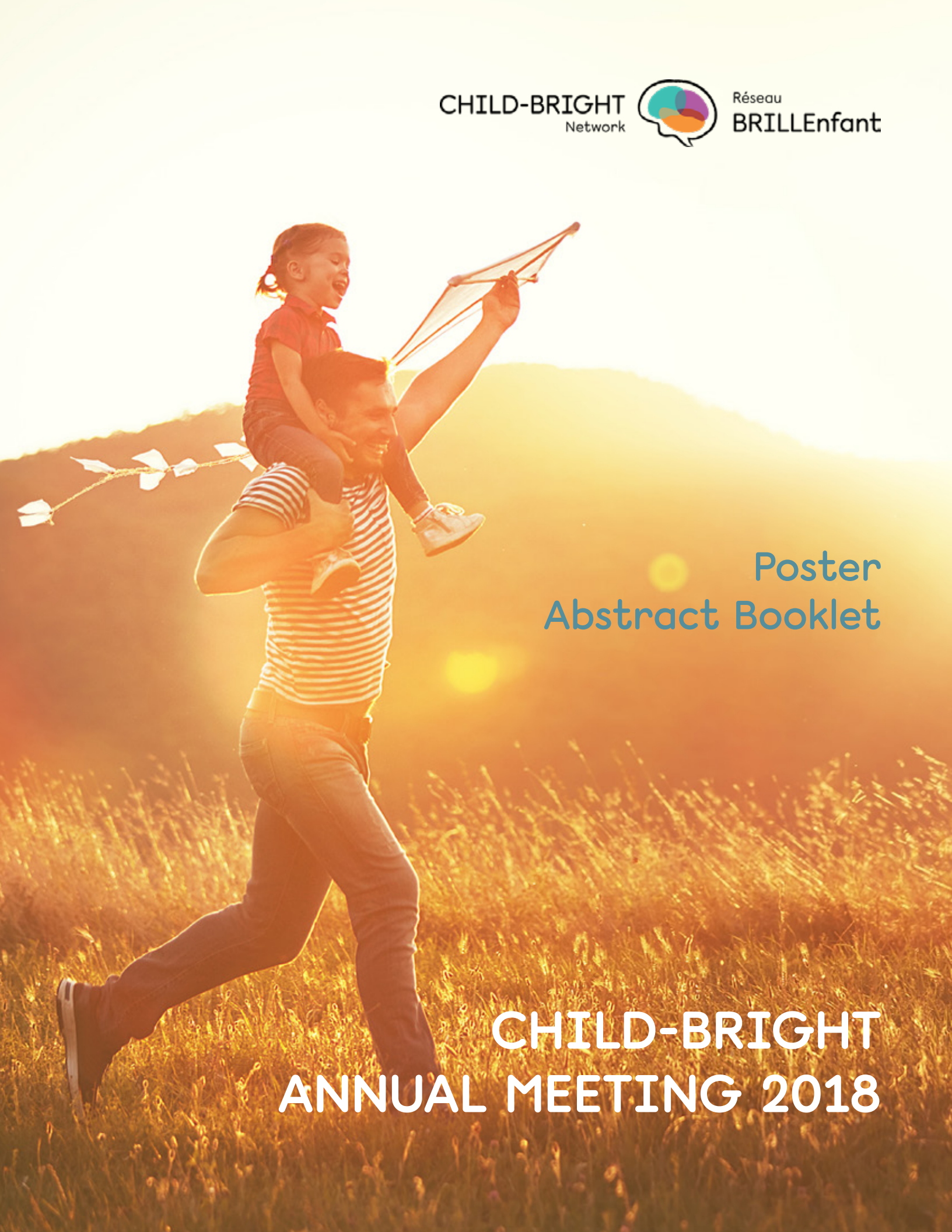
CHILD-BRIGHT Network

Réseau BRILLEnfant



Poster Abstract Booklet

CHILD-BRIGHT ANNUAL MEETING 2018

Poster Session Schedule

December 5, 2018

Poster Session: 3:15-5:00 p.m.
Poster *Cinq à Sept*: 5:00-7:00 p.m.

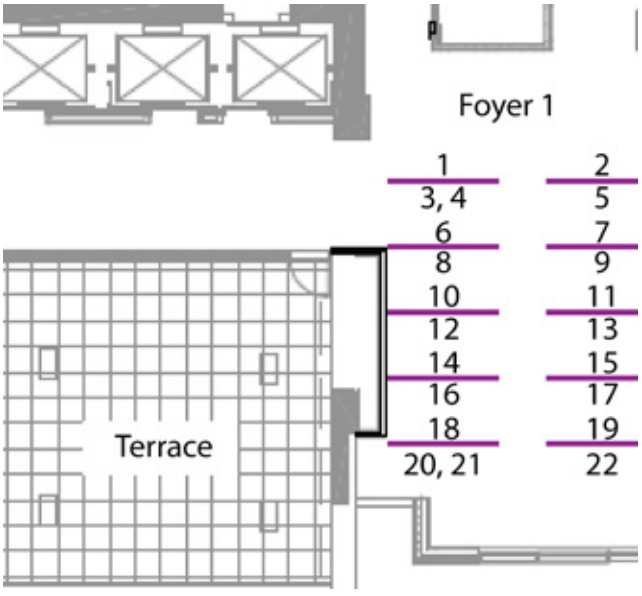
Poster Presentation Schedule

Poster #	Title	Presenter	Presentation Time
1	MATernal Hyperoxygenation in Congenital Heart Disease (MATCH) Study	Davide Marini	4:10-5:00 p.m.
2	Metformin for Motor and Cognitive Improvement in Children with Cerebral Palsy: A Feasibility Study	Darcy Fehlings	3:15-4:05 p.m.
3	Parent Integrated Evidence-based Practice to Improve Quality ("Parent-EPIQ"): Aim 1 – Meaningful outcomes for parents of very preterm children	Anne Synnes	3:15-4:05 p.m.
4	Parent Integrated Evidence-based Practice to Improve Quality ("Parent-EPIQ"): Aim 2 – Implement Parent-EPIQ	Anne Synnes	3:15-4:05 p.m.
5	Stimulation for Perinatal Stroke to Optimize Recovery Trajectories: The SPORT trial	Adam Kirton	4:30-5:00 p.m.
6	Parent Integrated Evidence-based Practice to Improve Quality ("Parent-EPIQ"): Aim 3 – Outcome Evaluation	Anne Synnes	3:15-4:05 p.m.
7	Genetic Testing in Children with Atypical Cerebral Palsy	Colleen Guimond	4:10-5:00 p.m.
8	Participants as Partners in Research: Communicating a timeline to research participants for results with a "fuzzy ending"	Nicole SY Liang	4:10-5:00 p.m.
9	The Indigenous Neonatal Abstinence Syndrome (INAS) Project: Coming Together to Understand Neonatal Abstinence Syndrome and Support the Well-Being of Opioid-Exposed Children.	Serene Kerpan	3:15-4:05 p.m.
10	Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairments	Sharan Sahota	3:15-4:05 p.m.
11	Strongest Families™: Engagement Experiences of Parent Involvement in Modifying an Online Parenting Program for Children with Neurodisabilities	Karen Turner	3:15-4:05 p.m.
12	Bringing understanding of sex and gender into health research, practice and policy	Nancy Poole	3:15-4:05 p.m.
13	Jooay App: 'Connecting the Dots' between Children with Disabilities and Leisure	Keiko Shikako-Thomas	3:15-4:05 p.m.
14	The effectiveness of a video-game based cognitive intervention (Mega Team) for children with neurodevelopmental conditions: updates on game-development, study design and progressresearch, practice and policy	Victoria Lishak	3:15-4:05 p.m.
15	Coached, Coordinated, Enhanced Neonatal Transition (CCENT): A multi-centre mixed-methods pragmatic randomized controlled trial	Arpita Parmar	4:20-5:00 p.m.

