used to calculate socioeconomic status (SES) with the Hollingshed Index of Socioeconomic Status.

Results: Overall, adequate health insurance for their child had the highest extent score (M=4.19), whereas whether or not their child had a mentor with SB had the lowest score (M=2.13). Hispanic mothers had higher extent scores for child self-care, talking to others with SB, and child group therapy, as compared to NHW mothers. Older mothers tended to have lower extent scores for accessible public transportation and child tutoring. At higher levels of SES, the extent scores for opportunities for child self-care, someone for their child to talk to for support, talking to children with SB, and child group therapy were lower. All p's <.05.

Discussion: Findings suggest that sociodemographic characteristics influence the extent to which community resources are being taken of. Clinicians and community partners should be aware of the unmet need for mentorship and support for individuals with SB.

Conclusion: Future research should explore the mechanisms behind these associations and assess the feasibility of accessible mentorship programs, to ultimately reduce disparities and increase access to community resources.

5. **Barriers to Care Experienced by Caregivers of Children with Cancer: Social Problem-Solving Skills as a Resilience Factor**

Taylor M. Dattilo

Introduction: Caregivers of children diagnosed with cancer must often navigate a new and complex medical system and are at increased risk for posttraumatic stress symptoms (PTSS). Barriers to care (BTC) are defined as specific factors that impede the ability to access or engage with the larger health care system. The current study evaluated perceived BTC and Social Problem-Solving Skills (SPSI) among caregivers of children with cancer as predictors of caregiver PTSS. We hypothesized that greater BTC would be related to increased caregiver PTSS, while better SPSI would be related to lower caregiver PTSS.

Methods: Caregivers (N=84; 91% mothers; 71% White; M_{age} =36.72 years) of children in the United States within 1-year post-cancer diagnosis (54% boys; 60% White; M age =8.77 years) completed measures assessing BTC, SPSI (i.e., dysfunctional/constructive), and PTSS. Hierarchical linear regression was conducted to examine the unique contribution of BTC and SPSI in relation to PTSS controlling for child ethnicity, age, and father ethnicity in Step 1, adding BTC subscales in Step 2, and SPSI subscales in Step 3.

Results: Caregivers' mean PTSS scores (M=26.15) were in the Severe range. In the hierarchal regression model, Step 1 was significant, explaining 10% of the variance in PTSS, R^2 =.10, F(1,59)=6.16, p=.016. Adding BTC subscales in Step 2 significantly improved the model, explaining another 22% of variance, total R 2 =.32, F(6,54)=4.10, p=.002. Finally, adding SPSI subscales in Step 3 significantly improved the model, explaining another 18% of variance, total R 2 =.50, F(8,52)=6.33, p<.001. Lower dysfunctional SPSI remained significantly associated with lower PTSS (β=.47, p<.001), while higher expectations for receiving poor-quality care remained significantly associated with higher PTSS (β=-.57, p=.020). All other BTC subscales and constructive problem-solving were not significantly associated with PTSS (p>.05).

Discussion: Less dysfunctional SPSI may be a protective factor for caregivers at risk for PTSS. Additionally, perceived expectations of poor-quality care may be an important target for clinical intervention.

Conclusion: Interventions targeting SPSI and perceived expectations of poor-quality care may help reduce symptoms of PTSS. Pediatric psychologists are in a unique position to assist caregivers in navigating complex healthcare systems while simultaneously bolstering adaptive skills and assisting with expectations of care.

6. **Body mindsets are associated with pain and pain-related risk and resilience factors in children with chronic pain**

Emily Dowling

Introduction: There is a need to identify psychosocial factors that shape outcomes in pediatric chronic pain to devise appropriate pain management strategies. In the literature, pain acceptance is recognised as a resilience process and both fear of pain and pain catastrophizing are recognised as risk processes for poorer outcomes. Uncertainty is also emerging as a common consequence of living with a childhood diagnosis of chronic pain. Mindsets–core associations about the nature and workings of things and processes in the world–shape how we make sense of and respond to uncertainty. By placing mindsets within the context of pain-related uncertainty, mindsets about the body may confer risk and resilience for poorer outcomes in pediatric chronic pain.

Methods: 102 children with chronic pain were recruited (M_{age}=13.76, SD=2.53, range=8-17; 72.3% female) who completed self-reported measures online. Exploratory maximum likelihood factor analysis explored the factor structure of the Body Mindset Inventory-Child Version (BMI-C). Descriptive statistics summarized body mindsets and Pearson correlations explored associations of body mindsets with pain, pain acceptance, fear of pain, pain catastrophizing, psychosocial and physical risk for poorer outcomes.

Results: The theoretically derived subscale structure of the BMI-C holds in the sample and explains 52.88% variance. There are individual differences in body mindsets within the sample (M=3.33-3.98, range=1-6). The mindset that the 'body is an adversary' was associated with lower pain acceptance, greater fear of pain, greater pain catastrophizing, and greater psychosocial risk (r= .276-.367). The mindset that the 'body is capable' was associated with greater pain acceptance, lower pain catastrophizing, and lower psychosocial risk (r= .322-.371). The mindset that the 'body is responsive' was associated with lower average pain intensity and lower pain catastrophizing (r= .211-.371).

Discussion: Children with chronic pain hold diverse body mindsets. The mindset that the body is an adversary may confer risk for children with chronic pain, while adaptive mindsets that the body is capable and responsive may confer resilience.

Conclusion: Interventions that instil adaptive body mindsets offer a promising approach to support children with chronic pain.

7. **Breaking Barriers, Building Bridges: How Demographic, Disease-Specific, and Parental Factors Influence Access to Healthcare for Children with Rare Diseases**
   Susanne Wehrli

   Introduction: Access to care is a pertinent factor that is closely related to health outcomes, especially for children with rare diseases. A better understanding of the predictors that perpetuate such barriers is key to successful interventions. Since children are too young to manage their own, often complex, pathways to healthcare, this responsibility often falls to parents, making parental factors important for their children's access to healthcare.

   Methods: With the aim of gaining more insight into such factors, we used an online survey to collect cross-sectional data from Swiss parents of children with rare diseases (N = 112), aged between 1-18 years. Data collection is still ongoing, and the analyses reported are preliminary. Barriers to health care were measured with the Barriers to Care Questionnaire (BCQ), which consists of a pragmatics (logistical and cost issues), skills (competent navigation of the healthcare system), expectations (expectation of receiving poor-quality care), marginalization (internalization of negative experiences with the healthcare system), and knowledge and beliefs subscale (belief in allopathic conventional medicine). Higher scores on the BCQ subscales indicate higher barriers related to the content of the subscales in question.

   Results: Predictors were categorized as sociodemographic, disease-related, and parental factors. Supervised machine learning was used to select predictors, and regression analyses were performed subsequently. Results showed that across all BCQ subscales, except pragmatics, increased trust in health professionals was a significant predictor of decreased barriers ($p < .05$), whereas higher trust in healthcare institutions was predictive of lower marginalization and knowledge & beliefs ($p < .01$). Higher health literacy was a significant predictor of lower scores on the skills subscale ($p < .05$). Parents facing financial burdens due to their child's illness exhibited higher barriers regarding the skills and the pragmatics subscale ($p < .05$). Whereas having private insurance coverage was associated with lower marginalization ($p < .05$). Finally, higher disease coherence was predictive of an increase concerning the expectations subscale ($p < .05$). Conclusion: Overall, these results show that factors of different pedigree impact access to pediatric health care in the context of rare diseases and suggest new avenues for potential future interventions.

8. **Childhood cancer diagnosis during the COVID-19 pandemic: the parent perspective of the impact on the family**

Anna Jones

Introduction: The impact of paediatric cancer on the whole family system is widely acknowledged. The COVID-19 pandemic posed many additional challenges for families, including fear of infection and social disruption caused by imposed restrictions. This study aimed to explore parents' perception of the impact of a paediatric cancer diagnosis during the pandemic on the family. Walsh's (2003, 2016) socio-ecological family resilience framework was used to highlight family processes, as well as to consider the broader influences on the family system, such as communication with healthcare professionals.

Methods: Six parents of children undergoing cancer treatment during the COVID-19 pandemic at Addenbrooke's Hospital, Cambridge, took part in semi-structured interviews.

Results: Using interpretive phenomenological analysis, three General Experiential Themes (GET) were identified. These themes simultaneously capture the stress that families experienced, while also describing family processes that buffered against the stress. GET 1: 'Isolation versus Connection', describes feeling isolated from support networks, as well as building and strengthening connections. GET 2: 'Managing Uncertainty', encapsulates parents' frustrations and fears related to information gaps linked to cancer treatment and COVID-19. GET 3: 'Loss versus Solace', describes lockdown-related loss of routine and experience, and also positive factors to the imposed restrictions.

Discussion: This study's findings emphasise the dynamic relational aspects of resilience, where relationships and communication with other parents, children with cancer, and hospital staff, were important in fostering family resilience during the COVID-19 pandemic. Areas where structural and relational resources could be better promoted are also highlighted. The project's socio-ecological lens drew attention to the impact of other extrafamilial factors, such as organisational constraints and the impact of policy on single parents.

Conclusion: The findings have practical implications for supporting family resilience in the aftermath of the pandemic, planning for future disaster situations, as well relevance to paediatric cancer more broadly.

9. **Children's experience of the Aim to Decrease Anxiety and Pain Treatment (ADAPT) for Functional Abdominal Pain Disorders within a Swedish community paediatric setting- preliminary results**
Emma Ramsay Milford

Introduction: ADAPT is a blended digital/physical cognitive behaviour therapy (CBT) treatment for children with FAPD and anxiety. It includes two clinic-based sessions and four self-paced web-sessions. Initially evaluated within a paediatric hospital setting in the USA, a Swedish version has been developed and is being trialled within a community paediatric setting. The research group is exploring the treatment's feasibility as an early intervention for pain related functional disability and anxiety. The current study aims to explore children's attitudes and experience of ADAPT.

Methods: Participants, aged 9-14, are recruited one month post completion. Semi-structured interviews are conducted and analysed using a thematic approach. The study is ongoing with planned completion in June 2023 and further participants are currently being recruited.

Results: Preliminary findings from the first four interviews resulted in three main themes; 1) From initial uncertainty to retrospective insight, 2) Digital vs physical: Complimentary not competitive and 3) Ways to tackle pain and worry. The results indicate a more positive attitude towards the treatment and outcomes than initially expected. Pros and cons with the clinic-based in-person sessions and the digital-format were described, suggesting that the blended format could be a good compromise. Adult support with web-based sessions was needed. Most children found some strategy that worked and reported positive outcomes such as increased school attendance. In one case prior experience of the strategies and no perceived change was reported.

Discussion: The importance of screening, children's continuous involvement, and ensuring early access to tailored treatment for FAPD is discussed.

Conclusion: Preliminary findings of children's experience suggest that ADAPT could be a feasible treatment within a community- based setting. Further study exploring treatment effects is required and will be conducted by the research group.

10. **Parent-reported Pain Intensity Predicts Cognitive Flexibility in Paediatric Patients with Sickle Cell Disease**

Yuhui (Iris) Chen

Introduction: Pain is a major complication of SCD and has been demonstrated to be associated with negative effects on quality of life and executive function (EF) difficulties. Yet, little is known about whether having severe pain over time impacts EF. The current study aimed to assess whether long-term pain intensity predicts EF or cognitive flexibility, a key aspect of EF, in children living with SCD.
Methods: Caregivers of 29 children between 8-16.99 years of age demographics and the Behavioural Rating Inventory of Executive Function (BRIEF). The Global Executive Composite (GEC) was used in our analyses. Caregivers reported the pain intensity of their child over the past 6 months. Three subtests of the Delis-Kaplan Executive Function System (D-KEFS) evaluated children's cognitive flexibility: the Trail Making, Verbal Fluency, and Colour-Word Interference Test. Data on covariates (Hydroxyurea [HU] or blood transfusion) was collected from the medical record. Four linear regressions examined the relationships between pain intensity, EF, cognitive flexibility, and covariates.
Results: Parent-reported pain intensity significantly predicted Trail Making Test scores ($p = .03$). Pain intensity trended towards predicting category-switching in the Verbal Fluency Test ($p = .06$). Pain intensity did not significantly predict the Colour-Word Interference Test ($p= .80$). Finally, parent-reported pain intensity did not significantly predict BRIEF-GEC ($p= .44$); however, treatment type was a significant predictor ($p = .02$); patients treated with HU had worse executive function than those who received blood transfusion.
Discussion: Our results demonstrate that higher pain intensity significantly predicted worse cognitive flexibility in children with SCD. Surprisingly, children living with treated with HU had worse EF scores than those receiving blood transfusions. These data emphasise that it may be important to investigate specific EF rather than overall cognition in future research involving children living with SCD.

11. **Cognitive Disengagement Syndrome, Depression, and Self-Perception among Pediatric Brain Tumor Survivors**

Eva Darow

Introduction: Pediatric brain tumor survivors (PBTS) are at risk for cognitive late effects (e.g., attention and processing speed deficits) that resemble symptoms of cognitive disengagement syndrome (CDS;previously "sluggish cognitive tempo"). Emerging literature suggests associations between CDS and internalizing symptoms. Limited research has examined CDS among PBTS, and no studies have examined psychosocial outcomes in this context. We hypothesized that relative to comparison classmates (CC), PBTS would report more depressive symptoms and poorer self-perceptions, which would be partially explained by CDS and less adaptive coping strategies.

Methods: PBTS who were at least one-year post-treatment (n=75, age 9-18, 42% female) and CC (n=68, age 8-17, 44% female) participated along with a caregiver (n=143, M age =40.35, SD=6.35, 93% female). CC were age, gender, race matched classmates selected 1:1 for each PBTS during earlier data collection. Caregivers completed the Response to Stress Questionnaire, which yielded factors for child Primary-Control (PCC), Secondary-Control (SCC), and Disengagement Coping with social stress. CDS was assessed via caregiver-report of four items from the Child Behavior Checklist. PBTS and CC completed the Children's Depression Inventory and the Harter's Self Perception Profile for Children, yielding Scholastic Competence, Social Acceptance, and Global Self-Worth subscales. Eight serial mediation models were tested using the PROCESS macro in SPSS. Bootstrapped 95% confidence intervals not exceeding zero determined significant indirect effects.

Results: Compared to CC, PBTS had significantly greater CDS, which in turn, was related to lower Scholastic Competence (β_{PCC} =-.16; β_{SCC} =-.16), Social Acceptance (β_{PCC} =-.16; β_{SCC} =-.16), Global Self-Worth (β_{PCC} =-.16; β_{SCC} =-.15), and higher depressive symptoms (β_{PCC} =1.39; β_{SCC} =1.28). Among these models, significance values were observed at $p < .01$. None of these effects were accounted for by differences in coping.

Discussion: PBTS demonstrated elevated CDS, which partially explained the negative impact of brain tumors on self-perception and depressive symptoms. Contrary to our hypotheses, control-based coping strategies did not affect these associations.

Conclusion: Future research is needed to further characterise the psychosocial correlates of CDS among PBTS, such as whether CDS impacts peer interactions and academic performance. Interventions could target CDS to improve internalising difficulties for PBTS.

12. **Development of a multimodal personalized executive function intervention for school-age children with complex congenital heart disease**
    Alenka Schmid
    Introduction: Children with congenital heart disease (CHD) are at risk of neurodevelopmental problems, and executive functions (EF) are most frequently affected. To date, interventions aiming at improving EF have shown limited effects in children and adolescents with complex CHD. To better determine what patients wish for from such an intervention, we performed a user-centred needs assessment to determine a targeted EF intervention.
    Methods: We performed a multi-step patient-centred needs assessment. Participating children and adolescents (age: 13.3 (1.4) years) were all born with a complex CHD, undergoing cardiopulmonary bypass surgery in infancy. In an online focus group interview, five families and their children with CHD ($n_{parents}$ = 7, $n_{children}$ = 5) were asked about their wishes and needs concerning the content and scope of an EF intervention. The interviews were interpreted in a structured Qualitative Content Analysis. The ideas derived from this analysis were transformed into items with a 9-point Likert scale for a Delphi survey, which was completed by a different sample of children with complex CHD (n = 6), their teachers (n = 5), parents (n = 6), and CHD and intervention experts (n = 5).
    Results: The results of the Delphi survey showed that the wishes and needs most strongly expressed by the participants were that the intervention should include strategies supporting homework (Median: 8, IQR = 1) and everyday life activities (median=9, IQR=1) and that the children should learn to develop strategies (median=8, IQR =1). Also, they wanted activities which did not resemble schoolwork (median = 8, IQR = 1), improved reasoning skills (median=8, IQR=0.5), and addressed academic future planning (median=7.5, IQR=1). Parents emphasised that starting age and implementation mode (e.g., online or in person) are highly child dependent, which the teachers and experts confirmed.
    Discussion: An intervention aiming at improving EF for children with complex CHD should teach strategies and be personalised. Findings of prior studies had to be consulted to refine the suggestions.
    Conclusion: Based on the needs-assessment, we developed a multimodal personalised EF intervention, including games in different implementation modes and strategy coaching. This intervention is currently being tested in a randomised-controlled feasibility study.
13. ***retracted***

14. **Digital self-management and peer mentoring intervention for young adult survivors of childhood cancer transitioning to adult healthcare**

Katie A. Devine

Introduction: Childhood cancer survivors require lifelong risk-based follow-up care, but many survivors are lost to follow-up during the transition from pediatric to adult follow-up care. This study evaluated the feasibility, acceptability, and outcomes of a novel digital self-management and peer mentoring intervention for young adult survivors of childhood cancer.

Methods: Participants ages 18 to 25 were recruited from the New Jersey State Cancer Registry and/or the local clinic. Peer mentors ages 21 to 29 were recruited from the local clinic, trained, and supervised. Participants were randomised 1:1 into the intervention (consisting of six peer mentor videocalls and five online self-management modules) or usual care. Feasibility and acceptability were assessed by recruitment rates, retention rates, engagement, satisfaction, and the Treatment Evaluation Inventory-Short Form. The Transition Readiness Inventory (TRI) and Readiness for Transition Questionnaire (RTQ) were completed at baseline, 2 months, 5 months, and 12 months. Descriptive analyses (frequencies, means) evaluated feasibility/acceptability. Multilevel modelling evaluating the time x treatment interaction was used to determine whether change in transition readiness differed between the two groups.

Results: A total of 50 participants (M_{age} =21; 60% male) enrolled (32% of the total pool was contacted; 76% of those were screened; 94% of those screening eligible enrolled). Twenty-two (88%) of the 25 randomised to the intervention arm completed the peer mentor calls. On average, participants completed 96.4% of the online modules. Participants indicated high satisfaction (M=4.64, SD=0.49) and acceptability of the intervention (M=38.0, SD=5.4; acceptability threshold> 27). Relative to usual care, participants in the intervention group demonstrated significantly greater increases in the overall TRI score (z=2.6, p=0.01) and knowledge and beliefs subscales (ps=.03 and .01). Differences in the total RTQ score and other TRI subscales were not significant.

Discussion: Results indicated high feasibility and acceptability of the intervention. Promising changes in transition readiness suggest further research.

Conclusion: Self-management tools paired with peer mentoring may improve transition readiness. An adequately powered efficacy trial is warranted.

15. **Eating habits profiles and physical activity levels of AYA cancer patients and survivors**
Sandra Soca Lozano

Introduction: Many AYA cancer patients/survivors do not engage in healthy eating and physical activity (PA) recommendations. The present study assessed the eating habits and PA levels of AYA cancer patients and survivors and its association with race/ethnicity, health literacy (HL), and home environmental influences.

Methods: 292 AYA patients/survivors from Moffitt Cancer Center took our anonymous online survey. The following measures were used: Demographic Questionnaire, Rapid Eating Assessment for Participants (REAP), Rapid Assessment of Physical Activity (RAPA), Brief Health Literacy Screening, Social Support and Exercise Survey, and Social Support and Eating Habits Survey. Descriptive statistics and Pearson product-moment correlation coefficients were calculated.

Results: REAP scores were negatively correlated to Black and African American, Body Mass Index (BMI) = obese, and encouragement from friends in healthy eating ($r = -.19$, $p < .01$, $r = -.29$, $p < .01$, $r = -.13$, $p < .05$). REAP scores were positively correlated to BMI = underweight/healthy and to family participation in PA ($r = .15$, $p < .05$, $r = .18$, $p < .01$, $r = .16$, $p < .01$). RAPA scores were negatively correlated to BMI = obese ($r = -.13$, $p < .05$) and positively correlated to friends' encouragement to healthy eating, family/friends discouragement to healthy eating and family/friends participation in PA ($r = .13$, $p < .05$, $r = .13$, $p < .05$, $r = .25$, $p < .01$, $r = .24$, $p < .01$, $r = .23$, $p < .01$). HL was not correlated to REAP/RAPA scores.

Discussion: The results of the present study suggest the importance of eating healthily and practicing PA to maintaining a healthy weight. It also shows that attitudes and behaviours from family and friends regarding healthy eating and PA might positively and negatively relate to participants' adherence to healthy eating and PA guidelines.

Conclusions: Clinicians should offer more detailed guidance to certain at-risk individuals within the AYA cancer population related to their eating habits, also helping increase support from family and friends in lifestyles behaviour change efforts.

16. **Executive Function and Parenting as Predictors of Health Care Self-Efficacy in Adolescents with Spina Bifida**

Olivia E. Clark

Introduction: Self-efficacy (SE), the belief that one can complete necessary behaviours in specific situations, is an important factor in symptom management for youth with chronic conditions. Spina bifida (SB) is a birth defect with multiple, varied medical impacts. Youth with SB must complete daily medical tasks with increasing levels of independence through adolescence, often in the context of executive dysfunction. Parent overprotectiveness has been associated with limited youth autonomy in SB. The current study evaluated executive function (EF), maternal protectiveness (MP), and independent medical management skills as predictors of youth SE.

