Attendees are encouraged to ask questions!

To ask a question use the chat feature or unmute your mic during the designated Q&A period

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Session #5

Maggie Chan
Hannah Chang
Mahnoor Faisal
Rita Jin
Caroline Ruus
Simran Gill

Chen Yu (Daisy) Sun
Erica Zeng
Serena Zhang
Athena Li
Maggie Chan
Undergraduate Student, University of British Columbia

Supervisor: Danielle Decker

The Patient Facing Roadmap as a Tool for Overcoming Language Barriers in New Cancer Diagnosis Education

Abstract & Poster - https://bcchr.ca/posterd
The Patient Facing Roadmap as a Tool for Overcoming Language Barriers in New Cancer Diagnosis Education

Maggie Chan, BSc.

Introduction
The experience of receiving a new cancer diagnosis is stressful for patients and their families, but language barriers present an additional challenge for families with limited English proficiency or who speak English as a second language (ESL) (1). Currently, the Oncology/Hematology/Bone Marrow Transplant (BMT) unit at BC Children’s Hospital (BCCH) has some measures to assist ESL families, such as interpreter services and some translated education materials.

Project Objective
Find additional resources that would be useful to further support ESL families.

Methods

Literature Review
A review of the current literature was performed for new cancer diagnosis education in pediatric patients with ESL families. Searches were performed on PubMed and Google Scholar.

Creation of the Patient Facing Roadmap
The roadmap was created from information about the typical stay of a patient with a new cancer diagnosis at BCCH. The roadmap will allow families to evaluate their learning progress and ask for clarification when needed, as it breaks down the pathway into steps that are easier to follow.

Feedback from Families
Feedback was collected from several families staying on the Oncology/Hematology/BMT unit to see if they would be interested in having the roadmap as a resource, and if they thought any sub-topics were missing.

Results
The literature review showed that language barriers can be difficult to navigate and may contribute to knowledge gaps and a lack of trust between the family and their healthcare team (2). The literature supported the use of multiple methods of education that are simple and culturally appropriate (Fig. 1). The patient facing roadmap was created with this in mind. Feedback from several families was positive, and led to the final version of the roadmap (Fig. 2).

Figure 1. Methods of Education as suggested by current literature.

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Figure 2. The Patient Facing Roadmap

Conclusion
While the patient facing roadmap cannot solve all of the problems surrounding language barriers in new cancer diagnosis education, it can be a valuable tool to help patients and their families better understand their hospital stay and may alleviate some stress.

Once the roadmap is made an official resource for the families on the unit, more work can be done to assess its efficacy and implement changes to further improve the resource. Further steps need to be taken to develop resources that address family needs along the roadmap.

References

Acknowledgements
Thank you to everyone who contributed to this work, including the staff and families of the Oncology/Hematology/BMT unit at BC Children’s Hospital and the INSPIRE Program. Special thanks to Danielle Decker, Lisa Jacques, and Monica Anand for their involvement in this project.
Hannah Chang
Undergraduate Student, University of Toronto

Supervisor: Mor Cohen-Eilig

The role of intersectionality in identity formation of young adults with ASD

Abstract & Poster - https://bcchr.ca/posterday
The role of intersectionality in identity formation of young adults with Autism Spectrum Disorder

Hannah Chang; Mayer Yael, PhD; Cohen-Eilig Mor, MD

Background & Rationale
- Despite increase in autism spectrum disorder (ASD) prevalence, identity development of autistic individuals remains unclear
  - Identity is closely linked to mental health
  - Problematic autism masking
- Gender dysphoria (GD) often comorbid with ASD
  - Intersectionality of gender role stress and ASD stigma creates unique implications that has yet been studied
- External social-cultural factors may affect the development of both ASD and gender identities

Methodology

Participants: 20-30 young-adults (age 18-35) with ASD.

Stage 1: Quantitative Measures
An Online Questionnaire
1. Autism, Gender Identity, Culture variables:
   - The Autism Spectrum Quotient
   - The Camouflaging Autistic Traits Questionnaire
   - Demographics
2. Mediator:
   - The Gender role stress scale
   - The minority stress scales adapted for autism
   - The Multidimensional Scale of Perceived Social Support
3. Mental Health Outcome:
   - The DASS-21 scale
   - The Satisfaction with Life Scale (SWLS)

Stage 2: Qualitative Measures
A Semi-structured interview

- Diagnosis disclosure
- Sense of belonging
- Gender and ASD identity development
- Ego-network map
  - Social relationships

Anticipated Results & Conclusion
- Lower identification with stereotypical gender roles + higher masking
  - Lead to higher gender role and minority stress
  - Detrimental to mental health (higher depression, stress, anxiety, and lower life satisfaction)
- Social support will act as buffer for mental health
- Implications:
  - Create meaningful interventions to support healthy identity development