Poster Presentation Schedule (Continued)

Poster #	Title	Presenter	Presentation Time
16	BRIGHT Coaching: a developmental coach system to empower families of preschoolers with suspected developmental delays	Tatiana Ogourtsova	4:10-5:00 p.m.
17	Meaningful Involvement of Patient and Family Partners in Phase 1 of the READYorNot Transition to Adulthood Project	Sonya Strohm	4:10-5:00 p.m.
18	Sharing Experiences with Agile Software Development Methodology in the READYorNot Project e-Health Intervention	Alicia Via-Dufresne Ley	4:10-5:00 p.m.
19	Disability Data Project: Navigating Disability Supports and Services Across Canada	Brittany Finlay	3:15-4:05 p.m.
20	Enabling Visions and Growing Expectations (ENVISAGE): An international parent-researcher partnership to support best starts for parents of children with disabilities	Andrea Cross	4:10-5:00 p.m.
21	Building capacity for families as partners in research: A Family Engagement in Research Certificate Program	Andrea Cross,	4:10-5:00 p.m.
22	Guideline Development for Rehabilitation in Arthrogryposis: Collaboration with youth, parents, and clinicians	Caroline Elfassy	4:10-5:00 p.m.

Poster Layout - Floorplan



Poster Abstracts

Poster Board #1

Poster Title: MATernal Hyperoxygenation in Congenital Heart Disease (MATCH) Study

Author(s) Davide Marini, Edward Hickey, Fraser Golding, Greg Ryan, Chris Macgowan, Susan Blaser, Edgar Jaeggi, John Kingdom, Tim Van Mieghem, Steven Miller, Mike Seed

Institution/Affiliation(s) SickKids and Mount Sinai Hospitals, Toronto, Canada

Funding Source(s) Strategy for Patient-Oriented Research (SPOR), SickKids Foundation, Thrasher Research Fund

Abstract

Introduction: Reduced cerebral oxygen delivery is believed to be responsible for impaired brain development in fetuses with congenital heart disease.

Aims: To investigate the neuroprotective efficacy of chronic maternal supplemental inhaled oxygen during the second half of pregnancy in pregnancies affected by fetal single ventricle congenital heart disease.

Design of the study: Pregnant patients between 20 and 32 weeks gestation whose fetuses have been diagnosed with a single ventricle heart will be invited to participate in a placebo controlled double blind randomized controlled trial. Subjects will be treated with continuous inhaled oxygen therapy via nasal prongs at 4L/min up to 24h/day, resulting in a FiO2 of approximately 40% versus medical air for at least 10 weeks. During this interval frequent clinical and echocardiographic assessments are established, as well as fetal cardiac MRI after 35 weeks of gestational age. Placental histology and neonatal brain MRI imaging will be performed within the first two weeks of life, and patients followed up with the Bayley III scales of infant development at 18 months. In an initial pilot study, the safety and feasibility the treatment will be checked.

Preliminary data: Nine pregnant women were approached: 6 were ineligible, one declined. Two consented and underwent 10 weeks of continuous inhaled oxygen therapy. Subject 1 declined fetal MRI and the baby underwent brain MRI after birth. Subject 2 underwent brain and heart fetal MRI.

Conclusions: Both subjects showed increased brain volume when compared both to normal controls and to fetuses with single ventricle CHD. Fetal CDO2 during maternal hyperoxygenation was similar to CDO2 in normal controls. More subjects and longitudinal assessment are needed to confirm these preliminary findings.

Poster Board #2

Poster Title: Metformin for Motor and Cognitive Improvement in Children with Cerebral Palsy: A Feasibility Study

Author(s) Darcy Fehlings, Donald Mabbott, Steven Miller, Wendy Ungar, Jennifer Zwicker, Blythe Dalziel, Amber Makino, Jenna Doig, Cecilia Lee, Daniel Warner, Cynthia de Medeiros, Lauren Switzer

Institution/Affiliation(s) Holland Bloorview Kids Rehabilitation Hospital & The Hospital for Sick Children

Funding Source(s) CHILD-BRIGHT Network - Canadian Institutes of Health Research (CIHR), Holland Bloorview Kids Rehabilitation Foundation, SickKids Foundation, Three To Be

Abstract

Children born pre-term are at risk for developing cerebral palsy (CP). The brain injury pattern is mostly to the white matter which results in motor problems. It can also lead to some long-term cognitive deficits in some, but not all, children with CP. White matter is important for fast and effective communication across the brain. We are looking at the medicine metformin, typically used to treat diabetes, as a potential effective treatment for CP. Animal studies suggest that metformin can 'turn on' the brain's own stem cells. If this works in a similar way in humans, the stem cells can help repair damaged white matter.

We will recruit children with CP who have a white matter injury pattern on brain imaging who are between the ages of 6 to 12 years and compare metformin to placebo (pills with no medicine). Both groups will receive physiotherapy, a standard treatment for CP. In total we will recruit 50 children – 25 for the metformin and physiotherapy group and 25 for the placebo and physiotherapy group. Our main goals are to see if the study is feasible and can be run the way it is designed. We are going to evaluate recruitment, whether the study pills are taken regularly, whether all the physiotherapy sessions are provided, and completeness of our outcome measures. Both children and their caregivers will answer quality of life questions. Importantly, we are going to look at safety and tolerability of metformin in children with CP. We will also look for evidence to see if metformin works like we think it will. To answer these questions, children will do motor tasks, thinking tests, set physiotherapy goals, and have pictures of their brain taken using magnetic resonance imaging (MRI).

If our study runs well and metformin appears to work, we will seek funding to do a larger study to find out how effective metformin is for treating children with CP.

Poster Board #3

Poster Title: Parent Integrated Evidence -based Practice to Improve Quality ("Parent-EPIQ"): Aim 1- Meaningful outcomes for parents of very preterm children

Author(s) Anne Synnes, TM Luu, A Janvier, CJ Bourque, P Church, K Robson

Institution/Affiliation(s) British Columbia's Women's Hospital, Hôpital Ste Justine, Sunnybrook Hospital, Canadian Premature Baby Foundation

Funding Source(s) CHILD-BRIGHT Network / SPOR

Abstract

Aim 1: To *define* outcomes that are meaningful to parents of very preterm children to be used by neonatal follow-up programs, including the Canadian Neonatal Follow-Up Network (CNFUN), when children are 18-21 months age corrected for prematurity.