Methods: Youth with SB (N =140 at T1; 54% female; 53% white; M_{age} =11.43) completed neuropsychological testing measures at T1 and a measure assessing SB SE at T6, approximately 10 years later. Their mothers (N=73 at T3; 60% white; M_{age} =44.82) completed measures of MP and independent medical self-management at T3. A hierarchical linear regression examined the contribution of MP and mother-report of youth self-management skills in relation to youth SE controlling for youth EF in step 1, before adding MP in step 2 and self-management skills in step 3.

Results: Youth reported high levels of SE (M=4.28), and mothers reported moderate MP and youth self-management skills (M=1.07; M=.80). EF explained 19% of the variance in SE, R^2 =.19, $F(1,31)=7.44$, p=.01. Adding MP improved the model and explained an additional 16% of the variance in SE, total R^2 =.35, $F(2,30)=8.16$, p=.011. Mother-report of youth self-management skills did not significantly improve the model, total R^2 =.356, $F(3,29)=5.34$, p=.681. Better executive function (β=.34, p=.04) and lower MP (β=-.40, p=.01) were associated with higher SE. Self-management was not significantly associated.

Discussion: MP may be detrimental to SE, while strong EF may support SE. Parenting strategies to promote self-efficacy in adolescence may be important for youth with SB. Bidirectional associations between SE and independence skills should be a focus of future research.

Conclusion: SE may play an important role in adherence to medical regimens in SB and may be affected by family factors. Providing guidance to parents regarding developmentally-appropriate transition of responsibility may be an important role for pediatric psychologists.

17. **Empowering New Habits and Nutrition after the Cancer Experience (ENHANCE): An obesity prevention and intervention for U.S. adolescent and young adult cancer survivors**
Melissa A. Faith

Introduction: Obesity poses serious risk for adolescent/young adult (AYA) cancer survivors because survivors have increased cardiovascular, endocrine, and psychological risks. Moreover, 20-30% of U.S. AYA cancer survivors are overweight or obese. This pilot study evaluated feasibility, acceptability, and preliminary efficacy of a newly-developed obesity prevention/intervention for AYA cancer survivors.
Methods: This pilot randomised controlled trial compared a newly-developed obesity prevention/intervention (ENHANCE; n=29) with an education-only-condition (EO; n=22). Participants were 15-22 year-old cancer survivors (age M(SD)=18.84(2.48) years; 33% Hispanic, 26% non-White), with-or-without another adult (e.g., mother). ENHANCE targets nutrition and physical activity using education, skill-building, motivational interviewing, and problem-solving during 12 weekly telehealth sessions. Participants completed measures at: pre-randomization (T1), 12 weeks (T2), 20-24 weeks (T3), 34-38 weeks (T4). Participants received Fitbits to track physical activity. ENHANCE-group participants also completed a post-intervention structured interview. We determined feasibility by percentage of eligible AYAs who (1) enrolled, and (2) completed all ENHANCE sessions. We determined acceptability by percentage of participants with Abbreviated Acceptability Rating Profile (AARP) score >30. We also qualitatively assessed feasibility/acceptability via the post-intervention structured interview. We assessed nutrition via the Rapid Eating Assessment for Patients (REAP) and physical activity via Fitbit data.
Results: Of eligible AYAs, 92% recruited in-person enrolled; 83% recruited via telephone enrolled. 95% of ENHANCE-group participants completed all ENHANCE sessions; one participant discontinued following a household family-member death. All ENHANCE-group participants obtained AARP scores>30 (M(SD)=39.80(5.63)). All ENHANCE-group participants described ENHANCE as feasible/acceptable in structured interviews. Per the REAP, nutrition improved from T1-T4 for ENHANCE participants but not EO participants. Per Fitbit, only the ENHANCE group achieved average daily active minutes consistent with American Heart Association recommendations at T4.
Discussion: ENHANCE was feasible, acceptable, and effective in improving nutrition and physical activity. ENHANCE is unique by targeting AYAs and caregivers, focusing on both nutrition and physical activity, demonstrating minimal attrition, and focusing on AYAs' perceptions of agency.
Conclusion: ENHANCE is a promising, highly acceptable tool to decrease obesity risk for AYA cancer survivors.

18. **Establishing a pathway for Mental Health screening in Paediatric Epilepsy Clinics**
Bethan Phillips

Introduction: Key findings from the Epilepsy12 project recommended paediatric epilepsy services: 1) routinely screen for mental health difficulties, 2) identify and utilise mental health referral pathways for children with comorbid mental health problems and 3) ensure that integrated mental health support be made available within epilepsy clinics.

Methods: A series of measures were reviewed and we selected the PI-ED, PHQ9 and GAD 7. Instructions were developed to support clinicians to introducing the measures to children and families; how to administer and score; and how to discuss onward referrals. Flow charts were designed to provide a visual representation of these pathways. External liaison was held with CAMHS colleagues around how best they could support the Epilepsy team when children or young people were in mental health crisis. Regular meetings are held within the Epilepsy teams to discuss the project.

Results: The project has enabled the cascading of psychological screening and assessment skills to the wider MDT. Referrals are now made in a coordinated, systematic way, allowing better management of waiting lists for the Paediatric Clinical Psychology service. A stepped level of care is able to be applied to these referrals with regards to psychological intervention, which allows for clarity and transparency to all those in the MDT

Discussion: Those young people who have been referred onto Paediatric psychology have been appropriate referrals, and were able to receive timely and appropriate psychological intervention. Screening has opened up conversations about mental health; and has also provided the opportunity for reflection and sharing of psychological theories and formulations between the Paediatric Clinical Psychologist and epilepsy team. A special interest group was established between Paediatric Clinical Psychology services across Wales and the UK. Methodology and results of this project have been shared with these services; and clinical pathways following the CTM model have now been established in several other services across the UK.

Conclusion: We plan to continue using the screening protocols and referral pathway as part of standard clinical practice within epilepsy clinics across CTM paediatric services.

19. **Exploration of Pediatric Life Satisfaction, Pain Interference, and Participation in Youth Adaptive Athletes**

Jessica Hoehn

Introduction Adaptive sports have been linked to higher quality of life for individuals with disabilities. However, these individuals can encounter many barriers to participating in sports, which limits access to these benefits. Additionally, youth with disabilities are often affected by multiple medical co-morbidities and pain that threaten to interfere with participation and life satisfaction. This study aimed to explore life satisfaction, pain interference, and barriers/facilitators to participation in recreational youth adaptive athletes.

Methods: This was a cross-sectional study design with a convenience sample of 18 adolescents (ages 10-17). Participants were recruited at various adaptive sport practices and completed a semi-structured interview. Transcriptions of interviews were coded according to common themes influencing adolescents' participation in sports. Participants also completed two PROMIS quality of life measures: PROMIS Pediatric Pain Interference and PROMIS Pediatric Life Satisfaction questionnaire. One-sample t- tests were used to compare the mean PROMIS T-scores to referent populations for all PROMIS measures.

Results: Adolescents participated in an average of 265.6 (SD=166.5) minutes of vigorous exercise per week. Pain Interference and Life Satisfaction T-scores of youth athletes did not significantly differ with the general population. There was a significant, positive correlation between total minutes of vigorous exercise and life satisfaction scores ($r(18) = .518$, $p= .028$). Qualitative analysis identified prevalent themes influencing participation in adaptive sports, including: social factors, intrapersonal factors, motivators to start sport, access, physical and mental health, and athletic identity. Barriers identified included perceived medical and financial barriers. Facilitators included receiving support from family, medical providers, and teammates, connecting with others with disabilities, and funding assistance were all identified as facilitators.

Discussion: Despite increased challenges regarding social and emotional functioning for children with disabilities, youth athletes participating in adaptive sports have no lower life satisfaction nor any increase in pain interference compared to the general population. Our findings also suggest that there is a dose response that the greater the amount of participation the more satisfaction. Our participants reported multiple benefits to participation despite perceived financial and medical barriers.

Conclusion: Our findings emphasise the value and benefits of youth adaptive sports for facilitating good quality of life.

20. **Facilitators and Barriers towards Implementing Shared Decision-Making in Pediatric Physical Therapy: Perspectives from Diverse Stakeholder Groups**
Selina Limmen

Introduction: The implementation of shared decision-making (SDM) in pediatric physical therapy (PPT) presents unique challenges, including the manner in which children are engaged in SDM and the involvement of family members/caregivers. The aim of this study is to gain insight into facilitators and barriers to implement SDM in PPT.

Methods: In this study we use two qualitative methods. First, in January 2023, an expert meeting has been conducted with stakeholders including patient organisations, professional associations, pediatric physical therapists, and experts in SDM. The Six Thinking Hats method (de Bono) was employed to investigate SDM in PPT from multiple perspectives. Each thinking hat represented a distinct cognitive perspective. Second, focus groups will be conducted between March and May 2023 with adolescents, 12-18 years of age, and parents of children aged 4-18 with experience in PPT, and pediatric physical therapists. These sessions will be recorded and transcribed verbatim. Qualitative analyses, using thematic content analysis by Braun and Clarke in an inductive approach, will be performed by two independent researchers using MaxQDA.

Results: The expert meeting showed that SDM in PPT is likely to enhance child and parental motivation and may improve efficacy of healthcare. However, barriers to implement SDM in PPT include challenges with time management and potential discrepancies in perspectives between children and their parents. Additionally, there is lack of information about financial implications, effectiveness, and techniques for engaging parents in SDM within PTT. To ensure participation of the diverse group of children attending PPT is perceived challenging. Findings from the focus groups will be presented at the conference.

Discussion and conclusion: Overall, this study highlights the importance of identifying barriers and facilitators of SDM in PPT and the need to develop strategies to enhance the SDM process in this context. By addressing these barriers and enhancing facilitators, pediatric physical therapists may improve healthcare outcomes of children and adolescents and promote family-centred care.

16.30 – 17.30 **Short oral presentations session 1 (Moderator: Kathleen Lemanek)**

Lecture theatre Pathfoot

1. **Implementation of a Novel Electronic Distress Screening Tool in Pediatric Medical Specialty Clinics**
   Amii C Steele, Megan McComas, Lori Wiener, Sima Bedoya & Maryland Pao
   Introduction: Youth with medical illnesses often experience emotional and behavioural distress related to their disease and treatment. International and US Standards recommend psychosocial distress be assessed routinely, documented, and treated during a patient's medical visit. This project aims to implement a novel, electronic distress screening tool, "Checking IN," and identify endorsed psychosocial stressors of children and adolescents with medical illnesses that are reported to be interfering with their life.
   Methods: English speaking youth (8-21yo) diagnosed with a medical illness electronically complete Checking IN. Patients have the option of completing the screener prior to clinic or upon arrival. Checking IN assesses 12 psychosocial domains and provides an immediate personalised distress summary report. The report is reviewed by a medical provider to inform the clinic visit and make treatment recommendations. This allows children to receive tailored, patient-centred care and referrals in real time (I.e., Pediatric Psychology, Integrative Medicine).
   Results: Thus far, 81 patients (74% Male; 63% White) have completed Checking IN in Cancer and Blood Disorders and Cardiology clinics. 89% of patients completed the screener upon arrival at their clinic visit. Patients most commonly endorse sleep (52%) feeling tired (47%), and difficulties paying attention (38%) as interfering with their lives. Screening is ongoing and current data trends will be presented.
   Discussion: Challenges associated with the implementation of an electronic screener include limited medical record integration, the person-power required for implementation, and obtaining buy-in from various disciplines. Implementation strategies as well as barriers will be discussed.
   Conclusion: Standardised, psychosocial screening can facilitate access to early intervention in pediatric medical specialty care. Psychologists and medical teams alike can quickly assess a patient's psychosocial needs and address them during a clinic visit. Psychologists can use this data to target their interventions on the symptoms that are reported to interfere most with the patient's life as well as track treatment progression. Checking IN provides a quick and comprehensive holistic overview of a patient's psychosocial functioning and can improve overall patient care.

2. **Meaningful Clinical Change and Treatment Responsivity in Pediatric Psychology Intervention Research**

Michael J. Dolgin

Introduction: Randomized-controlled trials (RCTs) in pediatric psychology form the foundation for evidence-based treatment and best practices in the field. Relying heavily on continuous outcome measures and group comparisons, questions concerning meaningful clinical change and treatment response rates remain open.

Bright IDEAS (BI) is a problem-solving skills training (PSST) program that has been demonstrated in earlier RCTs to be an effective and specific intervention for improving problem-solving skills and reducing negative affect in caregivers of children with cancer.

Objectives: The objectives of this study were to (a) offer an approach to defining meaningful treatment response and to determine the rates of responsivity to PSST; and (b) identify characteristics of PSST responders and nonresponders.

Methods: Data from 154 mothers receiving the BI intervention were analyzed. Drawing on the literature on Minimal Clinically Important Differences, two criteria for determining responsivity were calculated for the primary outcome of problem-solving skills: (a) The reliable change index (RCI) based on group data, and; (b) The effect size (ES) of each participant's pre/post-intervention change score as a function of the group's baseline SD.

Results: Thirty-three percent of the sample met both responsivity criteria immediately post treatment (39% at follow-up) and 38% (39% at follow-up) met neither. An additional 29% demonstrated a small or greater ES (>0.2) but did not meet the RCI criteria, suggesting possible benefit. The single consistent predictor of responsivity was participants' pretreatment problem-solving skills, with lower skills at baseline predicting greater improvement ($p < .001$).

Conclusion: These findings highlight the need to go beyond group data in interpreting RCTs and to incorporate measures of meaningful treatment response. Our ability to predict and screen for meaningful treatment response is critical to more precise targeting, enhanced outcomes, and better resource allocation.

3. **Gritting Through It: Caregiver Grit as a Source of Resilience in Families Affected by Pediatric Cancer**
Christina Sharkey

Introduction: Children treated for cancer and their caregivers exhibit considerable resilience, yet a significant subset are at risk for adjustment difficulties. Limited research has utilised a resilience-based framework, conceptualised as the process of harnessing resources. Examination of modifiable internal, external, and existential resources that could be targeted to promote resilience outcomes is warranted. Grit, an intrapersonal characteristic defined as perseverance and passion toward long-term goals, is one internal resource to consider due to the documented positive effects of grit on health-related outcomes. The present study investigates the role of grit in caregiver and child psychological adjustment following a pediatric cancer diagnosis.

Methods: Caregivers (N=55, 90% female, 72% White, 47% college or higher degree) of children within one year of a cancer diagnosis (mean days since diagnosis = 160.2) completed questionnaires at a Midwestern children's hospital. Parents provided self-reports of grit and posttraumatic stress symptoms, and proxy-reports of their child's behavioural and emotional problems. Bootstrapped linear regression analyses were conducted.

Results: On average, caregivers reported a grit score of 3.31 (SD=0.72), which is slightly below the general population. Per caregiver report, the majority of caregivers and children with cancer were resilient, yet a subset (34.5% of caregivers and 11.9% of children) had clinically concerning psychological symptoms. No demographic or disease characteristics were associated with primary outcomes. Caregiver grit significantly predicted caregiver posttraumatic stress symptoms ($F(1,52)=10.51$, $p=.002$, $R2 =16.8\%$) and child psychological difficulties, $F(1,40)=19.10$,$p<0.001$, $R2=32.3\%$.

Discussion: Among families affected by pediatric cancer, higher levels of caregiver grit were associated with lower caregiver posttraumatic stress symptoms and child psychological difficulties. Results suggest that grit is a potential target for interventions promoting both caregiver and child resilience in pediatric cancer. Longitudinal research is needed to better understand how caregivers harness grit, as a possible component of resilience, throughout the cancer treatment and survivorship trajectory.

Conclusion: The characteristic of grit appears to be an intrapersonal resource that may contribute to positive health outcomes for families affected by pediatric cancer.

4. **Parental experience and understanding of parent-provider discussions of treatment for infants with ureteropelvic junction obstruction**

Cindy Buchanan

Introduction: Ureteropelvic junction obstruction (UPJO) is a common condition affecting infants seen in a pediatric urology ambulatory clinic. The goal of surgical treatment of UPJO is to minimise the risk of kidney damage associated with obstruction, which may occur in 30-60% of infants with high-grade hydronephrosis. However, the benefit of early surgery compared to observation and potential later surgery to preserve kidney function has not been well-defined and evidence-based guidelines for treatment are lacking. The purpose of the current study was to understand what families identify as necessary information to guide decision-making in the treatment of their child with ureteropelvic junction obstruction (UPJO).

Methods: We conducted semi-structured interviews with parents of children with UPJO using phenomenological methodology. Data were systematically analysed according to principles of thematic analysis, using a team-based inductive approach.

Results: 32 parents were interviewed. Findings are organized by three major themes including barriers to meaningful participation in decision making, logistical aspects of the decision, and psychosocial aspects of the decision.

Discussion: This study serves as the initial needs assessment on the perspective of parents of children with UPJO and highlights parents' perspectives on how best to help them navigate the complexity of care for children with this condition. It is clear from the findings of the qualitative interviews that families would benefit from additional support designed to enhance understanding and preparation. Parents shared that they were emotionally impacted by their decisions about their child's health care needs, which can limit the ability of a caregiver to meaningfully engage in surgical decision-making process.

Conclusion: These findings suggest the need to increase parent education and understanding around medical and surgical decision-making, and the need to enhance psychosocial support for more meaningful parental engagement in the surgical decision-making process. Given that parents highlighted the often-overlooked psychosocial factors that contribute to their experience related to their child's diagnosis that may impact their decision-making, the important role of integrated psychological services in pediatric urology will be discussed.

5. **Reducing caregivers' perceived oral chemotherapy adherence barriers for United States youth with acute lymphoblastic leukemia**

Melissa A. Faith

Introduction: Pediatric acute lymphoblastic leukemia (ALL) treatment generally requires two-to-three years of daily oral 6-mercaptopurine (6-MP) during maintenance therapy. Unfortunately, many patients demonstrate sub-optimal adherence; missing even 5% of 6-MP doses can increase relapse risk up to 400%. Moreover, U.S. racial/ethnic minority children continue to have worse survival than White, non- Hispanic children. This study included three aims: (Aim 1) to examine adherence barrier endorsement across caregiver cultural groups, (Aim 2) to evaluate psychometric properties of the Parent Medication Barriers Scale (PMBS), revised to assess ALL 6-MP adherence barriers, (Aim 3) to evaluate whether motivational interviewing (MI) versus an education-only control condition (EO) reduced caregivers' perceived 6-MP adherence barriers.

Methods: Participants were 121 caregivers of pediatric ALL patients (caregiver age M(SD) = 36.66(8.02); 52.1% non-Hispanic, English-speaking [nHES], 24.8% Hispanic, English-speaking [HES], 23.1% Hispanic, Spanish-speaking [HSS]). We randomized caregivers 2:1 to MI or EO. Caregivers completed the modified PMBS pre-intervention and one-month post-intervention.

Results: Per previously-established cut-offs, 84% of caregivers had elevated non-adherence risk. Caregivers' endorsement of three specific barriers differed by cultural group (nHES/HSS/HSS). Principal Components Analysis (PCA) extracted a two-component PMBS solution: Regimen Adaptation (a=.83) and Disease Frustration (a=.76). Per ANCOVAs, after adjusting for baseline Regimen Adaptation, intervention group had a significant main effect on post-intervention Regimen Adaptation ($F(1, 85) = 4.77$, $p = .03$, partial $\eta 2 = .05$, Cohen's $d = .47$, medium effect size). MI-group caregivers reported fewer regimen adaptation barriers (M(SD) = .64(.11)) post-intervention compared to EO caregivers (M(SD)=1.32(.12)). Disease Frustration changes were not significantly different for the MI versus EO groups.

Discussion: The PMBS is a psychometrically promising scale to assess caregiver-perceived 6-MP adherence barriers for ethnically/linguistically diverse pediatric ALL families. MI could be a cost-effective way to help enhance diverse caregivers' perceived agency to address their child's adherence needs.

Conclusion: The PMBS could serve as a brief screening tool to evaluate non-adherence risk for pediatric ALL patients. MI could be a promising intervention to help diverse families decrease 6-MP nonadherence risk and ultimately decrease survival disparities.

6. **The stage conductors behind the cradles: Reflections on the role of family therapy alongside paediatric clinical psychology provision for a neonatal intensive care unit**
Tessa Saunders

Introduction: The journey for neonatal families often begins far before their baby/babies are admitted onto NICU, leaving footprints across large maternity systems. Once on NICU, it is another large system which the family are embedded within. Neonatal families are often faced with a number systemic challenges surrounding themes of grief/loss, family scripts, power, transition, ability vs disability and implications for social context. The systemic complexity regarding the neonatal journey can often require therapists to take the position a liken to a "stage conductor", with multiple systems, models and theories held in mind to inform what works well when supporting and coordinating systems surrounding and within the neonatal context. The clinical psychologist and family therapist from one NICU will reflect on the positions of staging the production for how family therapy provision alongside clinical psychology provision for neonatal families was run in one tertiary unit in Cambridge.
Methods: The proposed model for our NICU family therapy clinic will be presented within systemic theoretical models, including family scripts, power, transitions and context of social difference. Such models will align with trauma informed care in helping to protect and contain family dynamics implicated by the NICU experience. This relates to the term "stage production behind the cradle" as a metaphor to illustrate the lived experience of piloting this approach.
Results: The outcomes following our proposed model for family therapy provision alongside clinical psychology provision for NICU's will be discussed. Learning points and recommendations will be presented for NICU's nationally.
Discussion: The strengths and limitations of our model will be illustrated, alongside learning points. Personal and professional reflections will be illustrated throughout this.
Conclusion: Having a baby/babies on NICU can be a highly stressful and traumatic experience for families to endeavour. The associated impact on the wider system has implications for trauma informed care as well as mental health and relationship difficulties for families. Whilst clinical psychology provision for NICU's is beginning to grow nationally, the added value of family therapy provision could further strengthen and improve outcomes for neonatal families.