Study Purpose
- To investigate how -
  - ASD diagnostic pathway
  - ASD and gender identity development intersectionality
  - Socio-cultural factors
- May impact -
  - Identity formation
  - Mental health
  - Functionality of autistic individuals

(Example of Ego-network; Mayer et al., 2022)
Mahnoor Faisal
Undergraduate Student, University of British Columbia

Supervisor: Hal Siden

Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairment

Abstract & Poster - https://bcchr.ca/posterday
Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairment (PIOU)

Presenter: Mahnoor Faisal
PI: Hal Siden
Co-PI: Tim Oberlander


INTRODUCTION

Children with severe neurological impairment (SNI) are typically non-verbal, non-mobile, and cognitively impaired. Often, these children experience pain-like sensations called Pain and Irritability of an Unknown Origin (PIOU) on a daily basis. PIOU can be particularly difficult to treat. Children with SNI exhibit ambiguous pain signals, and physicians have no standardized method for investigating PIOU. These children are amongst the most vulnerable seen in any hospital or clinic, underscoring the importance of this research.

OBJECTIVE

Our goal is to improve the assessment and treatment of pain and irritability in children with complex health conditions such as limited communication and cognition. These patients are not able to tell their caregivers where it hurts yet exhibit different kinds of pain behaviours. This study puts participants through a clinical pathway, which is a series of assessments and tests that may help locate the source of pain.

METHODS

- Eligibility: children aged 6 months to 18 years with SNI and have PIOU
- Waitlist-controlled RCT design with children randomized to the PIOU Pathway or Waitlist (standard care) treatment groups

THE PIOU PATHWAY

1. History and Physical Exam
   - Screening tests:
     - Urinalysis
     - Ultrasound - abdominal
     - Gastric pH (if G-tube present)
     - Bloodwork

2. Pharmacology

3. -30% of pain is resolved or identified!

Of the participants who completed Phase I, 19.4% had their pain resolved and 9.7% had their pain identified.

If a participant scores in the lowest pain categories for two consecutive visits or their pain is identified, the PIOU pathway is deemed a success. Families benefit from the PIOU pathway as well as the relationships they build with our team.

PHASE II

In Phase II, our objective is to implement the PIOU pathway in community settings using implementation science principles. We will:

- Produce a guideline for pediatricians that can be implemented across British Columbia.
- Investigate the clinical outcomes for patients and families with the pathway in community settings.
- Examine if the nurse’s role is key to pain resolution even in the absence of identification.
Rita Jin
Undergraduate Student, University of British Columbia

Supervisor: Todd S. Woodward

Characterization of a Novel Task-Based fMRI Functional Brain Network: Auditory

Abstract & Poster - https://bcchr.ca/posterday
Caroline Ruus
Undergraduate Student, University of British Columbia

Supervisor: Rebecca Deyell

Whole Abdominal Radiotherapy in Children and Adults with Sarcoma: A CanSaRCC Study

Abstract & Poster - https://bcchr.ca/posterday
**Whole Abdominal Radiotherapy in Children and Adults with Sarcoma: A CanSaRCC Study**

Caroline Ruus(1), Sylvia Cheng(2), Hagit Peretz Soroka(3), Abha Gupta(3), Derek Tsang(4), Rebecca J Deyell(2)

(1)University of British Columbia, Vancouver, BC, Canada; (2)Division of Hematology/Oncology/BMT, BC Children’s Hospital, Vancouver, BC, Canada; (3)Medical Oncology, Princess Margaret Cancer Centre, The Hospital for Sick Children, Toronto, Ontario, Canada; (4)Department of Radiation Oncology, University Health Network, Toronto, Ontario, Canada

---

**Background**

- The Canadian Sarcoma Research and Clinical Collaboration (CanSaRCC) is a national registry and virtual biobank
  - Facilitates research to improve outcomes of sarcoma patients
- Sarcoma is an aggressive form of cancer that arises in bones and soft tissues in children, adolescents and young adults (AYA), and can present within the abdominal cavity
- Pediatric and AYA abdominal sarcomas rarely have peritoneal dissemination and/or malignant ascites
- Radiotherapy often has a role in local control in this location of disease
- *Whole abdominal radiotherapy (WART)* is recommended, however, there is limited data regarding toxicity or evidence of efficacy

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**Objective**

- To describe the indications for WART in pediatric and AYA sarcoma patients
- To evaluate the time to treatment failure (i.e. recurrence within the WART field), progression-free survival, and overall survival in pediatric and AYA sarcoma patients treated with WART