Background: The *CNFUN* created a national standardized health and neurodevelopmental evaluation at age 18-21 months corrected age (CA) for children born preterm at < 29 weeks gestational age (GA). The CNFUN database has tracked information including hearing, vision, cerebral palsy, its severity and developmental status (measured using the Bayley Scales of Infant and Toddler Development (Bayley-III)) since 2011 and categorizes children as having a "neurodevelopmental impairment" (NDI) or a "significant NDI (sNDI). NDI and sNDI rates are used to make critical healthcare decisions. Despite extensive research on the outcomes of prematurity, there is no consensus on how to measure, define and report outcomes. Parents have never been asked to voice which outcomes they perceive to be important. The aim of this study is to engage parents to identify outcomes of interest to parents and co-create definitions of NDI and sNDI.

Methods: *Overview:* Using a sequential mixed-method approach, our goal is to capture the breadth of parent perspectives. The four sequential steps are:

1) Ask all CNFUN parents how they perceive their own child's development and compare to current definitions.
2) Quantitatively and qualitatively, explore parent perspectives on the outcomes that matter to them and which outcomes they consider severe. One survey will explore their own child's health and another will use 11 vignettes. Dr Janvier et al are building on previous qualitative work.
3-4) Use the above results to revise and validate outcomes and definitions using an expert working group.

Progress to Date:
Step 1: The questionnaire has been developed, REB approved, incorporated into the CNFUN database and data collection started.
Step 2: Qualitative data collection is well underway in Montreal. The survey is in progress in Vancouver and will start in Toronto after REB approval. The vignettes were developed by a CHILD-BRIGHT summer student, finalized and awaiting REB amendment with anticipated start Jan 2019.

The questions and surveys will be shared in the poster.

Poster Board #4

Poster Title: Parent Integrated Evidence -based Practice to Improve Quality ("Parent-EPIQ") : Aim-2 Implement Parent-EPIQ

Author(s) A Synnes, TM Luu, CNFUN Steering committee members, K Aziz, R Grunau

Institution/Affiliation(s) British Columbia's Women's Hospital, Hôpital Ste Justine, Royal Alexandra Hospital, Canadian Premature Baby Foundation

Funding Source(s) CHILD-BRIGHT Network / SPOR/ local resources

Abstract

AIM 2 Implement Parent-EPIQ: *To use the quality improvement and knowledge translation strategy "Parent Evidence based Practice to Improve Quality (EPIQ)" to improve cognitive and language abilities in a preterm population at 11 intervention sites.*

Background: Cognitive and language impairments occur in more than one third of very preterm children in Canada. Cognitive and language development are influenced by maternal education and sociodemographic factors. Active synaptogenesis and preterm brain maturation in the first two years of life lead to infant brain plasticity and provide opportunities to positively influence cognitive and language outcomes. Systematic reviews show effectiveness with early developmental interventions for cognition and language. Parent-infant interactions show the most promise. Our hypothesis is that feasible sustainable evidence based locally targeted interventions will improve language and/or cognitive outcomes.

Procedure: A newly developed online EPIQ teaching tool with teleconference and coach support was used to teach teams at 9 sites (2 more in progress). At participating sites, a multidisciplinary neonatal follow-up team, with parent representation, will do 4-6 rounds of the EPIQ process over 2 years. They will use the 10 EPIQ worksheets to identify an outcome to target, an aim statement, develop a plan and complete an audit. The coordinating site supports teams with monthly teleconferences during the EPIQ training period and bimonthly during the intervention period. Teleconferences provide resources, evidence and a rapid fertilization of knowledge translation ideas. Nonintervention sites are controls.

Data Analysis: The hypothesis is that 75% percent of EPIQ cycles will meet their target and the successful interventions will be described. CNFUN data from 11 participating and 15 non-participating sites will be used for regression analyses to compare Bayley-III cognitive and language composite scores at 18 months CA pre- and post-Parent-EPIQ intervention after adjusting for known confounding variables.

Results: All sites have a Parent-EPIQ team, 9 have completed EPIQ training and have completed one or more EPIQ cycles. All have targeted improving language. Libraries are a great resource! There is lots of enthusiasm. Interventions to date will be described.

Poster Title: Stimulation for Perinatal Stroke to Optimize Recovery Trajectories: The SPORT trial

Author(s) Kirton A, Fehlings D, Metzler M, Zewdie E, Carlson H, Dlamini N, O'Grady K, Larson J, Hodge J, Fay L, Kang M, Warner D, Robertson A, Yaskina M, Andersen J

Institution/Affiliation(s) Alberta Children's Hospital, University of Calgary; Glenrose Rehabilitation Hospital, University of Alberta; Holland Bloorview and SickKids, University of Toronto

Funding Source(s)

Abstract

Rationale: Perinatal stroke causes hemiparetic cerebral palsy and lifelong disability for thousands of Canadian children. Intensive motor learning therapies can improve function but efficacy is limited. Non-invasive brain stimulation may enhance such training but has not been proven. We aimed to determine if brain stimulation is associated with larger functional gains in children with perinatal stroke undergoing intensive rehabilitation while exploring how the brain changes during such interventions.

Methods: SPORT is a phase 3, randomized, double blind, sham-controlled clinical trial. Eighty children (8-18 years) with MRI-confirmed perinatal stroke and hemiparesis will be recruited from 3 sites (Calgary, Edmonton, Toronto). At baseline, all receive measurements of motor function, psychosocial development and the brain (robotics, motor maps, imaging). After setting their own goals, participants enter a 2-week, full day, peer-supported, intensive motor learning camp, randomized to receive daily neurostimulation (tDCS) or sham during therapy. All measures are repeated 1 week, 2 months, and 6 months.

Results: Thirty-four children have participated across 4 camps: (median age 11.60 +/- 2.36 years, 46% female, baseline logit-based AHA unit 56.3+/-15.0). A predefined interim safety analysis found no serious adverse events, favorable tolerability, and no decrease in function of either limb. Advanced outcomes including actigraphy, MRI, TMS motor mapping, and KINARM robotics have been successfully obtained. Feedback from campers and parents has been consistently positive. Challenges have included contracts and distributing funds across the Network.

Summary: Child-centered intensive rehabilitation camps combined with trials of neurostimulation are safe, feasible, and engaging for families. The SPORT trial may ultimately determine the place of tDCS in motor rehabilitation of children with hemiparetic cerebral palsy.

Poster Title: Parent Integrated Evidence -based Practice to Improve Quality ("Parent-EPIQ") : Aim 3 Outcome Evaluation

Author(s) A Synnes, P Shah, CNFUN Steering committee

Institution/Affiliation(s) British Columbia's Women's Hospital, Mount Sinai Hospital

Funding Source(s)

Abstract

AIM 3: *Evaluate whether Canadian Neonatal Follow-Up Network (CNFUN) measured outcomes across Canada are improving using annual benchmarked reports for Parent-EPIQ intervention and non-intervention sites.*

Background: The CNFUN database showed, in children born 2009-2011 at < 29 weeks' gestation, that 46 % of children born preterm have a neurodevelopmental impairment (NDI) and almost 15% a significant NDI (sNDI) at 18- 21 months corrected age. In Aim 2, we are using a novel approach (Parent-EPIQ) to improve language and cognitive outcomes in 11 of the 26 CNFUN sites. We can only improve what we can measure! In this project we are creating an annual report to track site specific and overall NDI, sNDI and their components cognitive, language, motor, cerebral palsy, hearing and visual impairment.