18:00 - 19:00 Social Programme: mindful walk around the Loch

Weather dependent: Join us for a relaxing walk around the loch. The loch is an important part of community life at the university. It's 2.5km path is perfect for strolls, jogging or just sitting down to enjoy the peaceful views. The views are spectacular and different every day with the ever-changing weather and the passing of the seasons.
To join our mindful walk around the loch, come to *the Pathfoot reception by 18:00*. The walk around the loch takes about 45min and is an opportunity to take a relaxing stroll in nature, while exploring our local wildlife (e.g., swans, crows, ...) and reflecting on a busy first day of the conference. The walk will end at the reception of the Stirling court hotel.

PROGRAM THURSDAY August 31, 2023

08.00 – 09.00 **Registration**
Pathfoot Crush Hall

09.00 – 09.15 **Opening Day 2 (Moderator: Rikard Wicksell)**
Lecture theatre Pathfoot

9.15 – 10.15 **Plenary session 2: Helen Griffiths (Moderator: Yvonne Vance) (1 CE credit offered)**
"People can't see your values and intentions, but they can see your behaviour": Leadership in Paediatric Psychology
Lecture theatre Pathfoot

Learning Objectives

a. Identify the aspects of leadership models and theory that apply to their role in Paediatric Psychology
b. Create a personal action plan for developing their own leadership skills relevant to their stage of career.

10.15 – 10.45 **Short coffee break**
Pathfoot Crush Hall

10.45 – 12.15 **Parallel symposium session 2 (1.5 CE credits offered)**

Symposium 1: Pediatric Functional Neurological Symptom Disorder: Cutting-edge Research and Clinical Application Across Clinical Settings (Chair: Aaron Fobian) – Lecture theatre Pathfoot

Individual Talks

1. Background on FNSD: What do pediatric psychologists need to know? (Kelly Maynes)
2. Inpatient Evaluation and Management of Pediatric Functional Neurological Symptom Disorder (FNSD) (Kris Kullgren)
3. Words Matter. The Role of Psychologists in Functional Neurological Symptom Disorder (FNSD) Educational Efforts for Patients, Families, and Interdisciplinary Providers (Cassie Ross)
4. Outpatient Treatment of Pediatric Functional Neurological Symptom Disorder (FNSD) (Aaron Fobian)

Symposium Abstract

This symposium theme is the evaluation and management of pediatric Functional Neurological Symptom Disorder (FNSD) across clinical settings utilizing cutting edge research and evidence-based practice. The presenters are experts on pediatric FNSD practice and leaders of the SPP FNSD SIG. FNSD are characterized by the presence of neurological symptoms in the absence of structural neurological damage presenting as a range of motor and sensory deficits (i.e., tics, paralysis, non-epileptic events, etc.). Youth with FNSD can be severely debilitated, experience poor physical functioning, inconsistent school attendance, and disrupted socialization. Youth with FNSD have high healthcare utilization and costs (Stephan et al., 2019), and many medical providers lack of comfort with the diagnosis. Pediatric psychologists often evaluate the contributing psychosocial factors to the symptoms, support the medical team's management of these complex patients, and provide outpatient interventions. The goal for this symposium is to dispel myths regarding this diagnosis, reduce stigma, and increase psychologist confidence at providing care for youth with FNSD utilizing evidence-based practice and cutting-edge approaches across the spectrum of care. The symposium structure will be a lecture format with case discussion and ample time for interactive discussion. The four presentations will start with a foundation of FNSD diagnosis, conceptualization, and treatment challenges for the pediatric psychologist. The three presentations that follow will address 1) common evaluation and management strategies in the inpatient setting with a focus on clinical pathways and the benefits of a standardized approach to evaluation and management (Kullgren et al., 2020), 2) communication strategies to support concurrent mental health and medical management, and 3) evidence-based strategies for outpatient FNSD management (Fobian et al., 2021). All presentations will integrate a culturally-informed approach as racial and ethnic disparities in workup/diagnostic approach can delay care and impact outcomes for youth with FSND (Kline et al., 2022).

Learning Objectives

a. Identify core components of pediatric FNSD diagnosis, conceptualization, and treatment challenges.
b. Describe the benefits of interdisciplinary models, care pathways, and communication strategies to facilitate management of pediatric patients admitted with FNSD.
c. Identify practical strategies to develop and implement effective outpatient treatment plans for FNSD to increase access to evidence-based care.

Symposium 2: The complexity of improving quality of care (Chair: Amanda L. Thompson) *– Seminar room PD1*

Learning Objectives

a. Discuss the use of the Matrix and Guidelines to improve the standard of psychosocial care for children with cancer and their families.
b. Describe the distribution of family risk levels within a conceptual model to guide clinical care in pediatric psychology.

Individual Talks

1. Enhancing the Quality of Care in Pediatric Sickle Cell Disease (Kathleen L. Lemanek)

Abstract

Introduction: Sickle cell disease (SCD) is the most common severe blood disorder, affecting millions of people worldwide and about 100,000 Americans. Individuals with SCD may experience various complications, including vaso-occlusive crises, anemia, pulmonary hypertension, and cerebrovascular accidents. Despite the number of individuals being affected and the severity of complications, the percentage of funding contributed to research and clinical services is significantly less than other chronic illnesses, such as Cystic Fibrosis and Cancer. Systemic racism and social determinants of health are factors impacting the quality of and access to care.

Methods: The SCD & Thalassemia Center in the Department of Hematology/Oncology at Nationwide Children's Hospital in Columbus, Ohio (USA) has been involved in quality improvement projects and initiatives to enhance the care of pediatric patients at the State, county, and inpatient and outpatient hospital level. This oral presentation will focus on four initiatives that cross discipline collaboration. The first project is designed to track and enhance new born screening confirmatory testing at the national and State level. The second program is the Sickle Cell Outreach in the Schools (SCOUTS), which is intended to facilitate medication management in the schools. The third project is directed toward increasing adherence to national standards for using incentive spirometry for hospitalized patients with SCD. The fourth project is designed to encourage ambulation during admissions with collaboration between nursing, psychology and clinical therapies.

Results: Data on metrics for each projects will be presented, such as tracking numbers and barriers for confirmatory testing, monitoring education and adherence to medications, prevention of acute chest syndrome, and reducing length of stay.

Discussion: The outcomes of these initiates and projects will be discussed with respect to factors supporting and hindering implementation. The role of systemic racism and social determinants of health on development, dissemination and access to quality health care will be discussed.

Conclusion: The role of Pediatric Psychology in antiracism efforts, SDoH and direct service delivery will be complicated as social-political issues continue to influence our practices.

2. Matrix and Guidelines Guide Implementation of Standards of Psychosocial Care of Children with Cancer and their Families (Amanda L. Thompson)

Abstract

Introduction: A substantial body of research provides evidence of the impact of cancer on children and families with many calls for translating these findings into evidence-based interventions. In 2015, in collaboration with the Mattie Miracle Cancer Foundation (MMCF), the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)—over 80 interdisciplinary expert stakeholders, published 15 evidence-based Standards for pediatric psychosocial care. The Standards have provided centers a blueprint for providing evidence-based care. Since publication, pediatric oncology centers have requested guidance on best practices for Standards implementation.

Methods: In response, a Matrix (Institutional Scoring Measure) and Guidelines (how to implement Standards) has been developed for each Standard. The Guidelines include strategies (action steps) and resources/tools to help sites improve their score on the matrix and enhance their current practice.

Results: Using focus groups, an online rating tool and paper individual reviews, interdisciplinary pediatric psychosocial professionals (e.g., social workers, psychologists, psychiatrists, oncologists, nurses, educational specialists and child life specialists) from over 30 centers have reviewed the Matrix and Guidelines. The Matrix and Guidelines were revised based on the feedback received. Intended utilization of these tools will be demonstration thought a short case example, which will describe how the Matrix and Guidelines can be leveraged to increase psychosocial support at institutions.

Discussion & Conclusion: The Standards leadership group is committed to creating and disseminating a blueprint to support universally available psychosocial services for children with cancer and their families. With growing demand on cancer centers to meet new metrics of quality care, the pediatric psychosocial Matrix and Guidelines can help centers systematically identify and develop steps to address gap areas in their capacity to meet these new Standards.

3. Pediatric Psychosocial Preventative Health Model (PPPHM): A scoping review supporting screening and informing care delivery (Anne E. Kazak)

Abstract

Introduction: Psychosocial care is an important component of integrated pediatric care, yet models to guide delivery and that facilitate health equity, are needed. The Pediatric Psychosocial Preventative Health Model (PPPHM) is a three-tier model (Universal, Targeted, Clinical) of family psychosocial risk that can guide screening assessment and conceptualize personalized psychosocial care. Universal screening of all families to determine family psychosocial risk based on the PPPHM supports equitable care.

Method: This scoping review evaluated evidence from papers using the Psychosocial Assessment Tool (PAT), a brief caregiver-report measure of family psychosocial risk with scores that map to the PPPHM. Sources were PubMed, MEDLINE, Emcare, and PsycInfo. Articles were written in English, published in a peer-reviewed journal, and were original research using the PAT and reporting PPPHM data. We tested the prediction that across samples the distribution of risk on the PPPHM will be approximately 60% Universal (low), 30% Targeted (moderate), and 10% Clinical (high).

Results: Forty-seven samples from 43 papers were included. The PPPHM distributions were reported from PAT data from 17 types of conditions or settings, the largest being cancer (n = 24), followed by Sickle Cell Disease (n = 3). The papers represent the United States, Australia, Canada, Italy, Brazil, Israel, Japan, the Netherlands, and Portugal. Scores on the PPPHM were highly consistent across samples with median percentages of 55% Universal, 34% Targeted, and 11% Clinical. There is evidence of higher levels of risk for samples using the Spanish version of the PAT, from weight management programs, and with Autism Spectrum Disorder.

Discussion: Across conditions and countries, psychosocial risk in pediatric samples follows consistent distributions across the tiers of the PPPHM. The data support implementation of universal family psychosocial risk screening, followed by delivery of personalized care based on level of risk.

Conclusion: These data are informative in the implementation of integrated, personalized, psychosocial care to children and families and highlight the importance of assuring that all receive the opportunity to report on psychosocial challenges and strengths. Screening all families promotes health equity by normalizing the importance of understanding psychosocial risk and assuring family input in the delivery of care.

4. Using Patient Participation feedback to inform a collaborative model of care for a newly formed regional Complications of Excess Weight (CEW) service based in Cambridge. (Viktoria Cestaro)

Abstract

Introduction: We will talk about our experience of setting up a Patient and Public Voice (PPV) event, alongside an external agency called Association for Young People's Health. The aim of the event was to better understand how the multidisciplinary clinic approach was experienced by the families. Our hope was that by starting the journey with the families modelling the biopsychosocial model from day one we could establish a relationship quickly and this would create a sense of safety, provide hope, and reduce the power imbalance between the all knowing 'experts' and the family being done to. We wanted the family to share their story so that we could gain an understanding of the social graces that were influencing their Experiences. We will present qualitative data and the main themes/findings of the families experiences of the models of care used in the newly developed CEW service. We will then talk about how this feedback helped us further develop the approach we offer within the expanding service as we chose to include family therapy, counselling psychology and family support practitioners within our provision, some of these posts are unique to the Cambridge service. We will give a rationale about how these roles will complement the existing provision and enable us to provide individualised packages of care to suit each Individual family's needs.

Methods: Informed by PPV event, and literature on biopsychosocial model Reference The Biopsychosocial model was first conceptualised by George Engel in 1977.

Result: results from PPV event will provide further ideas about how to continue co shaping the model as we replicate the model when new sites are added. Learning points and recommendation will be presented for CEW nationally.

Discussion: examples of feedback provided from PPV event. How to continue hearing the patient's voice as we develop the service, throughout the three years of pilot phase.

Conclusion: As CEW is in the pilot phase using timely Patient feedback is crucial when thinking about expansion to meet the increasing demands for the service.

Symposium 3: Neurocognitive and Developmental Delays in Pediatric Chronic Medical Conditions: Current Research Findings and Treatment Implications (Chair: Kim Oostrom) *– Seminar room PD3*

Individual Talks

1. Comorbid Developmental Disabilities in Pediatric Obesity (Crystal S. Lim)
2. Developmental Disparities in Pediatric Sickle Cell Disease (Cynthia Karlson)
3. Brain, Neurocognition, Health related quality of life and adaptive functioning in children and adolescents with severe chronic kidney disease (Sophie Lijdsman)

Symposium Abstract

The research presented will highlight the importance of screening, as well as assessment, of neurocognitive and developmental functioning in various pediatric chronic medical conditions. Implications for pediatric psychology research and clinical practice will be discussed.

Theme: Screening and assessment of neurocognitive and developmental functioning in pediatric chronic medical conditions is important, as well as identifying international perspectives regarding tailoring interventions based on neurocognitive and developmental factors.

Structure: The symposium will consist of three 20 minute presentations, followed by the discussant providing conclusions for 15 minutes. The remaining 15 minutes will be for questions and discussion. The first speaker, Dr. Crystal Lim, will present rates of comorbid developmental delays in a pediatric weight management clinic. Physical activity behaviors will be examined, as well as clinic attendance and response to treatment. Dr. Cynthia Karlson, the second speaker, will present data on rates of developmental delays in infants from an Infant Pediatric Sickle Cell Disease clinic, as well as adaptive functioning outcomes. The broader context of developmental delays and longitudinal neurocognitive risks in youth with sickle cell disease will be discussed. The third speaker, Sophie Lijdsman, PhD-student, will present neurocognitive and brain imaging data in youth and young adults with severe chronic kidney disease. Associations between neurocognitive functioning, quality of life, and adaptive functioning will also be examined. The symposia moderator, Dr. Kim Oostrom, will provide a summary and offer insights for future research and clinical practice.

Relevance to conference: Neurocognitive and developmental delays occur as a related symptom or comorbidly in numerous pediatric chronic medical conditions. The symposium is relevant to the conference theme due to its inclusion of speakers from the US and Europe, which will provide international perspectives regarding this issue to inform future research and clinical practice.

Learning Objectives

a. Identify the importance of screening and assessing for neurocognitive and developmental delays in various pediatric chronic medical conditions
b. Identify how neurocognitive and developmental functioning may impact treatment engagement and response in pediatric chronic medical conditions
c. Explain how pediatric psychology clinical practice should be tailored based on youth neurocognitive and developmental functioning

12.15 – 13.30 **Lunch break with mentor lunch**
Pathfoot Eatery

13.30 – 14.00

European Paediatric Psychology Network Ukraine Taskforce Webinar Series: Supporting Mental Health Providers in Ukraine (Lauren Potthoff & Olya Chymbir) (Moderator: Rikard Wicksell)

Lecture theatre Pathfoot

Abstract

Introduction: In February 2022, Russian forces invaded Ukraine in a significant escalation of the Russo-Ukrainian War. The resulting casualties and destruction have been significant, with over 40,000 deaths and 14 million people displaced—the largest refugee crisis since World War II. The impact of this humanitarian crisis on the mental health of children and adolescents in Ukraine, though, is incalculable. In response, board members of the European Paediatric Psychology Network (EPPN), a Regional Interest Group of the Society of Pediatric Psychology, founded the Ukraine Taskforce with the goal of providing support to mental health providers in Ukraine. This presentation will detail the Taskforce's origins and initial accomplishments, with a focus on the Taskforce's main initiative: the Webinar Series. The goals of the Webinar Series are to educate Ukrainian providers in identification of pediatric mental health symptoms and provide tools to manage symptoms in everyday life.

Methods: The EPPN Ukraine Webinar Series consists of nine webinars, beginning April 20, 2023. Topics include depression, anxiety, trauma, risk assessment, eating disorders, neurodevelopmental disorders, sleep, supporting parents/caregivers, and psychopharmacology. Data will be collected through anonymous surveys administered to webinar attendees before and after each webinar; questions and responses will be translated. Questions will assess attendees' expectations for each webinar and if the webinar met their needs. Three months after the webinar series has ended, attendees will be asked if they have implemented webinar content and strategies into their work.

Results: Responses will be analyzed using a mixed methods approach including thematic analysis to evaluate open-ended questions and descriptive statistics for dichotomous questions and questions using a Likert scale.

Discussion: Findings from participant surveys will accompany an overview of the development and establishment of the EPPN Ukraine Taskforce.

Conclusion: The war in Ukraine has unleashed a humanitarian emergency, creating ripple effects across Europe and the rest of the world. The documented steps taken to create the EPPN Ukraine Taskforce, launch the Ukraine Taskforce Webinar Series, and achieve identified goals can provide a foundation of sustainability for mental health care for youth in Ukraine and a framework for similar initiatives in other contexts and crises.

14.00 – 15.30 **Parallel symposium session 3 (1.5 CE credits offered)**

Symposium 1: The key role of the psychologist (Chair: Amy Shayle) *- Lecture theatre Pathfoot*

Individual Talks

1. Development of a Difficult Asthma (DA) MDT Clinic with the psychologist as a core team member (Amy Shayle)

Abstract

Introduction: DA is defined by having 'persistent symptoms and/or frequent exacerbations despite treatment at step four or five of the treatment pathway'. Poor treatment adherence, psychosocial factors and concomitant conditions are associated with diagnosis. In 2020, the DA clinic at Cambridge University Hospital (CUH) was measured against London standards which state those referred to DA clinic should be discussed with psychology and offered assessment within 4 weeks. 28% of patents seen met this guideline. A 2021 sub-audit found an improvement, reflecting introduction of an MDT clinic. In 2022 the DA MDT took part in Institute for Healthcare Improvement (IHI) project to develop the Clinic.

Methods: Regular MDT clinic for new assessment established. Patients attending were sent clinic information including measures, including Revised Children's Anxiety and Depression Scale (RCADS) to be brought to appointment.

Results: June 2021 – May 2022 21 referrals to the clinic. 3 were redirected. 6 referrals were internal, and 12 were external. 10 were male and 8 female with mean age of 10 years (3-15 years). 12 patients completed the RCADS. 25% reported significant symptoms of Separation Anxiety, Panic, Social Phobia and Depression, 17% reported significant symptoms of Generalized Anxiety and OCD. All patients (N=18) were reviewed by psychology and offered assessment and input within 4 weeks (5 at CUH, 1 through local provision).

Discussion: Use of a psychology measure and presence at assessment ensured all patients referred to the DA clinic were discussed, triaged and then appropriately directed for follow-up. Patients attended fewer hospital appointments and received care from the MDT with consideration of the biopsychosocial impact on their asthma control. This provision required significant psychology commitment with regular attendance and review of measures. Participation in the IHI project facilitated this level of input, however, without expansion in the service provision it has not been possible to maintain. Going forward review of patient presentation will inform possible group interventions or resource development that can be easily provided to support patients and families.

Conclusion: With psychology being a core DA MDT clinic member all patients referred to the clinic were discussed and directed for appropriate support meeting standards.

Learning Objectives

a. Explain the importance of including a psychologist as a core team member in an MDT assessment.

2. Pediatric Psychologists as Catalysts for Youth Mental Health Education during a Pandemic: Social Media, Interactive Webinars, and Celebrity Partnerships (Meghan Walls)

Abstract

Introduction: The COVID-19 pandemic exacerbated pediatric mental health disorders and highlighted the need to support youth beyond the medical setting, including in homes, often via technology. During the pandemic, we created ongoing, easy-to- access behavioral health content for families. Expanding our role to include public health education resulted in reaching a larger audience and consequently, having greater impact.

Methods: Psychologists worked closely with our communications team to develop an omni-channel educational approach, positioning ourselves as a trusted, accessible and easy-to-understand pandemic resource. Our psychologists appeared in webinars, local and national media and high-engagement content across numerous social media channels. Psychologists wrote for the Nemours blog and were featured on Nemours Kids Health, one of the most visited websites for pediatric pandemic content. We also leveraged relationships we had with other foundations, e.g., partnering with the Michael Phelps Foundation to create the "Raising Resilient Kids" videos.

Results: Providing information across consumer communication channels expanded our reach significantly. In total, we engaged with millions with our educational content. Our social media posts (35) provided 996 engagements and a reach of 207, 205. Psychologists created blogs and YouTube videos, garnering over 5,000 views. Our online webinars had 5650 individuals registered and focused on parenting strategies and helping kids navigate COVID-19. The content on Nemours KidsHealth had over 6 million page views per year. Our Michael Phelps Foundation video series received 180,000+ views.

Discussion: By using new, innovative paths to reach families, we significantly increased our reach in educational efforts during a global pandemic. Psychologists are a perfect fit for external communications that exist broadly.

Conclusion: It is imperative that clinical experts use their knowledge and expertise to reach families to educate on mental and behavioral health. Leveraging omni-channel opportunities across our enterprise and elevating partnerships extended our ability to provide trusted, assessable, and easy-to-understand education to support families' mental health and well-being. These strategies continue to be employed as an extension of our new model of care beyond the doctor's office as it greatly enhances our ability to reach more families.

Learning Objectives

a. Describe at least one way that psychologists can become involved in disseminating scientific knowledge beyond their patient base to the general public.

c. Apply the tools shared during this presentation to engage with institutional and community partners to share information via popular or social media.

3. Psychology Adding Value: Epilepsy Screening (PAVES)- A Mental Health Screening and Intervention Pathway for Children and Young people with Epilepsy (Kirsten Verity)

Abstract

Introduction: Children and young people with epilepsy (CYPwE) are particularly vulnerable to mental health (MH) problems and reduced quality of life, leading to poorer long-term psychosocial outcomes. PAVES TM was developed in 2017 as a way of screening CYPwE to provide MH information and support. This model of delivery integrates a screening and stepped-care model of early intervention into the current existing pathways, increasing the provision of information for CYPwE at the right time and avoiding lengthy CAMHS waits.

Methods: All eligible CYPwE attending an epilepsy clinic are screened using an online version of the Strengths and Difficulties Questionnaire prior to attending. A traffic light metaphor allows the reported level of concern to be indicated to the Neurologist: green (no concerns); amber (some concerns); red (significant specific, or global concerns). Ratings indicate a potential route through the stepped, early intervention pathway and are triaged by psychological and medical professionals.

Results: PAVES has demonstrated a significant reduction in referrals to CAMHS. From a health economic point of view PAVES has demonstrated a reduction in cost when compared with business as usual. It is now integrated as part of standard clinical practice within NHS Lothian.

Discussion: The relationship between psychologist and medic in developing this approach must be active and collaborative. Direct psychology input to the CYP is minimised but the psychologist provides leadership and governance to the framework and undertakes group work. However, PAVES is not 'psychology hands-free' and requires commissioners to understand and appreciate the need to 'spend to save'. The setup of PAVES within a new geographical area or for a new health population is an upfront 'cost' in terms of psychology time. Expectations of senior management and medical teams may need to be managed in terms of output.

Conclusion: The PAVES model has been used as an exemplar mechanism to screen for and meet MH needs in CYPwE and has the potential to be rolled out across various populations and locations. The possibility of collecting large scale data regarding outcome is present within the framework. PAVES as a model is now being piloted in other health conditions.

Learning Objectives

a. Identify the key components of PAVES (Psychology Adding Value Epilepsy Screening) model, which be applied to other chronic health conditions and in other geographical locations/ services.

4. Using Competencies to Demonstrate Added Value of Pediatric Psychology within Pediatric Palliative Care Teams (Amanda L Thompson)

Abstract

Introduction: Pediatric palliative care (PPC) is interdisciplinary, patient- and family-centered care that targets the prevention and relief of suffering and supports the physical, emotional, and spiritual well-being of youth with serious medical illnesses and their families across the trajectory of disease, including but not limited to end-of-life. Pediatric psychologists have unique expertise to contribute to the care of youth with serious illnesses and their families yet are not routinely integrated into pediatric palliative care (PPC) teams. To better define the role of psychologists in PPC, support their systematic inclusion as part of PPC teams, and advance trainee knowledge of PPC principles and skills, the PPC Psychology Working Group developed core competencies for psychologists in this subspeciality.

Methods: A working group of pediatric psychologists with expertise in PPC met monthly to review literature and draft core competencies for PPC psychologists. Interdisciplinary review was conducted by a diverse group of PPC professionals and parent advocates, and competencies were revised accordingly.

Results: The six competency clusters include Science, Application, Education, Interpersonal, Professionalism, and Systems. Each cluster includes essential competencies (i.e., knowledge, skills, attitudes, and major roles) and behavioral anchors (i.e., examples of concrete application). Competencies highlight the skills and knowledge that psychologists possess and can offer to interdisciplinary PPC teams including assessment, intervention, research, teaching, and systems-level support.

Discussion and Conclusions: Competencies for PPC psychologists highlight our unique contributions to PPC patient care and research, demonstrate our value in this emerging subspecialty, and help to standardize best practices within PPC. Intended uses of the competencies are discussed in detail, including: psychology role definition and team integration, workforce expansion, and education and training.

Learning Objectives

a. Describe the roles of psychologists on pediatric palliative care teams

Symposium 2: The future of Patient Reported Outcome Measures in Pediatrics: Implementation, Standardization, Measurement Optimization and Participation (Chair: Kim Oostrom) *- Seminar room PD1*

Individual Talks

1. Patient Reported Outcome Measures in clinical practice: Barriers and optimizations in the KLIK PROM portal (Maud van Muilekom)
2. Towards standardized generic Patient Reported Outcome Measurement for children in specialty care; results from the Dutch "Outcomes-Based Healthcare Program" (Karolijn Dulfer)
3. Optimizing patient-reported outcome measurement in pediatrics: Translation, validation and implementation of PROMIS® (CATs) in the Netherlands (Michiel Luijten)
4. Participation and education of patients about PROMs in clinical practice. (Hedy van Oers)

Symposium Abstract

Theme: Over the past decade, there has been an increase in the use of Patient Reported Outcome Measures (PROMs) to assess the physical, mental and social health of pediatric patients through the eyes of patients themselves, both in research and in clinical settings. The use of PROMs in clinical practice has shown positive effects, however, the actual implementation in daily clinical practice remains a continuous challenge. This symposium aims to provide the audience with an overview of the current state of affairs and developments in the field of PROMs in pediatric clinical practice.

Structure: This symposium focuses on the use of PROMs in pediatric clinical practice. First, we provide an overview of our past two decades of experience with implementing PROMs in clinical practice through the KLIK PROM portal (www.hetklikt.nu). Several barriers were identified for which the other presentations provide and discuss possible solutions. Thereafter, the symposium is divided into three parts; 1) standardization, by defining a set of outcomes and accompanying measures using a generic approach through a government initiated project. 2) optimization of measurement, where we subsequently assess those outcomes on a common measure by applying advanced psychometric techniques using the Patient-Reported Outcomes Measurement Information System (PROMIS) and develop a visualization for PROMIS outcomes. 3) participation and education, which focuses on improving the participation of pediatric patients by providing information about and improving the feasibility of PROMs and empowering patients.

Relevance: It is important to include the patients' perspective in the entire process of healthcare, from research to clinical practice. The symposium will provide attendees with current developments and future perspectives in the field of PROMs and how PROMs can contribute to improvements in healthcare. The symposium provides a national perspective on the use of PROMs in a pediatric clinical setting, which may become an international standard.

Learning Objectives

a. Identify facilitators and barriers for the implementation of PROMs in clinical practice and how to overcome these barriers to further improve healthcare.
b. Explain why standardization of outcome measures is important in research and clinical practice
c. Assess outcome measures on an institute-wide and national level by applying advanced psychometric techniques such as those used in PROMIS.
d. Identify tools to engage and educate pediatric patients about PROMs in clinical practice.

Symposium 3: Translating biomarker research to behavioral treatments in pediatric pain: Time to reduce the gap (Chair: Rikard Wicksell) *- Seminar room PD1*

Individual talks

1. Biomarkers, behavioral science, and intervention: Where are we? Where do we need to go? (Rikard Wicksell)
2. The missing mechanistic link: Improving behavioral treatment efficacy for pediatric chronic pain (Christine B. Sieberg)
3. What can we learn from neuroimaging and experimental psychology on the role of pain-related distress in chronic pain? (Inge Timmers)
4. Using biomarkers to evaluate prospective relationships in pediatric pain: Can Quantitative Sensory Testing (QST) be useful? (Christopher King) ***- ONLINE***

Symposium Abstract

While there is robust evidence for the use of psychological treatments (e.g., Cognitive-Behavioral Therapy (CBT); Acceptance & Commitment Therapy (ACT)) for the treatment of pediatric chronic pain, there are substantial gaps in our understanding on how and why existing evidence-based behavioral pain therapies work for certain patients and not others. This panel includes an interdisciplinary and international group of pain researchers and psychologists. It focuses on an interactive discussion of research utilizing a variety of biomarkers (e.g., neuroimaging, genetics, hormonal, sensory) and ongoing mechanistic clinical trials that may inform behavioral pain management. Moderated by Dr. Wicksell, the presentations and panel discussion will focus on the translational research of Drs. Sieberg, Timmers, and King. Dr. Wicksell will provide a 5- minute overview of the topic followed by 10-minute research presentations by Drs. Sieberg, Timmers, and King. Dr. Wicksell then will spend 15-minutes specifically considering the clinical relevance of their research; thus, how this work can be used to inform behavioral treatments and what the status quo is of integrating this research into interdisciplinary treatment approaches. This will be followed by a 40-minute panel discussion. The session will be interactive and will include an open discussion. There will be ample opportunity to explore how basic science can address the gaps in current knowledge in pediatric behavioral interventions and highlight how the gap between research and the clinic can be reduced. The session will be interactive, including the use of live, online polls (i.e., Mentimeter) to involve the audience accompanied by the creation of word clouds that will be used to guide the discussion. This topic is relevant to the conference theme as it is an interdisciplinary and international panel focusing on cutting-edge developments in clinical applications and research in the area of pediatric pain.

Learning Objectives

a. List at least two biological correlates of psychosocial aspects of pain
b. Describe at least one example of how to implement biological correlates into clinical practice
c. Identify how to integrate biological markers into behavioral treatment approaches

15.30 – 16.30 **coffee break + poster session 2**

Pathfoot Crush Hall

1. **"A whirlwind of everything": The Lived Experience of Adolescent Girls with Co-Occurring Chronic Pain and Mental Health Symptoms**

   Sharon Bateman

   Introduction: Co-occurring chronic pain and mental health issues are prevalent in adolescents, costly to society, and can lead to increased risk of complications throughout the lifespan. Whilst research has largely examined paediatric chronic pain and mental health in isolation, little is known about the unique challenges faced by adolescents who experience these co-occurring symptoms. This idiographically focused study examined the lived experience of adolescents with co-occurring chronic pain and mental health symptoms to identify salient issues for this population.

   Methods: Semi-structured telephone interviews were conducted with seven adolescent (11-19 years) girls self-reporting diagnoses of both pain and mental health issues for a duration of three months or longer. Participants were recruited from UK-based schools, pain clinics and charities. Interview transcripts were analysed using interpretative phenomenological analysis.

   Results: Analyses generated two themes "a whirlwind of everything" and "putting up fronts", which described how the experience of co-occurring chronic pain and mental health symptoms typically disrupted adolescents' ability to regulate their physical, psychological, and social wellbeing and identity. Adolescents described their experiences as an internal storm over which the adolescents had no control. Such experiences required adolescents to embrace a variety of symptom management strategies, with adolescents reporting deliberate efforts to shield their symptoms from others.

   Discussion: Findings suggest that co-occurring pain and mental health symptoms impact the personal and interpersonal lives of adolescents. Such impacts extended to relationships with close family members and healthcare professionals, resulting in adolescents perceiving challenges with identifying safe supportive environments. These experiences are congruent with research describing toxic stress and concealable, yet stigmatised identities. As adolescence is a critical phase for identity and emotional regulation development, clinical care should be sensitive to the possible turbulence of this symptom experience.

   Conclusion: Co-occurring pain and mental health symptoms may be experienced in similar ways to individually experienced pain or mental health symptoms, but together, the experience may be both more difficult to manage and more socially isolating.

2. **Flourishing among children and adolescents with epilepsy only, epilepsy plus an emotional, developmental or behavioral comorbidity, and typical peers**

Jessica Emick

Introduction: Epilepsy is one of the most common neurological disorders in young people. Children with epilepsy (CWE) often live with severe symptoms – mainly seizures – that disrupt daily life, as well as an increased risk of emotional, developmental, and behavioral challenges. To improve the quality of life for CWE, overall well-being needs to be addressed. One central factor that reflects overall well-being is flourishing, however, there is limited evidence on how flourishing differs between CWE, CWE and emotional, developmental or behavioral comorbidities, and typical peers.

Methods: Data from the 2018-2019 National Survey of Children's Health, a nationally representative, cross-sectional survey was used. Data was limited to children aged 6-17 years for whom health data was available (N = 31,313). Hierarchical binary logistic regression was conducted to evaluate whether health related condition (CWE; CWE and emotional, developmental or behavioral issue; typical peers) significantly predicted flourishing after accounting for sociodemographic factors.

Results: Results revealed that health related condition was a significant predictor of flourishing over and above sociodemographic factors (age, sex, race, and poverty), (N=43213, χ 2 (1) = 203.69, p < .001). CWE were 2.94, 95% CI [2.08-4.16] times less likely to flourish (χ 2 (1) = 35.76, p < .001) when compared to typical peers. CWE plus an emotional, developmental, or behavioral problem were 20 times, 95% CI [12.5-33] times less likely to flourish, (χ 2 (1) = 168.66, p < .001) when compared to typical peers

Discussion: As expected, CWE and CWE plus an emotional, developmental, or behavioral problem are less likely to flourish than their typical peers. Of note, over half of the CWE also had the presence of a comorbid emotional, developmental, or behavioral issue which further reduced the likelihood of flourishing. Health related condition significantly predicted flourishing after accounting for sociodemographic factors.

Conclusion: This study highlighted the high prevalence and unique vulnerability of CWE and CWE plus an emotional, developmental, or behavioral problem. Further research and clinical focus are needed to promote flourishing and improve quality of life for this group.

3. **Gaze Fixation and Visual Searching Behaviors during an Immersive Virtual Reality Social Skills Training Experience for Children and Youth with Autism Spectrum Disorder: A Pilot Study**
T. David Elkin
Introduction: Children and youth with Autism Spectrum Disorder (ASD) display difficulties recognizing and interacting with behavioral expressions of emotion, a deficit that makes social interaction problematic. Social skills training is foundational to the treatment of ASD, yet this intervention is costly, time-consuming, lacks objectivity, and is difficult to deliver in real-world settings.
Methods: This pilot project investigated the use of an immersive virtual reality (IVR) headset to simulate real-world social interactions for children/youth with ASD. The primary objective was to describe gaze fixation and visual search behaviors during the simulated activity. Ten participants were enrolled and completed one social-skills training session in the IVR.
Results: Participants with mild ASD (n=7) looked at fewer places than those with moderate ASD (n=2), but there were no significant differences between the groups on total time spent looking. The one participant with severe ASD was not able to keep the headset on.
Discussion: Although the results are preliminary, these differences may shed light on phenotypes within the continuum of ASD. However, due to the small n and the nature of this pilot study, more participants are required before further conclusions may be drawn.
Conclusion: The results demonstrate differential patterns between participants with mild, moderate, and severe ASD in the location and duration of gaze fixation as well as the patterns of visual searching. There may be value in quantifying gaze and visual search behaviors as an objective metric of interventional effectiveness for social-skills training therapy.

4. **Happiness for Improvement of Premature and Parental Outcome (HIPPO): determining parental stress during and directly after NICU admission**

Hedy van Oers

Introduction: Premature infants admitted to a Neonatal Intensive Care Unit (NICU) are exposed to painful and stressful events with long-lasting effects. Former studies mainly focused on their effects on the neonate, however more extensive research into the effect on parents is necessary as NICU admission also greatly impacts parents' wellbeing. Therefore, in the national multicenter observational cohort 'HIPPO study', levels of parental stress during NICU admission and around expected due date were studied.

Methods: Parents of preterm infants (N=447) born at a gestational age of <29 weeks and admitted to a Dutch NICU were invited. From July 2020 to April 2022, parent couples completed Parent Reported Outcome Measures (ParROMs) using the KLIK PROM portal (www.hetklikt.nu) at three time points during and after NICU admission: 8-14 days after birth (T0), 28-34 days after birth (T1) and around expected due date (T2). Parents' answers at T0 were being discussed with them by a NICU psychosocial staff member. Constructs measured are: Post Traumatic Stress Disorder (PCL-5), depression (PROMIS CAT), parental distress (Distress Thermometer for Parents) and NICU environmental stressors (PSS:NICU). Medical outcomes of the child and sociodemographic data were collected.

Results: Preliminary results show that 15% of fathers report a clinical level of PTSD, which remains stable over time (T0-T2). Clinical PTSD levels in mothers range from 17% at T0 and increase to 33% at T2. A majority of mothers (52%) and 26% of fathers experience the NICU admission of their child as (very) stressful at T0, where seeing their child in pain is the most stressful factor. More results will be presented at the conference.

Discussion and Conclusion: This study provides insight into short-term psychological consequences for parents after preterm birth and NICU admission and sheds light on which parents should receive additional support during admission. Additional follow-up measurements at 6 (T3), 12 (T4) and 24 (T5) months corrected age will be added for long term outcomes of parent and child.

5. **Hidden Costs of Rare Pediatric Diseases: The Invisible Burden on Child Mental Health**
Susanne Wehrli

Introduction: Children with rare diseases have previously been found to be at increased risk for developing mental illness. Identifying the presence and predictors of decreased psychological adjustment in children with rare diseases is of great importance in addressing their mental health needs.

Methods: The aim of this cross-sectional online study was to investigate the occurrence of psychopathology and its predictors in Swiss children with rare diseases aged between 1-18 years, using three DSM-5 oriented Child Behavior Checklist (CBCL) subscales (depression, anxiety, and oppositional-defiant disorder) reported by parents (N = 112). Several measures of potential predictors were used, such as the Family Impact Scale and the PHQ-9. Data collection is ongoing, and results reported are preliminary.

Results: Linear regression combined with supervised machine learning revealed that higher levels of family strain ($\beta = .338$, $p < .01$) predicted higher levels of depression symptoms. Whereas the absence of parental mental problems predicted lower depression ($\beta = -.392$, $p < .05$) and anxiety levels ($\beta = -.450$ $p < .01$). Additionally higher levels of support within the family predicted lower child anxiety scores ($\beta = -.283$ $p < .01$). Increased anxiety was predicted by an increase in parental burnout ($\beta = .176$, $p < .05$). Higher levels of parental anxiety ($\beta = .226$, $p < .05$), maladaptive parental coping with child illness ($\beta = .194$, $p < .05$), and not knowing the child's diagnosis within the first three months ($\beta = .276$, $p < .05$), resulted in an increase in opposition-defiance levels in children with rare diseases.

Discussion & Conclusion: In conclusion, the study highlights the importance of family factors in predicting mental health outcomes in children with rare diseases. The findings suggest that interventions targeted at reducing family strain, providing support, and addressing parental mental health and coping strategies may be beneficial for improving mental health outcomes in this population. The study also highlights the need for early diagnosis and effective communication of diagnosis to families

6. **Holding the needs of neonatal families in mind: a proposed model for paediatric clinical psychologists and the wider neonatal workforce**

Sarah-Jane Archibald

Introduction: Neonatal families are constantly faced with a multitude of challenges surrounding their baby/ies health and welfare. A large number of families have reported that the trauma of the NICU experience starts to "hit" them once their baby/ies have been discharged home. This can, therefore, lead to emerging perinatal and paternal mental health outcomes, including (not limited to) post-traumatic stress symptoms, depression, anxiety, OCD, complex grief and secondary tokophobia. There is limited specialist clinical psychology provision for neonatal families, which can lead to poor outcomes for their mental health post discharge.

Methods: Given the limited provision for neonatal families nationally, we set up and delivered an outpatient model of support for all families with a baby/ies on NICU at one tertiary unit in Cambridge. Families could be referred at any point throughout their NICU journey and were able to self-refer. Our model reflected the offer of up to 6 sessions of clinical psychology provision with a review.

Results: The families seen in our NICU outpatient support clinics consisted of those families where we had supported them during their inpatient stay. However, a large number of outpatient referrals came from families who contacted us a few weeks post discharge with symptoms of psychological distress post NICU. We will present case studies to highlight the effectiveness of our proposed model, alongside quotes from those with lived experience who used this service.

Discussion: There is currently limited clinical psychology provision nationally for neonatal families, however, we recognise that this is an area of growth. As such, we recommend that neonatal clinical psychologists and the wider neonatal workforce consider a holistic model of care whereby outpatient support is considered of equal importance to inpatient.

Conclusion: Our proposed model can lead to improved treatment outcomes for neonatal families and will help to ensure such families are offered specialist evidenced based psychological interventions in order to prevent onset of perinatal and paternal mental health difficulties.

7. **Identifying and Managing Eating Disorders in Pediatric Obesity Treatment: Current Practices in Weight Management Programs throughout the United States**
   Eileen Chaves

   Introduction: Adolescents with obesity are at higher risk of disordered eating than the general population. The most common eating disorder (ED) in youth with obesity is Binge Eating Disorder (BED). Detection of EDs in pediatric weight management clinics (PWMC) is vital; however, its identification is not well established. Literature suggests screening questionnaires may aid in early detection and treatment of EDs. This study sought to understand current practices in the assessment and management of EDs in PWMCs in the United States.

   Methods: A 33-question survey was designed to assess PWMC's providers' comfort with assessing for and treating multiple ED diagnoses in adolescents with obesity. Using purposive sampling, this survey was distributed on the Childhood Obesity Multi-Program Analysis and Study System (COMPASS) listserv to 91 sites with a 44% completion rate, reaching a national sample. Chi-Square Tests or Fisher's Exact Tests (for cell counts <5) were used to determine p-values.

   Results: Thirty-nine obesity medicine clinicians responded, including 32 medical providers and 7 behavioral health (BH) providers from mostly multidisciplinary weight management programs (97%), with some in endocrinology (21%), gastroenterology/liver (10%) and primary care (8%). Most clinics regularly screened for EDs (74%); however, of these, only 31% used a validated instrument. Most respondents felt comfortable screening for EDs (69%) and making a BED diagnosis (62%), but comfort level was lower for diagnosing other EDs (49%) and for treating BED (44%). Compared to BH providers, fewer medical providers were comfortable making BED diagnoses (100% vs 53%; p=0.031). In addition, specialty clinics (endocrinology, gastroenterology/liver, primary care, etc.) were less comfortable diagnosing other EDs than programs that only identified as PWMC (21% vs. 64%; p=0.019) and treating BED (14% vs. 60%; p=0.008).

   Discussion: Most PWMC providers appear comfortable screening for BED compared to other EDs, though few consistently use validated instruments. Comfort level differs by provider and wanes when treating BED or diagnosing other EDs.

   Conclusions: Research, as well as training, is needed to improve screening and management of EDs by PWM clinicians as variability exists across the spectrum of multidisciplinary team members and subspecialty clinics that typically treat adolescents with obesity.