Methods: All sites uploaded NDI data to the CNFUN database for births 2009-2011 maintained at the Maternal Infant Care (MiCare) coordinating site at Mount Sinai Hospital as part of the CIHR Team in the MiCare study. Ongoing unfunded CNFUN data collection continued where possible. In this first CNFUN annual report, CNFUN participating sites are described, survival and follow-up rates calculated and rates of NDI, sNDI and individual components presented by gestational age, trends over time (birth cohort 2009-2015), crude and risk factor adjusted rates by site. These results will comprise our baseline pre-intervention results.

Data Analysis: Descriptive results will be presented as proportions and medians in figures. Standardized ratios, adjusted for gestation, sex, outborn, severity of illness, bronchopulmonary dysplasia, necrotizing enterocolitis and brain injury, will be displayed using funnel plots for site comparisons.

Results: Of 10,718 NICU admissions < 29 weeks gestation, 8,604 (80.3%) survived, outcome described in 6,463 and CNFUN with neonatal data for 4779. Outcomes improve with increasing gestation (sNDI 22 wks- 67% 28 wks-10%). From 2009-2015 hearing ('09-3.2% to'15-1.1%) and vision ('09-1.9% to'15-0 cases) have improved. Bayley-III cognitive, language and motor outcomes are unchanged. Definitive CP has decreased from 7.2% in '09 to 5.6% in'15. Overall sNDI is unchanged from 15.4% to 15.3%. Two sites have significantly better and one site worse adjusted standardized ratios of the 15 sites with adequate sample size.

Poster Title: IMAGINE Study Update: Genetic Testing in Children with Atypical Cerebral Palsy

Author(s) Colleen Guimond, Madeline Couse, Elisa Lau, Patricia H Birch, Nicole SY Liang, Dr. Anna M Lehman, Dr. Clara van Karnebeek, Dr. Jan M Friedman

Institution/Affiliation(s) University of British Columbia

Funding Source(s) CHILD-BRIGHT Network, SPOR

Abstract

Background: Brain injuries in early life are commonly thought to be the cause of cerebral palsy (CP), but in some children cerebral palsy-like conditions are caused by metabolic or other genetic abnormalities. Advances in genomics and metabolomics now allow us to diagnose genetic causes of CP in children in whom the clinical picture is not typical of an early brain injury. Doing so may enable us to devise more personalized treatments that improve the outcomes for affected families.

Study Design: British Columbian children who meet criteria for a diagnosis of atypical cerebral palsy are invited to participate. Most participants are referred from their health care providers who have been made aware of the study. Children with atypical CP and their parents provide biological samples (such as blood and urine) for whole genome sequencing and analysis, and metabolomic testing, to identify underlying genetic conditions that provide an explanation for their symptoms.

Results: To date, 54 families have been enrolled in this study, and whole genome sequencing has been completed and analyzed for 30 of these families. Ten (33.3%) families have had uninformative preliminary genomic results which have been relayed directly to the families by study personnel. Twenty families (66%) have had preliminary genomic results that suggest a cause or partial cause for the child's clinical findings. In total, 17 families have been informed of a genetic diagnosis to date.

Conclusions: This is a progress update for the IMAGINE study which is well underway towards the goal of recruiting and testing 100 families. Parent participants have been invaluable in driving family-oriented research models and guiding the way in which these families are contacted, consented, and kept abreast of their progress in this study. To this end, an electronic Patient-Oriented Progress Update (POP-Up) has been developed and implemented. Identifying underlying genetic and metabolic causes of disease in children with atypical CP is expected to alter the approach to clinical management of children with CP in the future. The IMAGINE study has provided at least a partial explanation for the cause of symptoms in the children of more than half of our participating families.

Poster Title: Participants as Partners in Research: Communicating a timeline to research participants for results with a "fuzzy ending"

Author(s) N.S.Y. Liang[1] , E. Lau[1] , B.C. Lenahan[2], I. Jordan[2], K. Ohs[2], J.M. Friedman[1], P.H. Birch[1]

Institution/Affiliation(s) [1] University of British Columbia, Vancouver, Canada; [2] Parent Partner, Vancouver, Canada

Funding Source(s)

Abstract

Background: The IMAGINE project uses whole genome sequencing and metabolomics to identify genetic causes of atypical cerebral palsy in affected children. Results take 6 months, during which time there is little contact with participating families. During this period, parents speak of powerlessness, anxiety, disengagement from the research, and concern that they may have been forgotten: *"There's nothing like the black hole of healthcare-waiting we spend our life in."*

Objectives: We aimed to engage parents in research by providing family-friendly, automated, informative study updates. Also, we wanted to introduce the concept of a "fuzzy ending" to represent the lack of firm diagnostic time point due to on-going analyses and increasing scientific knowledge. This is an important and foreign concept for families participating in genomics research.

Methods: We co-developed POP-Up, an e-timeline to visualize progress through the study. Families receive a status update, with optional pop-up text explanations. The timeline is modified through participant feedback.

Preliminary Results: We evaluated the POP-Up Timeline through a 10 question survey, alongside user data. 100% of families Agreed or Strongly Agreed that there was open communication about their study progress. Our focus on using layperson terms and descriptive graphics was also reflected by the 88% of families who felt like they had a clear understanding of their family's progress in the study. The timeline is also incorporated as an educational tool during pre-test genetic counselling to describe the study process.

Project Status: This is a participant-initiated and orientated sub-project within the IMAGINe Project in which families are given the option to receive automated study updates. To date, there are currently 22 families that are using the timeline tool, with this number expected to grow as the IMAGINe Project recruits more families.

Conclusions: The use of an automated visual timeline can facilitate communications between researchers and families, and keep families engaged during research studies. The inclusion of participants as partners allowed us to address unmet need and foster trusting relationships for the best research outcomes.

Poster Title: The Indigenous Neonatal Abstinence Syndrome (INAS) Project: Coming Together to Understand Neonatal Abstinence Syndrome and Support the Well-Being of Opioid-Exposed Children

Author(s) Kerpan, Serene; Guttmann, Astrid; Johnson, Brenda; Mazzucco, Aggie; McNaughton, Wendy; Naponse-Corbiere, Pam; Poulette, Christi-Ann, Sault; Kim, Walker, Jennifer

Institution/Affiliation(s) University of Ontario Institute of Technology, IC/ES, Laurentian University, The Southern Ontario Community Wellness Development

Funding Source(s) CHILD-BRIGHT Network

Abstract

Prenatal opioid exposure has risen substantially over the past two decades and can have lasting health impacts for infants and children, including potential long-term neurodevelopmental impairments. Neonatal abstinence syndrome is a withdrawal syndrome observed in the babies of mothers who are either using opioids or being treated for opioid dependence. There was a 15-fold increase in the incidence rate of neonatal abstinence syndrome from 1992-2011 in Ontario.

Our project team was formed in 2017 in response to First Nations concerns about the impact of prenatal opioid exposure on the health of children in their communities. Our team includes Indigenous and non-Indigenous health care providers, leaders, and researchers. The project goals are to: a) build strong relationships with First Nation communities; and b) gather and share community- and culturally-specific information about prenatal opioid exposure.

A participatory action research approach enables us to incorporate community engagement principles and conduct research that is reflective and flexible. Through community-based facilitated information and planning sessions, and individual community engagement, we have learned about the needs and desired processes of communities pertaining to this project.

Using mixed-methods, this project will provide communities with incidence rates and trends for prenatal opioid exposure and neonatal abstinence syndrome that are community specific. This project will also work with communities to gather meaningful qualitative data through focus groups and individual interviews. The questions that frame the qualitative research are: 1) What is the impact of prenatal opioid ex-posure on First Nation communities? 2) What strengths can be built on and what strategies could help address prenatal opioid exposure? 3) What strengths can be built on, and what strategies could help maximize the potential of children who have neurodevelopmental impairments due to prenatal opioid exposure?

To date, seven First Nation communities have opted to participate in this project. This presentation (poster) will focus on our process of collaboration, our engagement strategies, how we value and integrate Indigenous and Western knowledge, how the principles of OCAP® (First Nations ownership, control, access, and possession of data) are embedded in our project, future plans for data collection and knowledge mobilization, along with lessons learned.

Poster Title: Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairments

Author(s) Sharan Sahota[1], Hal Siden[1,2], Tim Oberlander[1,2], Tammie Dewan[1,3], Vithya Gnanakumar[3], Julia Orkin[4], Christina Vadeboncoeur[5], Bruce Carleton[1,2], Liisa Holsti[1,2], Eyal Cohen[4], Dean Elbe[1], Julie Hauer[6], Maria Marano[4], Adam Rapoport[4], Marli Robertson[3], Scott Schwantes[7], Joel Singer[1], Jen Stinson[4]

Institution/Affiliation(s) [1]University of British Columbia, [2]BC Children's Hospital, [3]Alberta Children's Hospital, [4]Hospital for Sick Children, [5]Children's Hospital of Eastern Ontario, [6]Harvard Medical School, [7]University of Minnesota

Funding Source(s) CHILD-BRIGHT Network

Abstract

Background: Many infants, children and youth with rare diseases and complex conditions affecting the central nervous system often experience pain and irritability. Sometimes the pain is due to medical procedures such as scoliosis repairs, or due to chronic conditions such as muscle spasms. There are, however, many times when it is difficult to find a source as these children often have severe language delays. Pain specialists may call this Pain & Irritability of Unknown Origin (PIUO).

Clinicians often do not agree on the best approach for determining the cause of this pain. The lack of a common treatment pathway results in inefficient and inconsistent care. In addition, a child is cared for by up to 10 specialist teams and communication among clinicians can make treating pain difficult.

Objective: To develop a pathway for uncovering and treating pain of unknown origin. Our goal is to improve treatment for children with complex conditions and PIUO, and to streamline their care.

Methods: Children between the ages 0-19 who have a central nervous system condition with impaired communication and pain or irritability of an unknown source will be enrolled at 4 different hospitals across Canada. Children who follow the treatment pathway will be compared with children who receive the current standard care. Each participant will be in the study for approximately 6 months.

Preliminary Results: Early recruitment is underway at 2 of the 4 sites and no data is available for analysis. Health services research projects with an Randomized Controlled Trial design can pose significant challenges and yet provide the best evidence level for these interventions.

Conclusion: If the pathway proves to be helpful in testing and treating pain & irritability, we will create guidelines and conduct workshops to inform clinicians, disease advocacy groups, and families about the best approach to assess and treat PIUO.

Poster Title: Strongest Families™: Engagement Experiences of Parent Involvement in Modifying an Online Parenting Program for Children with Neurodisabilities

Author(s) Lach, Lucyna; McGrath, Patrick; Aston, Megan; Thomson, Donna; Turner, Karen; Vanderlee, Emma

Institution/Affiliation(s) IWK Health Centre, McGill University

Funding Source(s) CHIR (SPOR); IWK Health Centre

Abstract

Mental health disorders occur more often in children with neurodisabilities (ND) than in their peers, with only a small percentage receiving mental health care. Parent-focused programs designed for typically developing children show mixed results for children with ND conditions and parents report significant barriers to accessing services. In this project, researchers partnered with parents to adapt an existing online parenting program to the needs of families of children across neurodisabilities and to ensure that the program and subsequent study were relevant. Parents provided researchers with unique insights into the expectations and priorities of families who face difficulties managing challenging behaviours in their children with ND. The purpose of this poster is to describe parent involvement in this project, progress to date and future goals.

A committee of fifteen parents, recruited from across Canada, were actively involved in the development of all aspects of the online parenting program and offered substantial guidance on study outcomes and measure selection. One parent, experienced in patient-engagement research, was recruited to fulfill a more intensive role as a parent representative at weekly research team meetings. We used online surveys, online and face-to-face meetings, a closed Facebook group, and email to facilitate communication. An iterative cycle of program modifications took place over several months between the parents, researchers and Strongest Families to ensure that parents' feedback was incorporated while maintaining fidelity to the original program.

A qualitative study was conducted to examine the experiences of the parent advisors and the researchers working on the project. Our research found that feeling valued, creating personal connections, being respectful and offering support were key to positively engaging parent advisors. Personal, authentic, in-person interactions between researchers and parent advisors can help facilitate successful research relationships.

Program modifications are nearing completion and an Ethics Board has reviewed the protocol for a Randomized Trial. As we begin recruitment for the trial, we will continue to strengthen relationships, support parents as "Ambassadors" and work to broaden our Integrated Knowledge Translation through our project newsletter, social media, conferences and events.

Poster Board #12

Poster Title: Bringing understanding of sex and gender into health research, practice and policy

Author(s) Nancy Poole, PhD

Institution/Affiliation(s) Centre of Excellence for Women's Health

Funding Source(s) Health Canada, Public Health Agency of Canada, CIHR and many other funding sources are supportive of sex and gender based analysis and equity issues (SGBA+)

Abstract

This poster is intended to be conversation starter on key concepts related to sex and gender. Sex/gender informed practices have been in place or in emerging in Canada for several years, and in some cases mandated by policy or funding criteria. It is important for researchers and research collaborators to understand how to bring these concepts into the studies they are undertaking.

Objectives:

1. To describe and illustrate key concepts of sex and gender and how they are relevant to research on child and parent health, as well as health service and health policy improvement.
2. To convey basic principles of gender informed and gender transformative practice and to invite critical thinking on the benefits and challenges in applying these approaches in varied research, practice and policy contexts.