8. **Identifying the Psychological Support Needs of Parents and Young People with Inherited Metabolic Disorders**

Kim Clarke

Introduction: Children with chronic illnesses are at increased risk of psychological distress and poorer quality of life than their peers. Parents of children with chronic illness are also at risk of emotional distress, in turn impacting their ability to respond to their child's psychosocial and medical needs. While a wealth of research has examined the challenges faced by families with other chronic conditions such as diabetes, less is known of the needs presented by those with rarer metabolic disorders. This study, therefore, aims to identify the specific support needs of parents and young people with inherited metabolic disorders.

Methods: This study involves gathering information on the areas of greatest psychological need presented by parents and young people with inherited metabolic disorders via an anonymous online survey. This survey will be circulated to all parents, and young people aged 13 to 18 years, attending the National Centre for Inherited Metabolic Disorders (NCIMD) in Ireland in a department-specific e-newsletter. Multidisciplinary staff members in the NCIMD will also be surveyed. The survey will be circulated to approximately 300 families and all 25 staff members.

Results: The survey is expected to be launched in April of this year, with data collected and analysed by June. Collected data is intended to identify the challenges encountered, and in turn the area in greatest need of support, for parents and young people with inherited metabolic disorders.

Discussion: Research has demonstrated that the rarity, uncertainty, treatment burden, and life-limiting nature of some inherited metabolic disorders can exacerbate the distress experienced by families with these conditions. Group interventions have proven effective in meeting the psychological needs of children and adolescents with chronic medical conditions. The present study intends to suggest specific group interventions that may be developed to address the needs outlined by parents and young people attending the NCIMD.

Conclusion: Research concerning the specific support needs of families with inherited metabolic disorders is needed in order to develop effective therapeutic interventions that ameliorate the disorder-specific challenges encountered by parents and young people alike.

9. **Illness Uncertainty, Caregiver Self-Efficacy, and the Mediational Effect of Problem-Solving Strategies**
Alexandra M. DeLone

Introduction: Complex outpatient and home care regimens result in caregivers having significant responsibilities managing their child's daily cancer care. Caregiver self-efficacy, which involves beliefs about one's ability to perform required caregiving tasks, has been identified as an important factor in daily disease management. However, factors intrinsic to the disease and treatment of pediatric cancer, including illness uncertainty, have been associated with reduced self-efficacy. Problem-solving strategies have demonstrated a mediational effect between illness uncertainty and parent psychological adjustment. This study aimed to examine if caregiver problem-solving strategies mediate the relationship between illness uncertainty and caregiver self-efficacy.

Methods: This United States based sample was recruited within a year of primary diagnosis of pediatric cancer. Parents/caregivers (N=83; 89% mothers; 75% married) of children (aged 3 months to 17 years; M_{age} =8.7 years; 53% male; 60% White) completed measures of illness uncertainty, caregiver self-efficacy, and problem-solving across 2 domains: constructive problem-solving (e.g., rational deductive thinking) and dysfunctional problem-solving (e.g., avoidance).

Results: A parallel mediation model was conducted on PROCESS Macro v.4.0 in SPSS. We found a statistically significant indirect effect of dysfunctional problem-solving (=-.06, 95% C.I.=[-.13, -.01] partially mediating the relationship between caregiver perception of illness uncertainty and caregiver self-efficacy while holding constructive problem-solving constant. Greater illness uncertainty was related to more dysfunctional problem-solving, which in turn, related to lower caregiver-self efficacy. However, constructive problem-solving was not a mediator between caregiver perception of illness uncertainty and caregiver self-efficacy in our model (=-.04, 95% C.I.=[-.14, .04]).

Discussion: While cancer directed education-based intervention strategies have been shown to reduce uncertainty, it may also be helpful to target problem solving in an effort to promote caregiver self-efficacy. As such, pediatric psychologists should aim to reduce dysfunctional problem-solving strategies, which may indirectly decrease some of the negative effects of illness uncertainty on caregiver self-efficacy.

Conclusion: Pediatric psychologists' expertise in helping caregivers adaptively approach how they manage situations may, in turn, increase their beliefs about their ability to successfully care for their child with cancer.

10. **Improving Access to Treatment in Pediatric Primary Care: A Mixed Methods Assessment of the STAMP Intervention**

    Leah Orchinik

    Introduction: Given long waits and other barriers to accessing quality mental health services across the United States, it is important to identify treatment modalities that are effective while also feasible and accessible within a clinic's model of service delivery. In an under-resourced, ethnically diverse, integrated primary care clinic in Delaware, we are currently implementing a 4-6 session CBT-informed intervention to address significant mood and anxiety concerns in youth ages 6-13. The current mixed methods pilot study aims to quantitatively investigate the intervention's efficacy and feasibility of implementation within the pediatric primary care setting, as well as to gather qualitative data on primary care provider (PCP) satisfaction with the intervention.

    Methods: Youth who presented to a pediatric primary care clinic were internally referred by providers to participate in a 4-6 session intervention (Short Term Anxiety and Mood Program; STAMP) to address clinically significant mood/anxiety concerns. Participating youth completed pre- and post-treatment measures assessing symptoms of anxiety (GAD-7) and depression (CES-D), as well as qualitative interviews with PCPs.

    Results: Preliminary data (n=4, data collection ongoing) indicate that integrating the STAMP intervention into pediatric primary care is effective in increasing access to care by reduction of wait times and has shown high pediatrician satisfaction ratings. Preliminary data analyses reveal that youth (M age = 9.6) demonstrate significant symptom reduction following the STAMP intervention, with significantly decreased average wait times between follow up visits (1 week) vs. average wait in primary care (6 weeks).

    Discussion: Preliminary data suggest the STAMP intervention appears successful in reducing anxiety and mood symptoms. It also provides increased access to consecutive (weekly) therapy visits for patients who present with clinically significant mood and anxiety concerns.

    Conclusion: Data collection is ongoing, however, STAMP appears to be a promising addition to the range of services that are offered within our primary care clinic. Future directions include expanding the implementation of STAMP by designating more treatment slots with additional providers and assessing the need for follow-up behavioral health care after completion of the intervention.

11. **Innovative non-pharmacological interventions for pain management in sickle cell disease**
Mariana Cecilia e Silva de Oliveira Nery

Introduction: Patients with sickle cell disease (SCD) can suffer from vaso-occlusive crises (VOC), extremely painful acute unexpected episodes that can occur frequently (3x/year), lasting from hours until days, and requiring opioid use to reduce pain. VOC negatively impacts quality of life and may cause negative long-term effects such as chronic pain syndrome, anxiety and psychological distress. We will study the effect of two non-pharmacological interventions (Virtual Reality technology – VRT and Eye Movement Desensitization and Reprocessing - EMDR) in reducing pain. Methods: We will conduct two RCT studies: *VRT reducing pain during VOC:* VRT produces analgesia via distraction: a person has limited attention capacity, and, if competitive stimuli retains the person's attention, the painful stimuli is perceived as less intense. VRT effectiveness on pain is shown in several studies, however not within SCD population during VOC. We will randomize SCD patients (8-25 years) to intervention (VR-sessions complementary to standard care) and control group (standard care). We will evaluate the efficacy of VRT in reducing pain during VOC. Secondary outcomes are the reduction in anxiety, opioid use, length of stay and complications. *EMDR reducing pain-related PTSD:* VOC hospitalization as well as intense pain experiences can lead to Post Traumatic Stress Disorder (PTSD). We hypothesize that PTSD symptoms can increase the pain and frequency of VOC. EMDR is effective in reducing pain in adults, but no research focuses on children. We will investigate the effect of EMDR on pain interference in SCD children. Secondary outcomes are the reduction of pain severity during VOC and of frequency and duration of VOCs. All children hospitalized with VOC in the past 2 years will be screened for pain-related PTSD. Patients (6-18 years) scoring high on PTSD symptoms will be randomized to waiting-list group (control) and EMDR (intervention).
Results: We expect the first results in 2025.
Discussion/Conclusion: If these innovative non-pharmacological therapies are effective, an important leap in the pain management of SCD children will be taken. Less pain will lead to less opioid use (and its complications), shorter hospitalization and a less negative impact on SCD children's quality of life and mental functioning.

12. **The Effect of Stigma of a Non-Visible Health Condition on Well-Being**

    Caroline Heary

    Introduction: For those with disabilities, often the stigmatising reactions and attitudes of other people such as friends, family and health professionals can have a worse impact than the disability itself. The present study draws on a model by Quinn & Earnshaw (2011) to determine the impact of a Concealable Stigmatised Identity (CSI) on psychological outcomes. The study investigated whether disclosure, concealment, internalising of stigma and stigma resistance predict well- being. This study further examined whether associations between resistance and internalising of stigma and well-being are mediated by outness.

    Method: Participants (N=173) consisted of emerging adults (18-25 years) with non-visible health conditions. Participants were recruited through various social media platforms, university student disability services and disability organisations. There were four core groupings of non-visible health condition amongst the participant group: mental health conditions, physical health conditions, co-occurrence of disabilities and other. Well-being was the criterion variable and gender, education level, internalising of stigma, stigma resistance, disclosure and concealment were the predictor variables.

    Results: The overall regression model was significant, accounting for 54% of the variance in frequency of well-being ($F(9,127) = 18.48$, $p < .001$, $R2 = .57$, adjusted $R2 = .54$). Gender, internalising of stigma and stigma resistance were found to predict well-being.

    Discussion: This study adds to the literature on disability stigma and demonstrates the need for interventions which increase stigma resistance among young people living with chronic illnesses. More research is required to fully examine the pathway by with these constructs affect well-being and health behaviours.

    Conclusion: Internalising or resisting the stigma associated with a concealable stigmatised identity is important to well-being

13. **Measures of identity in young people with long-term physical health conditions: A systematic review**

Tess Rugg

Introduction: Adolescence is a developmental period characterised by changes in social, psychological, physical, and cognitive areas, with a focus on moving from childhood to adulthood (Sawyer et al. 2018). A key task for young people is forming a sense of identity and research has explored how this process of identifying forming can be challenging for young people with long-term physical health conditions (LTC-P) (Jordan et al., 2018; Kirk & Hinton, 2019; Lindsay, 2014) . The aim of this systematic review is to identify existing measures of identity in young people with LTC-P and to what degree they have been psychometrically evaluated.

Methods: In this systematic review we searched APA PsychNET, PubMed, Web of Science, SCOPUS and CINAHL databases for available measures that assess identity in young people with LTC-P. We included papers available before 27 th February 2023, that included at least one measure of identity on participants aged 16-24 years old who experienced a LTC-P, whether diagnosed by a health professional or self-diagnosed. Data will be extracted from eligible papers using a data extraction form. Risk of bias in individual studies will be assessed using an adapted version of the COSMIN (Mokkink et al., 2018) checklist.

Results: Data synthesis will be through a narrative synthesis, providing an overview of the existing measures of identity in young people with LTC-P, alongside a critical analysis of their respective quality and assessment details. This will include a summary of findings table per measurement, including the pooled or summarised results of the measurement properties and its overall rating.

Discussion: The data analysis is ongoing and any results and considerations will be presented during the presentation.

Conclusion: The results of this systematic review will identify the current measures of identity of young people with LTC-P available for use in research and clinical practice. Additionally, it will highlight any areas for improvement, or gaps for future measurement development.

14. **Measuring recovery in pediatric chronic pain**

Emma Biggs

Introduction: In research on chronic pain there is often a need to classify individuals as 'recovered' or 'persistent'. Classifying individuals as above or below a threshold can be a useful tool in biomarker development or evaluating the efficacy of an intervention. Thresholds are commonly set by status or the degree of change, and the measurement scale varies depending on the research aims. In the present study we evaluated the variability in recovery classifications using several metrics.

Methods: As part of a larger study on pain recovery (Signature for Pain Recovery IN Teens), longitudinal data was collected from 152 adolescents undergoing multidisciplinary pain care across three sites. Measures included Functional Disability Inventory (FDI), Pain Interference subscale from the Brief Pain Inventory, and Perceived Global Index of Change (PGIC). These measures were collected at baseline, 3-, 6-, 9-, and 12-months follow-up. Data were analyzed using trajectory clustering analyses, status at follow-up, and threshold of 30% or greater percent change from baseline to follow-up. Contingency tests were used to assess the convergence of these groupings.

Results: When functioning (FDI) was used as a clinical endpoint, 57% (n=87) of the sample were classified as 'recovered' based on either trajectory, status at 12-month follow-up (FDI <13), or percent change from baseline to 12-month follow-up (>30%). However, only 4% of these participants were classified as 'recovered' by all three approaches. Participants with FDI trajectories showing improvement were also likely to have reduced pain interference trajectories (82%), as well as perceived improvement (very/much improved: 76%). However, participants that showed no change or a worsening of disability were equally likely to be classified as improved (50%) or worsened (50%) based on pain interference. Half (52%) of these participants reported perceiving no or minimal change, with 28% reporting (very) much improvement, and 20% reporting (very) much worsening.

Discussion: We observed variation in participant classification based on the type of clinical endpoint used, and how improvement in that measure was operationalized.

Conclusion: Recovery is a multifaceted phenomenon and individuals may show recovery trends in one domain but not another. Furthermore, participants may show overall improvements but not reach sub-threshold status. We will discuss the benefits and shortcomings of using multiple measures to capture a holistic view of recovery.

15. **Mental and social health of children and adolescents in the Dutch general population before, during and after the COVID-19 pandemic**
Michiel A. J. Luijten
Introduction: The COVID-19 pandemic outbreak and the restrictions profoundly impacted the mental and social health of children and adolescents. In this study we aim to assess the long-term impact on mental and social health of children in the Dutch general population on multiple measurement occasions during and after the COVID-19 pandemic and compare it to pre-COVID-19 reference data.
Methods: A representative general population sample of Dutch children aged 8-18y was approached bi-annually (spring/autumn) starting in April 2020 until March 2023 (7 measurements total). They were asked to complete six self-reported PROMIS ® questionnaires on mental and social health (Global Health, Peer Relationships, Anxiety, Depressive Symptoms, Anger, Sleep-Related Impairment). For these questionnaires pre-COVID reference data were available (N=2401). PROMIS T-scores between the various measurement occasions will be compared using linear mixed models.
Results: In total, 2401 (2018), 844 (April 2020), 746 (November 2020), 1128 (March 2021), 1032 (November 2021) and 833 (March 2022) children and adolescents completed the questionnaires. Data of November 2022/March 2023 is still being analyzed. Preliminary results show decreased mental and social health at all COVID-19 pandemic measurement occasions compared to pre-COVID-19 data and no return to baseline (2018) outcomes. Results including the November 2022/March 2023 measurements, a period without any COVID-related restrictions, will be presented at the conference.
Conclusions: Thus far this study has shown a reduced mental and social health of children and adolescents during the COVID-19 pandemic (up to March 2022). With the restrictions lifted throughout the Netherlands and other parts of the world, investigating the long-term outcomes will provide us with valuable information to bring mental health(care) to the forefront of political decision making now and for future pandemics.

16. **Mental health support for Children and Young People with Duchenne Muscular Dystrophy – who, when and how across the United Kingdom**

Chloe Geagan

Introduction: Duchenne muscular dystrophy (DMD) is a progressive neuromuscular disease caused by mutations in the gene that codes for dystrophin. Patients experience a gradual loss of muscle starting in childhood that usually leads to death in the late 20s. Whilst the physical impact is well documented, the psychological and neuropsychological impact of this condition on children and young people (CYP) with DMD and their families has been largely overlooked and is poorly understood. Objective To acquire qualitative and quantitative information about approaches to and provision for mental health (MH) needs in CYP with DMD across the UK. To identify areas of good practice as well as gaps in service provision and variation and inequity in access to services which will inform approaches to service improvement.

Methods: Professionals across the NorthStar network (consortium of all the UK neuromuscular paediatric centres) and parents/caregivers will be recruited using separate online surveys. Questions have been designed by the project team and cover a range of similar themes regarding psychosocial support allowing comparison across the groups. CYP with DMD and their parents/caregivers will be invited to separate focus groups or interviews to discuss their views on support for mental health in DMD.

Results: Work in progress.

Discussion: We hypothesise that MH support for CYP and their carers will be identified as an essential component of care that should be offered in the neuromuscular clinic, as part of a broader interdisciplinary integrated approach. Understanding viewpoints from different stakeholders is essential in the early stages of this project to help guide future research ideas and clinical practice. Further engagement with CYP and parents/carers regionally and nationally is crucial to service development.

Conclusion: This project will be part of the wider DMD Care UK project which aims to provide consensus and an evidence base for the highest standard of care for all aspects of DMD. This is leading to UK-wide care recommendations, referral pathways, prescription guidance and clinical practice guidelines. Our work will embed psychosocial care within multidisciplinary teams treating DMD throughout the UK

17. **Mixed methods analysis of the unmet needs of caregivers of young childhood cancer survivors**
Eva Darow

Introduction: Young childhood cancer survivors (YCCS), who are diagnosed with cancer in early childhood (i.e., less than age 7 years), are at elevated risk for developing psychosocial and neurocognitive late effects. However, research to date has largely focused on school-aged survivors and their families. In this mixed methods study, we aim to characterize the unmet psychosocial needs of YCCS and their caregivers in order to inform psychosocial intervention development.
Methods: Caregivers of YCCS are invited to participate from the cancer registry of a Midwestern institution in the U.S. Utilizing purposive sampling, the anticipated final sample (N = 30 families) will be stratified by diagnosis type (i.e., leukemia/lymphoma, brain tumor, and non-central nervous system solid tumors), current age group (≤age 7 years vs. age between 8-12 years), and geographic region (rural or Appalachian), and will be representative of the local population by race/ethnicity. Interested caregivers complete online surveys and a semi-structured interview related to unmet needs. Data collection and formal thematic analysis with three coders is ongoing, with preliminary themes from 10 caregivers (7 biological mothers, 1 biological father, 2 legal guardians; 40% rural or Appalachian) presented here.
Results: Caregivers note unmet needs pertaining to parenting challenges, such as being "overprotective" and having difficulty setting limits. Some caregivers describe challenges related to differentiating typical tantrums, medication side effects, and behaviors requiring additional intervention. Surveys indicate that caregivers desired additional resources (e.g., school services, insurance assistance, connection to other caregivers) and psychoeducation (e.g., impact of treatment on development, impact on family and siblings, self-care). All caregivers report at least one unmet need related to managing their child's current behavior (e.g., sensitivity, distractibility).
Discussion: Preliminary themes indicate that caregivers of YCCS have unique unmet needs compared to caregivers of older survivors, which vary by time since diagnosis and geographic region. Findings are limited by a small subsample and preliminary qualitative analysis. Conclusion: Tailored interventions should be developed in partnership with caregivers, to address the psychosocial needs of this vulnerable and understudied group.

18. **Neurodevelopmental Outreach Project Trial at East Midlands Congenital Heart Network**
Vicky Elliott

Introduction: It is recommended that children with congenital heart disease (CHD) are offered regular neurodevelopmental follow-up during childhood to screen for emerging psychosocial issues and offer early support.

Method: Children most at risk of neurodevelopment complications were identified from a database of patients of the East Midlands Congenital Heart Centre and invited to complete the PedsQL-C (Cardiac Module) and Strengths and Difficulties Questionnaire (SDQ) to screen for difficulties. Where difficulties were noted, or families asked to speak with a psychologist, appointments were offered.

Results: A total of 138 young people were invited across three age ranges (Young Child, Middle Childhood, and Adolescent). Response rates were similar across groups and all were lower than expected (ranging from 6-18%). Respondents reported a mix of many different levels of functioning. Assessments were undertaken with 12 patients and their families, resulting in primarily onward referrals for neurodevelopmental assessment (33%) and/or mental health support (25%). Three cases were taken on for continued work of different types.

Conclusions: While the offer was clearly helpful to some families, the majority of patients invited did not respond. This leads us to believe that a “cold-calling” opt-in approach may not be the most appropriate, and is certainly not an effective use of limited psychology resource.

Discussion: Suggestions are made regarding how clinicians in EMCHN can support with identification of children at risk of neurodevelopmental difference and in need of support. Implementations for routine screening and follow-up are discussed.

19. **Parent Mental Health: An Important Consideration in Pediatric Tube Weaning Treatment**
Dana Bakula

Introduction: Pediatric feeding disorder is one of the most common health conditions for children under the age of five; a subset of these children experience feeding issues so severe that they require enteral nutrition, or tube feedings (TF). Once children with TF are medically stable and ready to resume primarily oral intake, the goal is to wean them from the TF, but this process can be stressful to parents. Our goal was to understand parent anxious, depressive, and posttraumatic stress symptoms before they begin TF weaning with their child as part of a tube weaning study.

Methods: We recruited children ages 9 months to 9 years with TFs and their parents to the iKanEat trial, a 24-week outpatient TF weaning trial, which includes 4 physician visits, 14 virtual health coaching visits, and either megestrol or a placebo. At baseline, parents completed measures of anxious (GAD7), depressive (PHQ9), and posttraumatic stress (IES-R) symptoms, and we used established clinical cutoff scores for each measure.

Results: Fifty parent-child dyads participated in the study. Children were half female (53.1%) and parents were mostly female (87.8%) and 44 years of age (SD=7.8 years). Nearly half of the parents endorsed mild or greater anxious symptoms (47.5%, M=5, SD=4.4), 37.5% endorsed mild or greater depressive symptoms (M=4.5, SD=4.4), and 7.7% endorsed clinically elevated levels of posttraumatic stress (M=8.2, SD=9.7). More than half (56.4%) of parents had a clinical elevation on at least one of these three measures.

Discussion: Most parents of children entering a pediatric TF weaning trial endorsed mild or greater mental health symptoms in domains of anxiety, depression, or posttraumatic stress. Parents with elevated mental health symptoms may struggle with the stressful demands of TF weaning without additional support.

Conclusion: Clinicians engaged in TF weaning should screen parents for mental health symptoms and develop systems to support parents with elevated symptoms as they engage in TF weaning with their children. Future research is needed to identify how interventions to promote parent mental health as a part of pediatric TF weaning may impact child treatment outcomes. Additional research with deliberate recruitment of fathers is also needed.

20. **Psychosocial Functioning of Transgender Youth Seeking Psychological and Medical Services in a Comprehensive Pediatric Gender Clinic**

Anthony Alioto

Introduction: Assessment is an important part of multidisciplinary evaluations for adolescents seeking gender-affirming healthcare. Mental health professionals use broad-band assessments to screen for psychosocial functioning, clarify diagnostic impressions, and identify potential targets for intervention. There is limited research addressing how these assessments should be used and interpreted among transgender and gender diverse (TGD) youth. This study describes baseline data of one measure of psychosocial functioning, the Behavior Assessment System for Children-3 rd Edition (BASC-3; Kamphaus & Reynolds, 2015) in a sample of TGD youth establishing gender-affirming care in a comprehensive Gender Wellness Program.

Methods: Retrospective chart review was conducted for 193 youth ages 12-18 years (M=15.1, SD=1.5) establishing gender-affirming care. Data analyses included descriptive and inferential statistics (t-tests, one-way ANOVA) of demographic variables and self- and parent-report BASC-3 T-scores, using general combined norms.

Results: The majority of the sample was assigned female at birth (AFAB; N=148, 76.7%) and White (N=166, 86%). Most identified as male (N=82; 42.5%) or non-binary (N=76, 39.4%), followed by female (N=30, 15.5%). Adolescents self-reported significantly more problems than the reference group in most areas of functioning. Parents reported fewer mean problems than adolescents. There were significant differences based on sex assigned at birth, with adolescents AFAB rating their problems as significantly worse on many subscales compared to adolescents assigned male at birth (AMAB). Nonbinary adolescents reported significantly more problems in anxiety, depression, attentional problems, mania, and overall functional impairment compared to binary females. Nonbinary adolescents rated their self- reliance and adjustment lower than binary males.

Discussion: TGD adolescents in this study self-reported significantly greater levels of distress and impairment than their parents and the BASC-3 reference group. Compared to adolescents AMAB, adolescents AFAB and those who identified as nonbinary rated their problems significantly worse in a number of areas.

Conclusion: TGD adolescents are reporting high levels of distress on the BASC-3. More research is needed to inform use and interpretation of BASC-3 results in this population, to identify causes of higher distress among nonbinary adolescents, and to better understand differences in perceived distress between TGD adolescents and their parents.

16.30– 17.30 **Short oral presentations (Moderator: Eileen Chaves)**
Lecture theatre Pathfoot

1. **Associations between childhood emotional abuse and adolescents' somatic complaints: the role of mentalization, internalizing symptoms and identity**
Dovilė Mikučionytė
Introduction: The experience of somatic symptoms is common in adolescence. According to research, 4% to 30% of adolescents experience severe somatic complaints, interfering with engagement in developmentally appropriate activities and affecting the quality of daily life (Amendola et al., 2021; Barkmann et al., 2011). Therefore, understanding the psychosocial factors contributing to somatic complaints is essential. Childhood emotional abuse is considered one of the most important risk factors for developing somatic complaints in adolescence (Rueness et al., 2020; Sætren et al., 2022). Nevertheless, findings on possible mediating factors are inconsistent. There is also a lack of research focusing on protective factors such as mentalization, i.e., the capacity to understand self and other mental states. The current study aimed to investigate the role of reflective function, internalizing difficulties and identity diffusion in the relations between childhood emotional abuse and adolescents' somatic complaints.
Methods: A total of 453 (256 (58.8%) girls, 188 (41.5%) boys) adolescents between 11 and 18 years old (M=14.48, SD=1.70) were enrolled in this study. This study sample consisted of the community sample (N=379, 83.7%) and the clinical sample (N=74, 16.3%). Participants filled out the Adverse Childhood Experience Questionnaire (Dube et al., 2001), the Youth Self-Report Questionnaire (Achenbach & Rescorla, 2001), the Reflective Function Questionnaire for Youths (Sharp et al., 2009) and the Assessment of Identity Development in Adolescents (Goth et al., 2012).
Results: Symptoms of withdrawal/depression (but not anxiety/depression) and identity diffusion sequentially mediated the relationship between childhood emotional abuse and adolescents' somatic complaints, with low and medium levels of reflective function moderating the link between emotional abuse and symptoms of withdrawal/depression.
Discussion: This study revealed the importance of well-developed mentalizing capacities as protective against adolescent internalizing symptoms and, consequently, somatic complaints even with high levels of childhood emotional abuse experienced. On the contrary, poor and moderate mentalization increased the risk of internalizing difficulties, leading to higher identity diffusion and, consequently, more pronounced somatic complaints.
Conclusion: Adolescent somatic complaints could be related to a history of emotional abuse, the experience of withdrawal/depressive symptoms and identity diffusion. Interventions focusing on developing youth's capacity to mentalize could be an important perspective.

2. **Primary School Children's Experiences of Managing Long Term Conditions: Systematic review and thematic synthesis of qualitative research**

Daniela Ghio

Introduction: The management of long-term conditions (LTCs) usually includes behaviours that control or minimise the effect of the condition. In childhood, the management of LTCs can be shared amongst parent/caregiver and child, with an expectation of a slow transfer of responsibility. However, little is known about the barriers and facilitators to a child's self-management of LTCs. The aim of this systematic review was to identify and synthesise qualitative studies that have explored the views and experiences of primary school children managing LTCs.

Methods: Electronic databases (MEDLINE, CINAHL, PsycINFO, ProQuest, Scopus) were searched for qualitative studies conducted with children (5 to 11 years), reporting on self-management of LTCs. Reviewers independently screened titles, abstracts and papers against inclusion criteria. Thematic synthesis steps were followed with themes formulated using the capabilities, opportunity, and motivation for behaviour (COM-B) framework.

Results: Inclusion and synthesis of 22 studies out of 6,189 screened. The most common conditions were asthma and type 1 diabetes. Barriers and facilitators were organised at child, parent, peer/school level. Children were learning how to take responsibility, by memorising information or sticking to what they know but found some skills were complex and hard to remember or explain to others. This was also identified as a barrier for parents and teachers. The child had negative associations with treatment and fear of exacerbating symptoms whilst they recognised their parents were worried about treatment and transferring responsibilities. Lastly, treatments could be inconvenient to access during school, they made the child stand out, and reminders were interruptive. They felt they relied on parents to provide treatment and felt there was a lack of environment structure at school for support leading to exclusion and isolation.

Discussion: Whilst children understand what they need to do to self-manage their condition, there is often reluctance to engage in behaviours that make them stand out. Having to remind their teachers or having to be excluded because of the lack of adaptations at schools means they disengage with self-management.

Conclusions: This review identified gaps for potential interventions to support children self-manage and transfer of responsibility in managing their LTCs.

3. **Perceptions of recovery among youth with chronic musculoskeletal pain and their parents**
Alexandra Neville

Introduction: There is heterogeneity in outcome measures used to assess success in pain care. Few studies have sought to understand how youth with chronic pain and parents themselves define recovery. This study provided a detailed qualitative examination of youth's and parents' perceptions of recovery in chronic musculoskeletal (MSK) pain care to answer the question: How do youth with chronic MSK pain and their parents define recovery?

Methods: Narratives were elicited through individual interviews with 28 youth enrolled in tertiary level care for chronic MSK pain (12-18 years) and one of their parents. Interviews focused on exploring youth's and parents' experiences of pain care and perceptions of recovery. Narratives were analyzed using inductive reflexive thematic analysis.

Results: While parents and youth did describe recovery in terms of reduced pain and improved physical functioning, preliminary findings show that recovery was more nuanced, multifaceted (e.g., extended beyond physical abilities), and unique to each youth. For example, youth described there being different aspects to recovery (e.g., mental recovery vs physical recovery) and had different definitions of recovery (e.g., being able to own a pet). Youth's individual views or beliefs around recovery also appeared to be dynamic and change throughout pain care. Some youth noted difficulty picturing or thinking about recovery at all. Still others described a change in their perspective from a focus on reducing pain at the initiation of treatment to an increased focus on function despite pain as they progressed in their pain care. Youth and parents identified pain acceptance and changes in mindsets as pivotal in this shift. Some youth and parents also specifically described recovery in terms of improvement, progress, and building self-efficacy.

Discussion: Youth's and parent's nuanced descriptions of what successful treatment means to them points to the uniqueness of defining recovery for each individual. Broader and more individualized approaches to measuring recovery in pain care may be warranted.

Conclusion: A more nuanced understanding of how youth with chronic MSK pain and their parents define recovery can point to intervention and measurement targets that are most meaningful to youth and parents in pain care.

4. **Prediction of Social Difficulties in Youth with Congenital Heart Disease: Comparison of Neurobehavioral Factors That May Account for Risk**

Amber Riggs

Introduction: Children with critical congenital heart defects (cCHD) are at risk for executive functioning (EF) deficits that may undermine social competence. Sluggish cognitive tempo (SCT) is a pattern of diminished energy and cognitive engagement not previously investigated in children with cCHD. In other populations, SCT is linked to peer victimization and diminished social acceptance. Our research examines differences in EF and SCT between youth with cCHD and healthy peers, and tests whether EF and SCT account for group differences in peer victimization and social acceptance.

Methods: Children with cCHD attending 4 th or 5 th grade mainstream classrooms (N=104, M_{age} =10.69, 38% female, 76% white) and comparison classmates (CC) matched for age and sex (N=58, M age =10.60, 30% female, 86% white) completed the NIH Toolbox cognitive battery (EF- composite), Social Experiences Questionnaire (Overt & Relational Victimization), and Self Perception Profile for Children (Social Acceptance). Mothers (N mCHD =101, N mCC =56) and fathers (N fCHD =62, N fCC =29) completed the Child Behavior Checklist (SCT subscale; averaged if two parents participated). Hierarchical multiple regression with post-hoc bootstrapping examined indirect effects of group (via SCT and EF simultaneously) on peer victimization and social acceptance.

Results: Children with cCHD had more SCT symptoms (d=-0.46, p=.001) and lower EF (d=0.32, p=.035) than CC. EF and SCT were negatively correlated (r=-.21, p=.007). Compared to CC, the cCHD group also reported lower Social Acceptance (d=0.34, p=.026) but not more victimization (Overt: d=-0.23, p=.182; Relational: d=0.05, p=.750). Indirect effects of group via SCT were significant in predicting Overt Victimization, Relational Victimization, and Social Acceptance, even when controlling for EF. EF did not account for unique variance in victimization or acceptance.

Discussion: Children with cCHD are at risk for SCT and, when present, SCT increases risk of peer victimization and lower social acceptance. Diminished EF did not account for assessed social risk.

Conclusion: Future studies should examine the role of SCT in social difficulties longitudinally and spanning a broader age range of youth with cCHD, perhaps across developmental transitions. If replicated, results suggest that SCT might be a useful marker of social risk and target for interventions to foster positive peer relationships in cCHD survivors with SCT.

5. **SPINE Program: Specialized Progression of Independence and Wellness for Adolescents with Spinal Cord Injury: Program Description and Initial Outcomes**
Kindell R. Schoffner

Introduction: SPINE was created in 2022 to serve as a community outreach program to progress independence and wellness for young persons with a SCI through therapeutic modalities, unique community outings, and education targeting areas that have been identified to facilitate a successful transition to adulthood. The transition to independent adulthood can be difficult for persons who sustained a SCI as a child, resulting in a decreased likelihood to be employed, live independently, or have life satisfaction equal to that of their peers. Mental health issues, such as depression, can also be more likely in adults who sustained SCIs as children. SPINE is a one-week long program that is led by a physical, occupational, and recreational therapist, and pediatric psychologist to address the above issues and improve quality of life.
Methods: Design: Case study; pretest-posttest within-subjects design Setting: Outpatient, multi-disciplinary program at Children's Healthcare of Atlanta Participants: SCI diagnosis; uses wheelchair or assistive device; >6 months since injury; ages 16- 21. Total of 7 participants attended program across two separate weeks. Interventions: Curriculum includes skill practice and education for topics including: advanced wheelchair and mobility skills, driver's rehabilitation, peer support, community and financial resources, educational opportunities, vocational rehabilitation, adult medical care, health and wellness, adapted sports, accessible travel, and mental health implemented by specialists in the above topics. Education and skills practice occurs in a multimodal format, including lectures, direct skills training and practice, and unique community outings to provide hands-on learning opportunities. Measures: Pre- and post-program surveys using a 5-point Likert scale measured participants' self-reported satisfaction with improving the above areas of functioning.
Results: Paired t-test for all survey responses. Four of seven survey question responses statistically significant ($p<0.01$).
Discussion: Participants in the SPINE Program report statistically significant self-report improvement in life skills and independence.
Conclusion: Future goals of the program are to expand participation and outcome measures, as well as involve other institutions with the possibility of growing the program to including an international audience/participants.

6. **Secondary data analysis using pediatric databases: Lessons Learned**
   Jessica Emick
   Introduction: Secondary data analysis can be a powerful tool to answer complex pediatric health questions and yet it is underutilized. Secondary analysis of existing data has several advantages including decreased time and costs, better representation for diverse children and families, improved access to less common conditions but it can be daunting for a researcher to know where to start. The presentation serves as a starting point for pediatric psychologists interested in using archival databases and will review lessons learned from teaching graduate students how to use secondary data analysis in a clinical psychology doctoral training program.
   Methods: Through a literature review as well as a review of online databases a list of commonly used datasets that are readily available for pediatric psychologists was created and recommendations for addressing common challenges related to secondary data analysis was developed.
   Results: The results include the identification of numerous national and international pediatric databases that are readily available. Details about the databases will be shared in the results section as well as best practice recommendations for common challenges and key questions to consider.
   Discussion: Secondary data analysis has many benefits. From a social justice perspective, pediatric psychologists commonly face challenges representing diverse children and families in their research. Using larger archival databases may allow pediatric researchers to better understand the unique challenges experienced by diverse pediatric populations. Larger databases can also provide unique access to less common pediatric conditions. Despite these benefits, researchers may find it challenging to know where to start with secondary data analysis and struggle with ensuring the variables fit the intended questions, managing large unfamiliar databases, and understanding the design and purpose of the datasets.
   Conclusion: This presentation is designed to help reduce barriers to accessing pediatric databases. By sharing lessons learned with pediatric psychologists about the current and available databases and recommendations for getting started, it is hoped that this will encourage more researchers to consider secondary data analysis as a viable method.

19.00 - Conference dinner + Ceilidh

The conference dinner will start at 19:00 in the *Stirling Court Hotel restaurant*, we will be gathering in the bar. Any drinks bought at the bar before the start of the dinner will be at your own expense, but the 3 course meal and water served during dinner is included in the registration fee and comes at NO extra cost to you. At the end of the 3 course meal, you will have a chance to stretch your dancing muscles within a Scottish Ceilidh. Originally the word Ceilidh (kay-lee) comes from the Gaelic word for ‘gathering’ or ‘party' and still to this day means a fun filled night of dancing on Gaelic folk music amongst great company! A local band will entertain us with Gaelic folk music and everyone can take part in the traditional dances, as a "dance caller" will walk us through the dance steps. So there’s no need to be worried or shy!

PROGRAM FRIDAY, SEPTEMBER 1, 2023

08.00 – 09.00 **Registration**
Pathfoot Crush Hall

09.00 – 09.15 **Opening Day 3 (Moderators: Nicola Scott, Kim Oostrom, Caroline Heary)**
Lecture theatre Pathfoot

9.15 – 10.15 **Plenary session 3: Laura Simons (Moderator: Rocio de la Vega) (1 CE credit offered)**
When does collaboration become team science?
Lecture theatre Pathfoot

Learning Objectives

a. Identity advantages to de-siloing research efforts to tackle pressing issues facing the field of pediatric psychology.
b. Describe the contextual factors that influence the effectiveness and success of team science efforts.
c. Apply key characteristics underpinning effective interdisciplinary work to build a successful team.

10.15 – 11.15 **coffee break + poster session 3**
Pathfoot Crush Hall

1. **Clinicians' perspectives of the challenges in treating adolescents with co-occurring chronic pain and mental health symptoms**
   Sharon Bateman
   Introduction: Pain and mental health symptoms frequently co-occur in adolescents, often resulting in physical, social, and emotional challenges. Little is known about the potentially unique challenges these co-occurring symptoms pose to clinicians. Previous research has focused on clinician perspectives in the context of chronic pain in isolation. This qualitative vignette study focused on examining clinician perspectives of the challenges and barriers to treating adolescents who experience co-occurring pain and mental health symptoms.
   Methods: Using a cross-sectional qualitative online vignette survey, responses were collected from 40 clinicians, involved in the treatment of adolescents (aged 11-19) who experience co-occurring pain and mental health symptoms. Participants were recruited internationally through email and social media and included psychologists, physiotherapists, nurses, doctors, and consultants who work in pain and/or mental health settings. Vignettes were analysed using reflexive thematic analysis.
   Results: Whilst still being finalised, current themes generated include 1) "mistrust", 2) "siloed services". Theme one reflects how clinicians themselves are mistrustful of the adolescent's previous clinician encounters and a perceived need to 'undo' this anticipated harm. Theme two "siloed services" depicts clinician perceptions concerning the lack of 'joined up' thinking of pain and mental health services for adolescents, resulting in specialisms in both services but no overarching understanding of both pain and mental health in either service. Theme 3 "adolescent challenges" describes how co-occurring symptoms impact adolescent's ability to participate in treatment, and hinders social engagement and relationships, all of which may be detrimental to the success of treatment.
   Discussion: Clinicians perceive that previous adolescent-clinician experiences, relationship challenges and inadequate service provision are all barriers to effective treatment for co-occurring pain and mental health symptoms. This research highlights a need for clinician education across services to address the lack of understanding of the interactions between pain and mental health symptoms and calls for better links between service providers when treating co-occurring symptoms.
   Conclusion: Adolescent co-occurring pain and mental health symptoms are often initially mismanaged because they don't fit the mould of the services available to treat them, resulting in a more complex presentation to clinicians.

2. **Peer Interaction Interventions in Paediatric Chronic Pain: A systematic review of facilitators, barriers, and outcomes**

Kate Roberts

Introduction: Living with chronic pain can be an isolating experience for some children and young people. Paediatric patients have expressed an interest in opportunities to meet one another. However, guidelines (WHO, 2020) state that while group formats can be supportive and help normalize pain, they can also be "alienating" and "unappealing" for some patients. A systematic review of literature was conducted to understand the barriers, facilitators, and outcomes of interventions involving peer interaction for paediatric pain patients.

Methods: Details of the review strategy can be found on PROSPERO (CRD42022336685). Main inclusion criteria were: participants aged 0-19 years with pain persisting for at least 3 months; outpatient interventions involving meeting at least one other paediatric patient with chronic pain; available in English language; reports on at least one of the following: recruitment/attrition rates, participant feedback, outcome measure(s) completed at two or more time points. Included outcomes were those outlined in PedIMMPACT (McGrath et al., 2008) and quality of life.

Results: Thirty studies were found meeting review inclusion criteria. Studies reported on a range of intervention types, most frequently mindfulness groups, multidisciplinary pain management groups, and cognitive behavioural therapy groups. A summary of participant feedback and outcomes will be presented.

Discussion: A number of children with chronic pain seem to highly value the opportunity to meet with peers, but this is not universal. Patterns in when these interventions seem to be more or less helpful for participants will be considered. Limitations in the literature will also be discussed, notably the limited quality of the evidence, and lack of representation of groups of children who are more likely to experience chronic pain.

Conclusion: Services supporting children with chronic pain could benefit from offering opportunities for their patients to each other. However, this should not be the only service offer. Research would benefit from focusing on promising interventions progressing to larger studies with more robust designs. Consideration should also be given to improving the representativeness of participants within research studies.

3. **Physical appearance and body-related changes experienced by teenage and young adult (TYA) cancer survivors: A qualitative systematic review**
Alyxandra Hamilton-Smith

Introduction: The review aimed to systematically identify and synthesise findings in published qualitative research that explored the experiences of physical appearance and body-related changes in teenage and young adult (TYA) cancer survivors.
Methods: An electronic search utilising MEDLINE, PsycINFO, CINAHL, Embase and ProQuest Dissertations & Theses (PQDT) Global databases identified 411 articles; nine of which met inclusion criteria for the review. A thematic synthesis was conducted to identify emergent descriptive and analytical themes across all nine studies.
Results: Two overarching analytical themes were identified: (1) Striving for social safety and (2) Navigating an unfamiliar body. The reviewed studies described the distress associated with changes to their body and appearance as well as the strategies TYAs engaged with to manage the alterations. Overall, themes captured the social, identity and restorative processes that TYAs detailed post-treatment.
Discussion: The review highlighted that TYA survivors often experience a difficult period of adjustment to cancer-related body and physical appearance changes. Findings suggest that it is important for healthcare services to support TYAs in their exploration of identity and social settings post-treatment. Based on the results of this review, facilitating a meaning-making process that prioritises the redefinition of social and personal implications of appearance change may be beneficial in promoting more positive body-related adjustment. Accordingly, increasing or enhancing open and honest conversations about appearance change at every stage of cancer treatment can be recommended. Additionally, naming and discussing appearance difficulties may have the potential to diminish their strength and, in turn, empower TYAs by providing opportunities for them to express concerns (Atkinson et al., 2020). More specifically, designing interventions that explore TYA's experience of self-discrepancy (Higgins, 1987; see theme "Navigating an unfamiliar body") and promote self-compassion (Gilbert, 2005, 2009; see theme "Striving for social safety") may prove beneficial in encouraging more positive appearance-related adjustment for TYA survivors.
Conclusion: Our findings acknowledge the continued impact of cancer-related BI and physical appearance changes, as well as the perceived psychosocial implications of these alterations, within the TYA survivorship period.