Discussion:

Nancy is the gender champion with the CHILD-BRIGHT team and a leading Canadian advocate for applying sex and gender concepts in health research. She has published over 125 reports, book chapters and academic journal articles on gender and equity related issues and 5 books with Dr Lorraine Greaves including one published in 2017 entitled Gender Unchained: Notes from the Equity Frontier. Dedicated to motivating, connecting and creating new ways of learning and doing, Nancy is a maven of ideas and a respectful educator, who enjoys engaging in conversations with all those interested in sex and gender issues.

Poster Title: Jooay App: 'Connecting the Dots' between Children with Disabilities and Leisure

Author(s) Keiko Shikako-Thomas[1], Annette Majnemer[1],Nicholas Katalifos[2], Joanne Charron[2], Helene Louise[2], Stephanie Glegg[3],Robert Simpson[4], Emma Steven[4], Melanie Bergthorson[4], Michelle McClure[5],Janet McCabe[6], Marla Cable[7]

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Funding Source(s) CIHR Strategy for Patient-Oriented Research, CHILD-BRIGHT Network, Operation Enfant Soleil, The Montreal Children's Hospital Foundation, Kids Brain Health Network

Abstract

'Jooay' is an interactive application for mobile devices that uses geo-location to allow parents of children with disabilities, educators and rehabilitation specialists to find out about nearby arts programs, social recreation, sports, day camps, respite homes and support groups. Originally launched in 2015, a revamped version of the app was released in September of this year. The App features almost 2000 adapted and integrated leisure activities across all ten provinces, and continues to update these activities.

Our research aims at promoting participation in leisure activities for children with disabilities, an important part of living a full and healthy life. We also want to use the information gathered from the app to promote evidence-based policy-making across Canada. Our plan is to address the information gap that exists between programs that currently exist in the community and the potential users of these recreational programs. They also aim to highlight community program gaps to decision-makers who could create programs and policies that better meet these children's needs.

In mapping activities with Jooay, the researchers can pinpoint where activities are not available, information that can guide service creation and resource allocation by municipal governments and policymakers. These gaps in activity offerings often overlap with deprivation areas, clusters of social and material inequality as measured by the Canadian deprivation index. In other words, areas lacking adequate leisure programs also suffer from a lack of other resources. In such an area, a single-parent household, for example, could already be struggling for time and in need of after-school activities for their child with a disability, but be unable to locate any.

Meanwhile, where policies already exist, the data gathered from Jooay can facilitate knowledge exchange among those who can facilitate changes, creating awareness about disabilities, and disseminating information among key stakeholders.

In short, since its inception more than three years ago, Jooay has been connecting the dots between policymakers, researchers, parents, community leaders, school boards, and NGOs, working together to get children with disabilities where they should be: at play.

In this poster presentation we share our engagement strategies, the challenges to date and our plans for the future.

Poster Title: The effectiveness of a video-game based cognitive intervention (Mega Team) for children with neurodevelopmental conditions: updates on game-development, study design and progress

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Funding Source(s) CHILD-BRIGHT Network

Abstract

Emotional and behavioural regulation difficulties are one of the most troubling and treatment-resistant aspects of many neurodevelopmental conditions. Executive func-tion deficits are believed to underlie these difficulties. Children with executive func-tion deficits find it difficult to regulate their emotions (anxiety or anger) or to control their behaviours. We developed a video game-based intervention program, Mega Team that targets executive function deficits in children with neurodevelopmental disorders. The pilot was conducted in a small group of children with ADHD yielding promising results. The current poster will summarize and describe the progress our team has made in developing the video-game based cognitive rehabilitation pro-gram and studying its effectiveness since our initial pilot study.

The feedback we received from our patients and families was used to create addi-tional versions of the game. The new games are available on a tablet and are de-signed to be more engaging and appealing to older children. Using the new version of the video game, we have designed and initiated a large-scale study that deter-mines its effectiveness in improving the executive function deficits. We have includ-ed three different populations: children with ADHD, autism, and congenital heart-disease. The study design and rationale for selecting these specific populations will be discussed. We will also describe how the outcome of this intervention program will be measured and the difficulties associated with assessing outcome in game-based cognitive interventions. To determine if the intervention is successful, we are looking at children's performance on executive function tasks, academic tasks that resemble everyday classroom activities, and their everyday functioning. As our study is conducted in three separate stages, we continue to seek feedback from our partic-ipating families, as well as evaluate our progress to be able to make the necessary adjustments following the completion of each stage.

Poster Board #15

Poster Title: Coached, Coordinated, Enhanced Neonatal Transition (CCENT): A multi-centre mixed-methods pragmatic randomized controlled trial

Author(s) Julia Orkin[1,2,3], Nathalie Major[4], Paige Church[5], Arpita Parmar[2], Kayla Esser[2], Doug Miller[2], Kate Robson[5], Andrew Willian[2], Marilyn Ballantyne[6], Lesley Barreira[5], Tammie Dewan[7], Anne Synnes[7], Hema Patel[8], Elise Couture[8], Karel O'Brien[9], Linh Ly[10], Theirry Daboval[4], and Eyal Cohen[1,2,3]

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Funding Source(s) CIHR, CHILD-BRIGHT Network

Abstract

Background: Medical advances have led to increases in survivors of neonatal intensive care units (NICU) including those born with extreme prematurity, congenital heart disease or other genetic conditions. Improved survival for vulnerable infants requires an extended and intensive NICU stay. Parents experiencing long-term NICU stay have increased anxiety, depression and even post-traumatic stress, which interferes with attachment to their infant. Parental wellbeing mediates attachment, parental capacity, and long-term neurodevelopmental outcomes for the infant. Additionally, these vulnerable neonates and their families experience ongoing challenges while transitioning from the hospital to home as parental, psychosocial and care-coordination support is limited after NICU discharge.

We propose that a **C**oached, **C**oordinated, **E**nhanced **N**eonatal **T**ransition (CCENT) model will facilitate successful transition home from the NICU and improved outcomes throughout the first year of life should involve. The CCENT model provides a nurse navigator to work with families and provide support in the following ways: 1) parental coaching and support within Acceptance and Commitment Training (ACT) framework, 2) care coordination 3) anticipatory guidance and education from resources designed in partnership with a parent-advisory committee.

ACT is a recently established framework, which incorporates mindfulness-based techniques to increase psychological flexibility and reduce suffering. Although novel in the NICU setting, ACT has been shown to be effective with parents of children with autism and chronic pain.

Objectives:

1. To compare the effect of the CCENT model on parental stress (primary outcome) at 12 months with that of standard neonatal care/follow-up.
2. To compare the effect of the CCENT model with that of standard neonatal care/follow-up on the following secondary outcomes: parent and infant interaction, parental empowerment, parental mental health and emotional wellbeing, family experience with the health care and service delivery systems, and infant development at 18 months.
3. To explore health utilization patterns, out-of-pocket cost and work force opportunity costs in relation to the CCENT model and its association with maternal mental health, stress and empowerment.

Study Population & Design: High-risk neonates identified from level III NICUs in 4 cities (Montreal, Vancouver, Ottawa, and Toronto). This is a parallel group randomized-controlled trial with a 1:1 allocation ratio to the CCENT model vs. standard neonatal care/follow-up.