4. **Provider perspectives on trauma informed care education: if we build it will they come?**
Kristin A. Kullgren

Introduction: Trauma informed care (TIC) is a healthcare model recognizing the widespread impact of trauma, that providers should recognize the signs/symptoms of trauma in patients/families and staff, that TIC should be integrated into the health system, and that retraumatization be avoided. In pediatrics, many children are admitted following traumatic injury or illness and the lifesaving care provided can be traumatic to children, families, and staff. Despite the known risk, it is unknown what experience providers have with TIC, particularly in settings like the pediatric intensive care unit and surgery suite where youth are at greater risk for trauma and retraumatization. A needs assessment was developed to understand provider knowledge and acceptance surrounding TIC education for providers in pediatric critical care medicine (PCCM) and pediatric anesthesiology (PA) in our pediatric hospital.

Methods: A 28-item anonymous survey was emailed to PCCM and PA providers from multiple disciplines at a Midwestern United States pediatric hospital. Questions included: demographics, TIC specific questions related to knowledge, comfort, and training history/interest, and barriers to TIC education and practice.

Results: Participants (n=154) represented multiple disciplines (nursing (61.2%), physician attendings (19.5%), physician fellows (6.5%), respiratory therapists (9.1%), patient technicians (2.6%), pharmacists (0.6%) in PCCM (70.7%) and PA (27.3%). Half were familiar with TIC while only 44.2% know what Adverse Childhood Events are. Around two-thirds think TIC is important but reported moderate to low levels of comfort in providing TIC. Most (80.4%) had no previous TIC training but would like more (72.5%). Time was identified as the most common barrier to learning about TIC; most (71.5%) would devote < 60 minutes for training.

Conclusions: Most pediatric providers in settings with elevated risk for causing trauma and retraumatization are motivated to learn more about TIC despite many lacking knowledge, previous training, comfort, and time to engage in training/practice. Pediatric psychologists can play a role in tailoring TIC education to medical professionals that acknowledges the barriers to practice and learning. TIC curricula must be very brief, cross-disciplinary, highlight the value of TIC in the specific setting, and incorporate confidence building exercises to enhance TIC delivery in high-risk pediatric settings.

5. **Psychosocial functioning in adolescents with a congenital heart disease: The role of attachment and emotion regulation**

Saskia Mels

Introduction: Because of their medical vulnerability, youngsters with a congenital heart disease (CHD) are not only at an increased risk for developing psychological problems but already at young ages they may also face more challenging parent-child interactions. It is the aim of the present study to examine whether insecure attachment relationships with parents and the use of maladaptive emotion regulation strategies explain the psychosocial functioning in adolescent patients with a CHD.
Methods: A sample of 11 to 18-year-old adolescents who were born with a CHD (percutaneous and/or invasive surgically corrected) was recruited (N = 106; 48% boys and 52% girls). Participants completed online questionnaires about emotion regulation (FEEL-KJ), attachment towards mother and father (ECR-RC) and psychosocial wellbeing (SDQ).
Results: Results show that higher levels of attachment anxiety towards mother and attachment avoidance towards mother were significantly associated with worse psychosocial functioning. In addition, higher levels of attachment anxiety towards father and attachment avoidance towards father were also significantly associated with worse psychosocial functioning.
Conclusion: In line with the hypotheses, the adolescent's use of maladaptive emotion regulation strategies mediated the associations between insecure attachment and psychosocial functioning.
Discussion: Future research should further unravel the role of emotional processing in explaining psychosocial functioning in youth with CHD. Clinical practice may benefit from strengthening parent-child relationships and emotion regulation training in order to strengthen this vulnerable sample's wellbeing.

6. **Sleep Disturbance and Frequent Pain in Pediatric Sickle Cell Patients**
   Hannah M. Spears

   Introduction: Sickle Cell Disease (SCD) is an inherited blood disorder characterized by pain and multi-system organ damage. Up to 40% of youth with SCD experience frequent pain. It is well established that sleep disturbance and negative emotions are associated with increased pain in other pediatric pain conditions. There is less data examining these variables in pediatric SCD. This study aimed to examine these relationships in pediatric patients with the most severe form of SCD, genotype SS.

   Methods: Participants (N = 47; 40.4% girls; M_{age} = 16.1) included youth with SCD, genotype SS ages 12 to 21 years. Half of youth (48.9%) had frequent pain (>15 pain days/month) and half (51.1%) had infrequent pain (<2 pain days/month). We extracted demographics and medical history from the electronic health record. Youth wore a sleep Actigraphy watch for 7 days and completed a 7- day diary that measured pain and affect. Youth also completed the PROMIS Pediatrics Sleep Disturbance scale. Pearson correlations, one-way ANOVA, and independent t-tests examined group differences and relationships in pain severity, sleep, and affect.

   Results: Youth with frequent pain tended to report more sleep disturbance on self-report but this difference was not significant. On actigraphy measures, sleep efficiency ($p = .019$) and sleep percent ($p = 0.01$) was significantly lower for youth with frequent pain compared to youth with infrequent pain. On daily diary report, children with frequent pain reported more negative affect and increased pain severity ($p's < 0.001$). Across both groups, increased pain severity was correlated with increased negative affect ($p < 0.001$) and more days of sleep debt ($p = 0.19$).

   Discussion: Results validate that youth with SCD who experience frequent pain also experience decreased sleep efficiency and sleep percent, as well as increased negative affect, compared to youth with infrequent pain. Across both pain groups, youth who experience increased pain severity also experience increased negative affect and sleep debt.

   Conclusion: Youth with SCD experience poor patient-reported outcomes. Future studies should aim to further examine and address modifiable sleep and affect outcomes in relation to pain for youth with SCD genotype SS.

7. ***retracted***

8. **The Effect of Online Experiences, Connection, and Resilience on Sibling Adjustment to Pediatric Cancer Stress**

Sarah Wawrzynski

Introduction: Pediatric cancer disrupts the lives of siblings in many ways including physical separations from family and friends that may exacerbate their risk for distress. Our research suggests that siblings rely upon technology, including texting and social media, to help stay connected with friends and family and garner social support. However, technology use may also expose siblings to negative online experiences that can erode self-esteem, potentially reducing their resilience. This study explored the relationship between online experiences (both positive and negative), connection to friends and family online, resilience, and psychosocial health among siblings of children with cancer.

Methods: Participants included a U.S. sample (N=81) of adolescent siblings (aged 12- 17; M=14.58 years) of children with cancer. Associations between self-reported assessments of online experiences, online connection, resilience, and psychosocial health were analyzed using structural equation modeling (SEM).

Results: Most participants were female (n=46; 56.8%), and white (n=45; 55.6%); however, 50.6% (n=41) represented racial or ethnic minorities. A substantial subset of siblings reported moderate-to-severe levels of post-traumatic stress symptoms (PTSS) (n=48; 59%) and emotional and behavioral difficulties within the clinical range (n=43; 53%). Encountering more positive online experiences was associated with greater perceived connection to family and friends online ($p < .001$), but was not associated with resilience, PTSS, or emotional and behavioral difficulties. In contrast, higher negative online experience scores were significantly associated with more PTSS ($p<.001$) and emotional and behavioral challenges ($p<.001$). Additionally, the associations between negative online experiences and PTSS ($p=.140$) was completely mediated by a negative association between negative online experiences and resilience. This indirect effect on emotional and behavioral difficulties was reduced but remained significant ($p=.016$).

Discussion: Positive online interactions are linked to greater perceived connection to friends and family online for siblings of children with cancer. However, negative online experiences may erode resilience and contribute to poorer psychosocial adjustment for siblings dealing with pediatric cancer.

Conclusions: While social media may be an important tool for helping siblings of access social support, negative online experiences may be detrimental to their adjustment. Efforts should be made to optimize online experiences toward resilience.

9. ***Moved to Thursday Poster session, poster #12***

10. **When Caregivers Decline Care in Acute Pediatric Medical Settings: A Clinical Practice Guideline**
Cassie Ross

Introduction: In pediatric acute medical settings, it is common for medical providers to experience a parent/family decline a recommended care for their child. These situations tend to be ethically and psychosocially complex, happen frequently, can result in harm to the patient due to delays in care, and potentially fracture relationships with medical teams. As such, with significant input from a pediatric psychologist, an evidence-informed, integrated clinical pathway (CP) was developed to guide medical teams in navigating declination of cares. To our knowledge, there is limited report on the role of psychologists in system-wide CP development as well as lack of CPs that address navigating care declinations in pediatric medical settings.

Methods: The authors discuss the role of the pediatric psychologist in the development of a system-wide CP for a freestanding children's hospital in the United States that focuses on response to parental/familial care declinations.

Results: Parental/familial care declinations are ethically and psychosocially complex situations that require a high level of communication skills and awareness of biopsychosocial factors. As such, the pediatric psychologist played a key role in the content of the CP as well as engaging with various stakeholders to obtain feedback and approval.

Discussion: This presentation will provide education on how psychologists' unique skillset can be utilized to support systematic issues within pediatric medical settings. In addition, this presentation will provide opportunities for discussion amongst audience members to support problem solving surrounding the role of psychologists in multidisciplinary teams and engaging in CP development.

Conclusion: Pediatric psychologists' expertise in effective communication, the complexities of biopsychosocial factors, and health outcomes are uniquely suited to development of CPs and contribution to larger systematic issues within medical centers. CPs are valuable tools in healthcare that make research applicable to clinical contexts, improve efficiency and efficacy of care, and may improve clinical outcomes.

11. **The use of pediatric PROMIS® item banks in Dutch boys with haemophilia**
Lorynn Teela

Introduction: Legacy haemophilia-specific Patient Reported Outcome Measures (PROMs) can be experienced as a burden due to their length and sometimes irrelevant questions. Patient Reported Outcomes Measurement Information System (PROMIS®) item banks, including short forms (SF) and Computerized Adaptive Testing (CAT), could solve this problem. The objective of this study is to assess the psychometric properties and feasibility of eight PROMIS item banks within a clinical sample of boys with haemophilia.

Methods: In this multicentre study, all boys with haemophilia (8-17 years) from five Dutch Haemophilia Treatment Centres completed eight PROMIS measures (Pain Interference, Fatigue, Anxiety, Depressive Symptoms, Mobility, Peer Relationships, Anger, Global Health) and two legacy instruments (Haemo-QoL and PedHAL). Reliability was assessed as the proportion of reliable scores (standard error ≤4.5). Feasibility was determined by the number of completed items and the presence of floor/ceiling effects. Furthermore, construct validity was assessed by comparing the PROMIS T-scores with (subscales of) the legacy instruments.

Results: In total, 77 boys with haemophilia responded. Reliability was good for almost all PROMIS measures, except for the PROMIS item bank mobility. Regarding feasibility, the mean number of completed items per CAT varied from 9-12, whereas the legacy instruments administered 6-8 items per domain (total: 53-77 items). Floor/ceiling effects were observed in both the PROMIS measures and legacy instruments but were more pronounced for the legacy instruments.

Conclusions: The PROMIS paediatric measures are feasible and reliable to use for paediatric patients with haemophilia. PROMIS instruments should be considered by clinicians when assessing different aspects of physical, mental and social health in boys with haemophilia. With the use of the PROMIS measures in haemophilia care and research a step can be taken towards worldwide standardization of PROM administration.

12. **Understanding and overcoming factors preventing parents of children with life-threatening illnesses engaging in interventions to improve their sleep: a three phase study**
Ellen M. Henderson

Introduction: Parents of children with life-threatening illnesses (LTIs) report sleep disruption impacting on their physical, social and emotional functioning and in some cases limiting their ability to provide care for their child as they may wish. Engagement by this group in recommended sleep improvement interventions is low. This study aims to determine why engagement in sleep improvement is suboptimal and explores, with parents of children with LTIs, how to optimise advice on sleep improvement for other parents.

Methods: This study includes three phases: 1) Focus groups with 13 parents of children with LTIs (n=3 parents of children with malignant disease, n=10 parents of children with non-malignant disease) to explore issues around sleep, specific to them; 2) Co-production of improvements to advice on sleep improvement available to parents with parent participants of phase one; 3) Dissemination of results to parents and stakeholders through a variety of traditional and novel techniques and evaluation of these dissemination techniques.

Results: Parents in phase one identified the lifestyle and equipment required to provide to care of children with LTIs in the home as the primary barriers to better sleep within this space. Together they identified seven ways to optimise recommended interventions for sleep which they felt more appropriate to their caregiving. They also produced recommendations for professionals in hospital settings to support and improve sleep of parents of hospitalised children with LTIs. Parents endorsed approaches to dissemination of findings including social media, on pillowcases given to parents and through word of mouth from their child's clinical teams. Findings for professionals were disseminated through reports submitted to key personnel within paediatric hospital organisations. Evaluation of these approaches is ongoing, but appears to have reach to key groups.

Discussion: Improving sleep for parents of children with LTIs remains a challenge. Tailoring existing evidence based interventions to account for caregiver's roles and responsibilities is an essential way to ensure success.

Conclusion: Co-production is an appropriate way to identify how best to optimise sleep interventions to overcome barriers reported by parents of children with LTIs and to identify how best to disseminate advice to stakeholders.

13. **Unmet needs of youth with chronic pain without access to multidisciplinary pain management**
Rocio de la Vega

Introduction: Children with chronic pain are a vulnerable population who very often lack the resources to manage their condition. Therefore, there is a clear need to improve children's access to effective and empirically validated multidisciplinary treatments. In many countries, such as Spain, there are no well-established Pediatric Pain Clinics where children with chronic pain can receive appropriate specialized care. A first step to develop a tailored and culturally relevant treatment for this population is to learn about their needs. The aim of this work is to learn about the unmet pain care needs of children with chronic pain in Spain.

Methods: Focus groups will be conducted in the Spring at 5 reference hospitals (one per hospital or until saturation is reached). Informed consent and assent will be obtained before participation. Field notes will be taken and interactions will be audio recorded and transcribed. In case there is missing information after the focus groups conclude, further interviews will be conducted. Inclusion criteria are: 1) Children age 10-17 years; 2) Has had non-oncologic chronic pain for at least 3 months, 3) Speaks and reads Spanish.

Results: At this point, ethics approval has been obtained and recruitment has started at three hospitals. Once data is collected, a qualitative framework analysis will be used to synthetize the information. Information will be integrated in the updated CFIR framework. Outcomes will be reported following the COREQ checklist. Additionally, basic demographic information will be collected and the Public and Patient Engagement Evaluation Tool (PPEET) participant questionnaire will be administered.

Discussion: With this study, we aim to understand the pain care needs that adolescents with chronic pain in Spain have.

Conclusion: Knowing the specific needs of this group of youth, we will have a starting point to develop a tailored psychological treatment to complement the medical treatment (usually medication) that they are currently receiving.

14. **Utilization and Sustainability of an Integrated Pediatric Primary Care Psychology Service in the United States**

Meghan McAuliffe Lines

Introduction: Mental health concerns are among the most prevalent health concerns for youth in the US, with 10-20% of youth annually meeting criteria for a mental health diagnosis, but more than 50% of them never receiving needed treatment. Emerging data suggest that integrated primary care (IPC), in which behavioral health providers deliver care as members of the primary care team, can provide earlier and more acceptable access to care through a shorter wait time to service and earlier referral to care.

Method: Pediatric psychologists and psychology trainees (graduate students, interns, postdoctoral fellows) were integrated into 12 pediatric primary care clinics in a U.S. healthcare system. Retrospective electronic chart review was used to explore service utilization and access data for 2022.

Results: During 2022, there were 4,361 completed psychology visits across clinics. 2,200 patients with a new referral to psychology had a completed visit, with an average wait time of 31 days from referral to visit. 15% of these referrals received a “warm handoff (WHO)” (same day access to care). Significantly more WHOs were completed in clinics with medical residents (M=88.3, SD=96.7) than in clinics without medical residents (M=8.78, SD=9.9), $t(10)=2.7$, $p=.02$.

Discussion: This pediatric integrated primary care program provides access to care in a trusted setting, with significantly less wait time for services than outpatient clinics. Some patients were seen for a WHO directly from their pediatrician to the psychologist, and this occurred most frequently in medical resident clinics, suggesting that integrated services may be of particular value to doctors in training. Of note, grant funding was utilized to support initial program development and growth and will be further discussed.

Conclusion: This program provides a model for development of a pediatric integrated primary care program that can provide access to much-needed care in a safe, comfortable and destigmatized environment. IPC is a key approach to addressing the growing behavioral health needs of youth, and spreading and scaling of pediatric IPC models is needed.

15. **Utilization of Bilingual Resources: Exploring Perceived Barriers for Behavioral Health Providers Working with Spanish-Speaking Families**

Anne Malkoff

Introduction: Despite widespread efforts to increase the availability of interpretation services, non-English speaking patients continue to experience increased challenges with communication with their health care providers, which often results in poorer understanding of their diagnosis or treatment plan (Guerrero et al., 2011). This is particularly salient for Spanish-speaking families, given that Spanish is the second most spoken language in the U.S (Shin & Kominski, 2010). As such, we sought to understand behavioral health providers' (BHPs) experience in using bilingual psychoeducational resources and perceived barriers when working with Spanish-speaking families.

Method: A 9-item survey was developed and completed by BHPs (N = 48) working in an academic medical center. It assessed utilization of linguistically appropriate psychoeducational materials through the electronic medical record (EMR) and perceived barriers to providing linguistically appropriate care, when working with Spanish-speaking patients.

Results: Among monolingual (n = 40) and English/Spanish bilingual (n = 8) BHPs, 55% reported "never or rarely" using psychoeducational materials in the EMR when working with Spanish-speaking patients, and identified "being unsure of where to locate bilingual resources" (43%) and "limited time in session" (17%) as the top two barriers in accessing linguistically appropriate psychoeducational materials. Over 80% of providers across training levels identified the lack of psychoeducational materials available in Spanish as a significant area of inequity within their clinical practice.

Discussion: This data-driven approach has helped to inform dissemination efforts, such as the creation of a repository of bilingual psychoeducational materials within the EMR system and monthly email blasts to notify BHPs of newly available bilingual resources. Post-data collection relating to BHP utilization, barriers, and satisfaction with dissemination efforts will be collected and discussed.

Conclusion: Despite efforts to improve access to linguistically appropriate mental health services across our hospital system, inequities persist in BHP's utilization of linguistically appropriate psychoeducational resources for Spanish-speaking families. There is a clear need to enhance system-wide processes and resource dissemination across providers to promote equitable care for Spanish-speaking patients and families.

16. **What support do families find supportive on the path to a childhood-onset diagnosis?**
Helen Dolling

Introduction: Recent rapid technological advances have greatly expanded the availability of whole exome and genome sequencing (WES/WGS) in the Neonatal and Paediatric Intensive Care Units (NICU/PICU) and the NHS more widely. Worldwide, the Next Generation Children Project (NGCP: French et al., 2019, 2022) was the first large cohort of children (521 families) to have received rapid trio whole genome sequence analysis (rWGS) for any suspected single gene disorder. The Peregrin* follow-up study explores how early genomic testing and results impact parental experiences and early family relationships, with a view to elucidate benefits or harms, including decisional regret, and to identify risk and protective factors for family adjustment.

Methods: 96 parents from 63 NGCP families participated in Peregrin* study, of whom 57% received a diagnosis of mostly rare/ultra-rare disease in their child. 96 parents (58 mothers and 38 fathers) completed online questionnaires, and 91 completed in-depth semi-structured interviews and the Five-Minute Speech Sample (FMSS) via Zoom. Interview audio-recordings were transcribed verbatim and analysed by framework and content analysis methods. FMSS transcripts were coded for narrative coherence (Sher-Censor, 2019) to explore parents' sense of competence, adaptive parenting, and parental attitudes and schemas regarding their child.

Results: Interviews illustrate the clinical and personal utility of genomic testing, but survey responses indicate widespread ongoing parental anxiety and uncertainty about the future, coupled with contrasting attitudes and support needs over time and across parent gender. Condition-specific support groups are helpful to many, but parents' information needs and ability to cope with diagnosis and prognosis vary.

Discussion: Parents of children with serious health problems view early genomic sequencing and results as helpful and important. However, waiting for the results and adjusting to their child's diagnosis, medical condition or prognosis is stressful, anxiety-provoking, and emotionally complex. Interviews and FMSS offer a valuable window into parental experiences, concerns, and mental health, and the dynamic and complex nature of contrasts in family experiences.

Conclusion: Families undergoing early genomic sequencing require holistic family support pre- and post-testing, as well as person-specific opportunities to make sense of their parenting journey from intensive care to long-term family life.

17. **Paternal Roles on Biopsychosocial Outcomes of Children with Cancer: A Scoping Review**
Anna Olsavsky

Introduction: Fathers are more involved parents than ever, yet their role in caring for children with chronic illness, specifically cancer, is understudied. Existing reviews have examined paternal involvement in pediatric illnesses, paternal experiences with children with cancer, and how pediatric cancer effects family functioning. However, no review has linked fathers' roles to the biopsychosocial outcomes of their child with cancer. This scoping review aimed to assess paternal involvement in their child with cancer's biopsychosocial outcomes.

Methods: Review protocol was preregistered on Open Science Framework. We included studies of fathers of children diagnosed with cancer under 18 years old that examined the role of fathers on childhood biopsychosocial outcomes. Studies were excluded if they only reported fathers' experiences, did not link fathers' roles to children's outcomes, or included fathers grouped only among other caregivers within analyses. Studies were first located on Medline to identify keywords and index terms to create a search strategy. This strategy was adapted for Ovid Medline, Embase, PsycINFO, and Cochrane Central. Identified citations were entered into Covidence. Titles and abstracts were screened by 2 independent reviewers. Currently, full texts are being assessed against inclusion criteria by ≥2 reviewers. Final scoping review results will be presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review.