Acknowledgment and thanks to Rosana Manarin, Eleanor Warren, Chantal Horth, Rebecca Grimwood and the CCENT Family Advisory Committee

Poster Board #16

Poster Title: BRIGHT Coaching: a developmental coach system to empower families of preschoolers with suspected developmental delays

Author(s) **Investigators (*PIs):** Ballantyne M, Cohen E, Collet JP, Dewan T, Elsabbagh M, Grant P, Hanlon-Dearman A, Filliter F, Lach L, McElroy T, McGrath P, McKellin P, Miller A, Patel H, Rempel G, Shevell M, Wittmeier K, Majnemer A*; O'Donnell M*;
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Coaches (*Lead coach): Baker A, Brown A*, Haley A, Mounsey A, Szulzinger T;
Trainee: Ogourtsova T.

Institution/Affiliation(s) Montreal Children's Hospital-MUHC Research Institute, McGill University; Child Health BC; Children's Hospital Research Institute of Manitoba; Halifax IWK Health Center

Funding Source(s) CIHR Strategy for Patient-Oriented Research (SPOR) Networks in Chronic Disease

Abstract

In parents of children with suspected developmental delay, the *BRIGHT Coaching* randomized clinical trial aims to determine the extent to which a 12-month health coaching intervention (manualized, self-management online education and support) vs. usual care is feasible and effective in improving parent empowerment and other parent-related outcomes and cost-effectiveness. The BRIGHT Coaching trial is currently in its pilot phase as of August 2018. We have four fast-tracked (n=4) pilot participants recruited, three (n=3) new pilot participants and four operational sites. The coaches (n=4) are trained by the lead coach in delivering the inter-vention. They are being evaluated by the lead coach through the pilot phase on their treatment delivery fidelity via standardized measures developed by our team.

Recruitment is one of the challenges that we are experiencing. We are working with clinical intake teams referring eligible and interested participants to us who are on their waiting list to access developmental services. We are now looking to expand our strategies to include social media advertisements and a website blog. As such, we aim to increase the visibility of our pro-ject and to attract participants. Those adjustments are presently undergoing REB review. Moreover, we are reaching out to additional clinical teams to include more sites, in order to in-crease target numbers.

The patient-partners engaged in the *BRIGHT Coaching* trial have been invaluable in guiding patient-oriented developments related to the trial: pilot phase outcome measurements, coach-ing intervention content development, online platform selection and usability, recruitment strat-egies, and refinement of the parent manual. We continually engage our patient-partners through meetings and email communications, and keep them updated on the progress of the study.

In terms of the knowledge translation products, we conducted a national webinar hosted by the CAPHC on the subject of health coaching in childhood disability. We also produced two publi-cations: (1) a commentary outlining the terms related to coaching (status: POTP, accepted); (2) a systematic review on health coaching for parents of children with developmental disabili-ties (status: DMCN, in review). The latter was also presented recently at the AACPDM Annual Meeting in the form of a poster.

Poster Title: Meaningful Involvement of Patient and Family Partners in Phase 1 of the READYorNot™ Transition to Adulthood Project

Author(s) J.W. Gorter[1], D. Thomson[2], K. Amaria[3], R. Rozenblum[4], S. Strohm[1], L. Nguyen[1], B. Galuppi[1], A. Kovacs[5], S. Doucet[6], A. Via-Dufresne Ley[7] & A. Marelli[7] for the READYorNot™ Project Team

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Funding Source(s) Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR), CHILD-BRIGHT Network, Hamilton Health Sciences, McGill University Health Centre Foundation, McMaster Children's Hospital Foundation, McMaster University, New Brunswick Health Research Foundation, The Montreal Children's Hospital Foundation

Abstract

Recently there has been an exciting shift in the way health research is being conducted, with patients and their families involved in the process as much and as meaningfully as possible. Patient-oriented research refers to a continuum of research that engages patients as partners, focuses on their priorities and ultimately improves the value of research. Under this model, patients and families with lived experiences, healthcare professionals, and researchers work together as partners. The entire research team collaborates to design and conduct the research, and disseminate its findings. Most importantly, what patients and families contribute is the sharing of their values and priorities. Their contributions ensure that the research conducted is meaningful and impactful.

In the READYorNot™ project, a collaborative team of healthcare professionals, technology designers, youth, and families, have worked together to create the MyREADY Transition App. The App is designed for youth between 15 and 17 years old with Autism Spectrum Disorder, Cerebral Palsy, Epilepsy, Fetal Alcohol Spectrum Disorder, or Spina Bifida. The App is designed to help them begin to take charge of managing their health as they prepare for the move to adult health care. In the App, a virtual mentor guides users on their journey through a city landscape; By watching videos and completing challenges, youth learn and practice managing medical information and other skills to get ready for adult healthcare.

The purpose of our poster is to highlight the meaningful involvement of the Patient & Family Advisory Council (PFAC) throughout Phase 1 of the READYorNot™ project, by:

1. Giving examples and generating discussion about the types of contributions patient and family partners can make to the research process;
2. Emphasizing the importance of evaluation in patient-oriented research; and
3. Sharing the lessons we have learned about patient and family partnership in working together so far.

We recognize and believe that good partnerships with patients and their families evolve when their perspectives are integrated into every step of the research process. We hope that this poster will be relevant to those wishing to learn more about strategies for meaningful patient and family engagement in research.in research.

Poster Title: Sharing Experiences with Agile Software Development Methodology in the READYorNot™ e-Health Intervention for Brain-Based Disabilities

Author(s) R. Rozenblum[1], K. Amaria[2], J.W. Gorter[3], A. Kovacs[4], A. Via-Dufresne Ley[5], S. Strohm[3], B. Galuppi[3], L. Nguyen[3] & A. Marelli[5,6] for the READYorNot™ Project Team

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Funding Source(s) CIHR SPOR with partner support from Montreal Children's Hospital Foundation, McMaster University Faculty of Health Sciences, Hamilton Health Sciences, McMaster Children's Hospital Foundation, and New Brunswick Health Research Foundation

Abstract

Introduction: There is a growing need for health interventions that bridge care between pediatric and adult providers by providing a Health Information Technology (HIT) solution.

Progress Update: In the READYorNot™ project, a multidisciplinary collaboration was formed— combining thought leadership in clinical psychology, translational medicine in congenital heart disease and brain-based disability, as well as patient and family insights— to design, develop, and clinically validate the MyREADY Transition e-Health intervention for Brain-Based Disabilities. The intervention is designed to educate and empower youth as they prepare for transition from pediatric to adult care. To ensure that the e-health intervention is attuned to all stakeholders' needs and particularly the needs of youth; it is essential to incorporate the patients', families', health care providers' and researchers feedback throughout the HIT development process. This process includes the creation and validation of the HIT components such as the interface design, the content of the mobile and desktop applications and their features. Agile software development methods offer developers the flexibility to adapt to changing user requirements and to facilitate user acceptance and project success. Regular Patient and Family Advisory Council (PFAC) meetings, focus groups, and interviews have been useful to identify important technology accommodations and knowledge gaps. Participatory design sessions and formative user testing engaged participants in technology design, user interface optimization, and feature integration. The MyREADY Transition e-Health intervention is currently undergoing final iterations of internal and summative usability testing for quality assurance and assessment of user experience before we begin the randomized control trial in 2019. The READYorNot™ e-Health for Brain-Based Disabilities intervention team will share experiences and lessons learned with Agile software development methodology and stakeholder engagement.