Results: 14,670 articles were identified. 4,551 duplicate articles were removed. 10,119 articles were reviewed by two reviewers for title and abstract screening. In this step, ambiguous articles (e.g., mentioned parents/family) were included for full-text review if they linked caregivers/family to children's biopsychosocial outcomes (e.g., quality of life, adherence) to evaluate whether they meet inclusion/exclusion criteria. 618 articles advanced for full-text review, which is in-progress with expected completion ahead of conference.

Discussion: It is important to elucidate what is currently known about paternal contributions to the biopsychosocial outcomes of their children with cancer to develop father-inclusive, targeted interventions to improve child outcomes.

Conclusion: Through understanding what is known about fathering in the context of pediatric cancer, novel targets for future studies and interventions will be identified.

18. **Project Pivot - When Implementation is the Barrier to Effectiveness and a Virtual Reality RCT Becomes a Single Arm Feasibility Trial**

Courtney W. Hess

Introduction: Within pediatric chronic pain care, supporting engagement in physical therapy can be challenging given fear of pain and avoidance of activity, however, virtual reality has demonstrated effectiveness in addressing these challenges. However, beyond demonstrating effectiveness, there is a need to establish therapies as feasible and useful in the context of clinical care. Historically, intervention trajectories have followed similar pathways moving from demonstrating intervention effectiveness to evaluating the implementation of established interventions. However, in the context of the current intervention trajectory, the need to alter this often-linear process was clear. As such, we adopted an implementation science lens and made substantial changes to the protocol to support improved implementation into standards of physical therapy care. The purposes of this presentation are to: (a) present the protocol for an RCT examining the effectiveness of physical therapy for the treatment of chronic pain with and without the use of augmented virtual reality, (b) describe challenges and roadblocks that emerged in the context of the trial which illuminated implementation barriers, and (c) present findings from interviews with participants, caregivers, and stakeholders that informed our pivoting the trial to a single-arm feasibility trial.

Methods: Analysis of enrollment, dropout, and engagement data were evaluated to identify the scope and nature of implementation roadblocks. We conducted qualitative interviews with stakeholders (N=12) involved in the study and content analysis was used to illuminate barriers and facilitators to implementation according to three critical stakeholders—the patients, caregivers, and physical therapists.

Results: Since trial initiation, N=50 patients have been eligible for participation. During this time, N=14 participants have been enrolled, however, 2 of the 14 participants have dropped out of the project. Engagement with the VR device revealed a trend toward reduced engagement over time. Qualitative analysis revealed several barriers to effective implementation including high research burden, frustration when allocated to non-intervention arm, and technology hesitation and fear of disrupting clinical care for physical therapists,

Discussion & Conclusion: Results from our quantitative and qualitative analyses will be presented alongside how we attempted to adapt to identified implementation barriers. Implications and next steps in our trial will also be discussed.

19. **Feasibility of a generic digital group treatment for adolescents with chronic disease and their parents**

Elisabet Bergenmar Ivarsson

Introduction: The incidence of psychosocial symptoms is higher in adolescents living with a chronic disease, and in their parents, compared to the general population in the same age range. Previous studies underline the need to address issues connected to the chronic disease, in treating anxiety and depression in this group. Op Koers (On track) developed in the Netherlands, is a cognitive behavioral therapy-based program focused on preventing and treating psychosocial symptoms related to coping with chronic disease. Studies indicate that there are more similarities than differences regarding psychosocial challenges met by adolescents with different chronic diseases. The generic groups allow adolescents with rare diseases to participate, and the accessibility is enhanced by the digital format. The program consists of 6 group sessions incl. home assignments using a digital platform. The aim of the study is to explore the feasibility of Op Koers in a Swedish context.

Methods: Inclusion criteria are adolescents with a chronic disease aged 12-17 and their parents. Data collection is performed at baseline- before the start of the treatment, after three weeks mid-treatment and after six weeks at the termination of the treatment, through self- and parent questionnaires of psychosocial symptoms and quality of life and parents' self-reports of psychosocial symptoms and stress. The participants rate each session in terms of usefulness and meaningfulness on a scale from 1-10. Experiences of the program is investigated through semi-structured interviews and analyzed with thematic analysis.

Results: The data-collection is ongoing, to be completed in June 2023. We plan to include 12 adolescents and 24 parents. Results will be presented comparing pre, mid and post measures as well as main themes from the interviews. The rating will add a quantitative dimension of the experience of usefulness and meaningfulness of the intervention.

Discussion: The findings will be analyzed and discussed in relation to the planning of the upcoming randomized controlled trial (RCT).

Conclusion: This study aims to explore the feasibility of Op Koers and the results will focus on the program's content, format, and impact in preparation for the upcoming RCT.

20. **How can we understand the barriers and facilitators to communicating chronic pain in medical and social settings in emerging adults aged 18-30 years old**
Emma Scott-Smith

Introduction: Introduction: Chronic pain is defined as a pain lasting for 6 months onwards from an underlying issue, or an injury that has healed (Fisher, 2018), and is a life limiting condition which can affect 1 in 5 people in Scotland alone (NHS Inform, 2021). Pain can impact aspects of a person's life in multiple respects: employment, sleep hygiene, physical, emotional functioning, and stigma (Goubert and Trompetter, 2017). A key difficulty related to this invisibility of pain is effectively communicating pain experience to others, to gain other people's full understanding of the impact of this long-term condition. These communication difficulties are apparent in clinical as well as everyday social settings (Liesch and Elertson, 2018). The focus of this research is to understand the main barriers to communication and which creative tools (drawing, painting, Apps) can be used to communicate chronic pain.

Methods: Current assessment tools are limited by verbal description of an individual's experience, which is demonstrated by the inconsistencies found in tools provided to young children, and young adults (Zieliński, Morawska-Kochman, & Zatoński, 2020; Atee et al., 2017). What this project aims to do, is provide a proof-of-concept visualization tool for healthcare support. To do this, I scoped out the current literature that explores communication in young adults with chronic pain by systematically searching three databases: PubMed, Web of Science and Science Direct. In addition, I reviewed creative tools used in healthcare and non-healthcare settings by systematically searching databases.

Results/Discussion: The scoping review identified 6 relevant articles and identified as main barriers the ability to communicate pain. This scoping review also found that creative tools help to communicate pain through visual and audio practice. Tool use can help to overcome challenges of invisibility by making the pain visible, build trust and validation when patients have experienced being disbelieved or stigmatised. In reviewing the content of the creative tools, a wide variety was identified from painting, drawing, collage imagery, photography, storytelling, digital technology, to web-based imagery. The goals of employing creative tools in therapeutic settings is important for individuals who are unable to express their pain verbally, and to visually gain an understanding of the difficulties of day to day coping of this condition.

Conclusion: As pain is difficult to perceive by others in the absence of an obvious physical impairment, communication skills are vital for chronic pain patients to share their feelings. Modern technology has allowed for greater patient engagement with their personal healthcare by providing accessible interactive platforms for monitoring themes like nutrition and exercise. This project hopes to expand on these well-established methods which will provide patients an option to conceptualise, visualise, and monitor their pain (Liesch and Elertson, 2018).

11.15 – 12.30 **EPPN Town Hall (EPPN co-chairs: Rikard Wicksell & Line Caes)**
Lecture theatre Pathfoot

12.30 – 13.30 **Lunch break**
Pathfoot Eatery

13.30 – 15.00 **Parallel symposium session 4 (1.5 CE credits offered)**

Symposium 1: Intervention development, implementation & evaluation (Chair: Sinead Hannan) *– Lecture theatre Pathfoot*

Learning Objectives

a. Identify and describe pain education as an effective method for preventing and reducing chronic pain/disability in a high-risk population.
b. Explain the ways in which CBT may be personalised to address the specific needs of children and young people with chronic physical illnesses
c. Describe programs and intervention strategies designed to overcome barriers to care in pediatric psychology.

Individual talks

1. A Randomized Controlled Trial (RCT) Examining the Effect of a Psychologically Informed Video Series to Treat Adolescents with Patellofemoral Pain. Or, How Pediatric Psychologists Can Better Disseminate Care through Collaborating with Allied Health Professionals. (Jessica Hoehn)

Abstract

Introduction: Adolescents with patellofemoral pain (PFP) often develop chronic pain, with most adolescents (51-91%) reporting persistent pain even after intervention. Physical therapy (PT) is the standard-of-care treatment; however, most adolescents report ongoing pain and functional disability even after PT completion. Maladaptive psychological beliefs (pain catastrophizing, kinesiophobia, and fear-avoidance beliefs) have been found to predict increased pain and functional disability for adolescents with PFP. Psychologically informed interventions to address maladaptive beliefs have been shown to be effective in improving pain and functioning in adolescents with PFP. However, there are multiple barriers to receiving these interventions, including access/availability of pediatric psychology, time-intensiveness, and expense. Given these factors, adolescents with PFP would greatly benefit from innovative and accessible interventions to address and reshape maladaptive pain-related beliefs. Thus, the purpose of the current study was to create and evaluate a series of brief psychologically- informed pain education videos designed to be delivered as part of standard-of-care PT.

Methods: A physical therapist and pediatric psychologist collaborated to create a series of three brief (5-8.5 minutes each) psychologically-informed pain education videos. Video content was designed to address maladaptive psychological beliefs, and included education on pain neuroscience and cognitive restructuring. The video series was evaluated via a double-blind RCT in 68 adolescents presenting to PT clinic with PFP. Participants received either the psychologically-informed videos or control videos (knee anatomy education) across three PT visits. Pain, functional disability, and maladaptive psychological beliefs were measured at baseline, six weeks, and three months.

Results: When compared to the control group, the pain education video series lead to significantly greater improvements in pain and functioning at both 6 weeks and 3 months. The psychologically-informed videos also significantly reduced maladaptive psychological beliefs.

Discussion: The psychologically-informed video series was an effective intervention for addressing maladaptive beliefs and reducing pain/functional disability. The video series is easy to implement and disseminate in a PT clinical setting.

Conclusion: The video education could contribute to prevention of chronic pain/disability in this high-risk population. This collaborative intervention approach is an excellent method for psychologists to disseminate knowledge, share expertise, and provide psychology-informed intervention across a broad scale.

2. Bridging the Gap Between Academia and Industry: Solutions for Developing Digital Interventions with Limited Funds and Technological Skills (Lauren Harrison)

Abstract

Introduction: Digital behavioral health interventions offer solutions to access to care barriers (e.g., shortage of services outside of urban areas, significant treatment related costs, long provider waitlists), but only 28% of digital interventions are disseminated adequately or timely, leading to suboptimal health care innovation and significant research waste. Researchers who develop digital behavioral health interventions identify challenges to development and implementation, including lack of programming skills required to develop a digital tool, timeline, cost, uncertainties related to partnering with software developers, and sustainability/maintenance. The aim of this study is to present our process of developing a digital behavioral health intervention and solutions for challenges and barriers identified by researchers in this field.

Methods: The development of our digital intervention utilizes the mHealth Agile Development and Lifecycle model, a framework to integrate the rapid, iterative development process used in industry with behavioral change theories of academia to produce a useable, efficacious, widely disseminated digital solution. During prototype development we conducted semi-structured interviews with end-users (N = 15) in cycles of n = 5, allowing for iterations to the intervention between interview cycles. Data on comprehensiveness and acceptability of treatment content, useability of the platform, and anticipated barriers to utilization was collected.

Results: Processes for engaging end-users in the development process and an iterative, agile approach to prototype development will be presented. We will also discuss software/online tools for organizing end-user data, pros/cons of existing platforms to house the intervention and present a how-to guide for building the intervention on a low-cost, no code platform.

Discussion: Following the finalization of the digital intervention prototype, we will launch a feasibility and preliminary effectiveness trial (N=20) utilizing single-case experimental design methodology to support rapid, iterative evaluation.

Conclusions: While the technical knowledge and resources required to develop digital behavioral health intervention can feel daunting, these do not have to be limiting factors to developing a digital behavioral health intervention that mirrors what is developed in industry.

3. Implementing a Behavioral Health Four-Session Concussion Treatment Program (Maia Noeder)

Abstract

Introduction: Almost 20% of teenagers have experienced a concussion with 5.5% of adolescents experiencing more than one concussion (Veliz et al., 2017). Concussions impact the physical, cognitive, emotional, social, and academic areas of a child's life and can have an extended impact for the 14-20% of patients that experience postconcussion syndrome (PCS; Taylor et al., 2015). Cognitive behavioral therapy is a first line treatment for PCS (McNally et al., 2017) but long wait times for behavioral health services and difficulty obtaining family buy-in at the time of referral are barriers to care.

Methods: We developed a four-session concussion treatment program (Concussion Abbreviated Treatment Intervention; CATI) with the goals of reducing wait times and increasing family buy-in. CATI session content included psychoeducation, sleep and physical activity interventions, relaxation strategies, and mindfulness strategies. Referral information was gathered through a review of the electronic medical record. Pre- and post-intervention symptoms were measured using the parent- and self-reported Total and Emotional Scores from the Postconcussion Symptom Inventory (PCSI; Sady et al., 2014) and analyzed using t-tests.

Results: Of the 247 referrals that were placed, 53% were scheduled for a behavioral health visit. This was an improvement over our pre-implementation scheduling rate of 35%. Median wait time from referral to first visit decreased by 16 days after implementation of CATI. Post-intervention PCSI scores demonstrated a statistically significant improvement in parent- and self-reported Total and Emotional scores.

Discussion: Results demonstrate that a four-session concussion treatment model improved concussion- related aspects of functioning. Our abbreviated model also resulted in improved scheduling rates and reduced wait time. Limitations of this study include lack of a control group and collection of data during the COVID-19 pandemic which led to variation in scheduling protocols and referral rates. Future directions include use of a waitlist control and developing a consistent pipeline for patients that need to transition to other forms of care after completion of behavioral health services.

Conclusion: A four-session behavioral health treatment model is recommended for the pediatric concussion population.

4. Mental Health Intervention for Children with Epilepsy (MICE): A randomized controlled, multi-center clinical trial evaluating the clinical effectiveness of psychological therapy in addition to usual care compared to assessment-enhanced usual care alone for children and young people with common mental health disorders and epilepsy (Sophie Bennett)

Abstract

Introduction: Mental health difficulties are elevated in children and young people with Long Term Conditions (LTCs) such as epilepsy but many of those in need cannot access evidence-based psychological treatments such as CBT. This talk will present the clinical outcome of a large RCT of an integrated mental health treatment delivered remotely by Health Care Professionals within physical healthcare services for young people with epilepsy.

Methods: The study design was a multi-centre, parallel group, blinded, randomized controlled trial including 334 participants aged 3-18 years, attending epilepsy clinics, who met diagnostic criteria for a common mental health disorder. They were randomized to receive a Mental Health Intervention for Children with Epilepsy (MICE) intervention based on MATCH-ADTC in addition to usual care, or assessment-enhanced usual care alone (control). The primary outcome, analysed by intention-to-treat was the parent-report Strengths and Difficulties Questionnaire (SDQ) at six months post-randomization.

Results: At six months the mean (SD) SDQ difficulties for 166 MICE patients was significantly lower than for 168 control patients (p<0.01). MICE also demonstrated significant positive results for the mental health of the parents/carers compared to the control arm.

Discussion: The trial demonstrates that multiple mental health comorbidities can be effectively treated within a singular intervention across a wide range of age groups and in the context of additional complexities, including LTCs and neurodevelopmental disorders.

Conclusion: The presentation will end with a discussion of the implications of the development and evaluation of MICE for the treatment of mental health disorders in the context of other chronic illnesses.

5. mrI sCAN: A low intensity psychological intervention to increase the number of young children who undergo MRI scans without General Anaesthetic (Sinead Hannan)

Abstract

Introduction: Magnetic Resonance Image (MRI) scans are challenging procedural experiences for children and caregivers due to the requirement to lie still for prolonged periods in a confined space with loud noises and vibrations as well as coping with anxiety leading up to and during the scan. General Anaesthetic (GA) is requested to ensure the quality of diagnostic images, despite associated risks, costs and decreased appointment availability. The purpose of this study was to assess whether using a low intensity psychological intervention increases the number of MRI scans without GA in children.

Method: A stepped care low intensity psychological intervention was designed based on patient needs for children under 9 years of age on the GA waiting list. Quantitative and qualitative methods were used in the evaluation of the intervention.

Results: 88% (15/17) had successful MRI scans without GA with sufficient diagnostic quality imaging from May 2022 to February 2022. 10/17 children had ID, ASD or ADHD. Reduction in MRI-related procedural anxiety and increase in readiness and confidence ratings. Positive feedback was provided by all families with suggestions for further improvements. A conservative estimate of a cost avoidance of £665 per scan was estimated. The total waiting time saved for children ranged from 75 weeks to 147 weeks with an average of 107 weeks.

Discussion: A cross-directorate initiative established a new clinical pathway with the aim of reducing the number of young children undergoing an MRI scan with GA. A new low intensity stepped care intervention was designed and offered to children currently on the GA waiting list. The majority of children under 9 years of age were able to successfully complete an MRI scan without the use of GA, including children with learning disability, ASD and ADHD.

Conclusion: A low intensity psychological intervention has improved patient safety; improved patient experience & skills so families are empowered, informed, engaged and active participants in their healthcare; optimised use of resources; reduced waiting times and provided a cost avoidance.

Symposium 2: From the clinic to the lab, and back again: what can experimental paradigms tell us about paediatric pain and its treatment? (Chair: Lauren Heathcote) *– Seminar room PD1*

Individual talks

1. A new experimental approach to studying and training pain-related attention in children with chronic pain (Lauren Heathcote)
2. Probing parents' empathic responses to their child's pain using an experimental paradigm (Inge Timmers)
3. A window into the multifaceted neurophysiology of pain in adolescence: From healthy neurophysiology to altered cortical functioning in Juvenile Fibromyalgia (Marina Lopez Sola)

Symposium Abstract

Paediatric psychologists have learned a great deal by studying patient experiences and behaviours in the clinic. Yet, moving this research into the lab enables more tightly controlled experiments that help us to dig deeper into underlying mechanisms and to disentangle cause and effect. But can lab-based research be translated back into meaningful clinical insights? In this symposium, three researchers will share their cutting-edge translational research programmes which use experimental paradigms to understand mechanisms underlying pediatric chronic pain and thereby inform novel intervention approaches. First, Dr. Heathcote will present on how experimental paradigms have been used to understand pain-related vigilance and attention in children with chronic pain. She will share how these findings have directly informed a new pilot trial of gamified sensory attentional flexibility training for children with chronic musculoskeletal pain. Next, Dr. Timmers will show how a novel experimental paradigm can capture empathic responses in parents of children with chronic pain, and discuss how these findings could inform clinical interventions to reduce parents' distress. Last, Dr. López-Solà will present a novel lab-based visual-sensory integration paradigm and share how new findings from this paradigm are unveiling the brain mechanisms underlying chronic pain in youth with fibromyalgia. Together, these talks will showcase what experimental paradigms can tell us about paediatric pain and their promise for innovation in treatment approaches.

Learning Objectives

a. Identify how experimental paradigms can be useful for pediatric pain research.
b. Describe three new, cutting-edge experimental paradigms that are unveiling insights into children's pain-related attention, parental distress, and abnormal neural sensory integration in paediatric fibromyalgia.
c. Describe how experimental paradigms can be informed by clinical insights and can then be translated back into clinical innovation.

Symposium 3: Developing interventions with reach: Family-centered psychosocial care in pediatric oncology (Chairs: Christina Amaro and Melissa Alderfer; Discussant: Ulrika Kreicbergs) *– Seminar room PD3*

Individual talks

1. Engaging Community Members in the Development a Web-Based Single-Session Intervention for Adolescent Siblings of Youth with Cancer (Christina Amaro)
2. Adapting Evidence-Based Interventions for Delivery in the Community: The Surviving Cancer CAMPetently Program (SCCamp) (Melissa Alderfer)
3. Family Bonding as a Result of the Family Talk Intervention in Pediatric Oncology—Siblings' Experiences (Kerstin Ivéus): ***ONLINE***

Symposium Abstract

Childhood cancer affects the whole family, including the diagnosed child, parents/caregivers, and siblings, all of whom are at-risk for poor adjustment outcomes. This is why family-centered care is at the core of pediatric health care delivery. Although this approach is reflected in the Psychosocial Standards of Care in Childhood Cancer, many barriers limit the capacity to fully implement evidence-based family-centered care (e.g., siblings are frequently absent from the hospital setting), especially now given increased precautions related to infectious disease.

A key principle of family-centered care is providing care and support in the context of family, home, and community while recognizing and building on the strengths of the family. To reduce barriers to psychosocial care, it is critical to develop innovative interventions in the various settings within which families present. This session aims to describe the development of novel family-centered interventions designed for a variety of contexts. The presentations will also cover various stages of intervention development— from the initial idea to piloting the intervention.

The first presentation will discuss a qualitative study aimed at understanding community members' perceptions of and preferences for digital health interventions; data collection will begin this summer and findings will inform the future development of a web-based single-session intervention for adolescent siblings of youth with cancer. The second presentation will describe an intervention currently in development: adaptation and integration of the Surviving Cancer Competently Intervention Program into community- based pediatric oncology Family Camps. The third presentation will focus on a pilot study of the Family Talk Intervention and present data on siblings' experiences with this family-centered program. After these three presentations, the discussant will reflect on the implications of these studies and future directions in family-centered intervention development across settings to ultimately improve evidence-based care for youth and families affected by childhood cancer.

Learning Objectives

a. Describe family-centered care in pediatric cancer.

b. Summarize the development of three novel interventions in a variety of settings to support family-centered care in pediatric cancer.

c. Describe innovative strategies for overcoming barriers to supporting families of youth with cancer.

15.00 – 15:30 **Conference closing & Award ceremony (Moderator: Line Caes)**

Lecture theatre Pathfoot