Poster Board #19

Poster Title: Disability Data Project: Navigating Disability Supports and Services Across Canada

Author(s) Brittany Finlay, Stephanie Dunn, Jennifer Zwicker

Institution/Affiliation(s) University of Calgary School of Public Policy

Funding Source(s) University of Calgary School of Public Policy

Abstract

Background: Effective and accessible disability supports and services are essential to achieving Canada's commitment to the UN Convention on Rights for Persons with Disabilities (Convention). Limited data on the fragmented patchwork of disability supports and services in Canada makes it difficult to understand, let alone evaluate existing supports. In line with this, the Convention Committee noted that Canada "does not have up-to-date quantitative and qualitative data on the situation of persons with disabilities". This creates difficulties in understanding the extent to which provinces are meeting the needs of persons with disabilities and how Canada is meeting its Convention commitments.

Aim: The aim of this project is to describe how federal and provincial governments support persons with disabilities by creating a database of supports and services delivered by each of the Canadian provinces.

Methods: Data on total direct government expenditure on supports and services, individual benefit design and caseload information over the past two decades was collected from public accounts, annual reports and through government collaborations. Our analysis uses a mixed approach. Time series analyses of quantitative data shows key changes to these programs across time and provinces. Qualitative document analysis of government publications identifies context for these changes.

Results: Preliminary results from our database indicate that total public expenditure on disability as a share of GDP has remained relatively consistent across provinces over the past decade at approximately one percent. This places Canada on the lower end of disability expenditure among other OECD countries. Different provinces utilize different policy instruments to support persons with disabilities. The majority of disability expenditure is on disability services in British Columbia and Manitoba, whereas the remaining provinces spend more on disability social assistance.

Future Directions: We will use our analyses to discuss the extent to which provinces are meeting Convention obligations, and by extension the needs of persons with disabilities, and where resources should be dedicated to better meet obligations. Collaboration with stakeholders to develop timely research questions based on the developed database is a key objective to improve disability data in Canada to better monitor and evaluate services for Canadians with disability.

Poster Title: Enabling Visions and Growing Expectations (ENVISAGE): An international parent-researcher partnership to support best starts for parents of children with disabilities

Author(s) Rachel Martens, Andrea Cross, Kinga Pozniak, Peter Rosenbaum

Institution/Affiliation(s) CanChild, McMaster University

Funding Source(s) American Academy for Cerebral Palsy and Developmental Medicine (2017); CIHR (2018)

Abstract

The tides are changing and a new wave of conducting children's health research is here. Moving beyond traditional approaches in which researchers were solely responsible for conducting and delivering research, we now recognize the importance of researcher-stakeholder partnerships. ENVISAGE is a five-week online workshop series offered to parents raising a child with a neurodevelopmental disability (NDD). The premise of the program is that 21st century concepts provide a strengths-based approach to child and family development in the context of parenting a child with a disability. The workshops focus on five themes: 1) New ideas about health: WHO's ICF Framework & the F-Words in Childhood Disability; 2) Child, sibling, and family development; 3) Parenting; 4) Taking care of oneself; 5) Connecting, communicating, and collaborating. ENVISAGE is an international integrated research project involving clinician-scientists and parents from Canada and Australia. All workshops have been developed with parent input and co-led by both parents and researchers. The program will be carefully researched to assess its value to parents before being manualized and promoted internationally.

Through this poster, we will outline the integrated research process, proposed structure and content of the research program, and our main lessons learned thus far working together as an integrated research team.

Poster Title: Building capacity for families as partners in research: A Family Engagement in Research Certificate Program

Author(s) Andrea Cross*, Donna Thomson*, Connie Putterman*, Dayle McCauley, Patty Solomon, Jan Willem Gorter
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Funding Source(s) Kids Brain Health Network

Abstract

Introduction: Despite the value of family engagement in research (FER), adoption among the research community has been limited by lack of clarity on how to do so effectively. Recognizing the need for training, Kids Brain Health Network recently launched a "Family Engagement in Research Certificate Program" in partnership with McMaster University. This course is unique in that it brings parents of children with neurodevelopmental disabilities together with graduate student research trainees to gain knowledge and understanding of FER, and build a cohort of future enlightened and engaged partners.

Methods: The certificate program is a 10-week online course, which involves synchronous and asynchronous discussions, review of written materials and case studies, as well as collaborative group exercises. The course was co-designed and now being delivered by both experienced parents and researchers. The process of developing the course, as well as feedback from course participants to date will be presented. Using a before-after follow-up study design, we are conducting a pilot evaluation to explore the feasibility of the program, and the impact of the program on participants' knowledge, attitudes, and self-confidence in FER.

Results: The first cohort of 18 students is in progress, with a second cohort planned for Winter 2019. There is a currently a waiting list for the course. Data collection is in progress.

Conclusion: Families and trainees have expressed the need for training in family engagement. By bringing families and trainees together we hope to learn from each other and enhance the way FER is implemented ensuring both quality and good governance.

Poster Title: Guideline Development for Rehabilitation in Arthrogryposis: Collaboration with youth, parents, and clinicians

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Funding Source(s)

Abstract

Arthrogryposis is a term used to define congenital joint contractures in two or more different areas of the body and occurs in 1 in 3000 live births. Contractures can lead to decreased range of motion and strength, and may affect ambulation and autonomy.
Early intensive occupational and physical therapy (OT/PT) is essential to promote independence in mobility and daily life activities, and to improve function. Since arthrogryposis is a rare condition, OT/PT in community settings may feel unprepared and uninformed when providing care. There are currently no practice guidelines for rehabilitation for this population.

Objective: To develop practice guidelines for rehabilitation in collaboration with youth living with arthrogryposis, parents, and OT/PT.

Methods: The development of rehabilitation guidelines involves six phases: Identification of rehabilitation needs; Literature review; Expert opinion; Integration of evidence and expert consensus; Knowledge Translation; and Implementation and evaluation. Rehabilitation priorities for the guidelines were identified through individual interviews, focus groups and a semi-structured questionnaire. These priorities are:

1. Daily activities
2. Muscle and joint function
3. Mobility
4. Pain management
5. Participation.

The rehabilitation guidelines will be shared using various tools (e.g., infographic, annotated flowchart, manual) which will be comprehensive, clear, and easy for OT/PT to use. The development of the rehabilitation guidelines for arthrogryposis was conducted with input from youth, parents and OT/PT.

Practice Implications: Family-centered rehabilitation guidelines will promote evidence-based, coordinated services, and improve the rehabilitation care provided to children with this rare condition. These guidelines will inform OT/PT, and prepare youth and families for their rehabilitation journey.

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