---

**Methods**

- Sarcoma patients aged 0-39 years at diagnosis who received WART between January 1, 2000-May 1, 2023 will be identified from CanSaRCC nationally
- Data collection includes patient demographics, clinicopathologic factors including histology, age, extent of disease and therapy, radiation planning and therapy techniques, toxicities and survival outcomes
- Estimated sample size is 40 patients across Canada
- Descriptive statistics will be used to summarize the treatments received
- Kaplan-Meier method will be used to analyze time to treatment failure and survival outcomes

---

**Study Progress**

- A total of 45 patients at BC Children’s Hospital have been enrolled in CanSaRCC
- 5/45 patients received WART for the diagnosis of rhabdomyosarcoma or desmoplastic small round cell tumor
- In collaboration with pediatric and adult cancer sites nationally, we are undertaking work to systematically identify, collect data and analyze outcomes of these patients

---

**Conclusion**

We anticipate study results to describe indications, tolerability and efficacy of WART for young patients with abdominal dissemination of sarcoma in Canada.

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**Acknowledgements**

This study is supported by the Canadian Sarcoma Research and Clinical Collaboration and lead by UHN. A CanSaRCC Summer Studentship was awarded for data entry.

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**References**


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**Confidential**

**Figure 1:** Sagittal view of abdominal cavity

**Figure 2:** Example PET scan of patient with indications for WART

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**Fig. 2:** Patient diagnosed with diffuse peritoneal embryonal rhabdomyosarcoma. Extensive ascites seen in abdomen and pelvis. Subsequently received WART.
Simran Gill
Master’s Student, University of British Columbia

Supervisor: Christine Voss

Physical activity behaviours and determinants thereof in children with type 1 diabetes in the Interior of BC: a mixed methods feasibility study

Abstract & Poster - https://bcchr.ca/posterday
Physical activity behaviours and determinants thereof in children with type 1 diabetes in the Interior of BC: a mixed methods feasibility study

Simran Gill1,6, Ty Sideroff2,6, Trent Smith3, Tricia S Tang4, Christine Voss5,6

1Faculty of Medicine, Women+ And Children’s Health Sciences, UBC, Vancouver, BC; 2School of Health and Exercise Science, UBCO, Kelowna, BC; 3Interior Health, Kamloops, BC; 4Division of Endocrinology, Department of Medicine, UBC, Vancouver, BC; 5Department of Pediatrics, Faculty of Medicine, UBC, Vancouver, BC; 6Centre for Chronic Disease Prevention and Management, UBC, Kelowna, BC

Background

More than 2500 children in B.C. live with Type 1 Diabetes.1

- With no known cure, management of type 1 diabetes (T1D) requires extensive lifestyle education, lifelong insulin therapy and frequent monitoring of blood glucose levels.2
- Individuals with T1D are at a higher risk of developing cardiovascular disease. Regular physical activity is encouraged as it is related to better glycemic control.3
- Children with T1D may be significantly less physically active compared to their peers due to fears such as being unable to control blood glucose levels.3

Aims

Aim 1: Describe objectively-measured (moderate to vigorous) physical activity (MVPA) levels of children with type 1 diabetes (T1D) aged 8-15yrs in the BC Interior

Aim 2: Explore patient- and parent/legal guardian)-reported barriers, facilitators and experiences related to their physical activity

Methods

Study Design: sequential mixed methods

Sample: 15 parent-child dyads

Figure 1. Study Participants per Local Health Area

![Map of study participants per local health area](image1.png)

This map was created in ArcMap (VII, Esri Inc., Redlands, CA).

Figure 1 illustrates the geographical distribution of participants per local health area (LHA). Interior Health Pediatric Diabetes Education Centers (DEC) have also been noted.

Figure 2. Physical Activity Data from Accelerometer

![Graph showing physical activity data](image2.png)

Figure 2. Physical Activity Data from Accelerometer

- N = 1 (15-year-old male)
- An accelerometer (ActiGraph GT3X) was worn around the waist for 7 consecutive days in September 2022. Conventional wear time validation4 (≥3 days of ≥600 min wear) and intensity cut-points5 were applied using ActiLife software. Note the significant contribution of school travel (8:00 and 15:00) to daily physical activity.

Figure 3. Moderate-to-Vigorous Physical Activity per Day

![Graph showing moderate-to-vigorous physical activity per day](image3.png)

Figure 3. Moderate-to-Vigorous Physical Activity per Day

- N = 15 participants
- Figure 3 illustrates the distribution of participants’ average daily moderate-to-vigorous physical activity

Figure 4. Weekday vs Weekend Moderate-to-Vigorous Physical Activity

![Graph showing weekday vs weekend moderate-to-vigorous physical activity](image4.png)

Figure 4. Weekday vs Weekend Moderate-to-Vigorous Physical Activity

- N = 15 participants
- Children were more active during weekdays (47.1±26.8 mins/day) compared to weekends (29.7±26.4 mins/day) p=0.002.

Quotes from interviews:

- “I always look at how much insulin I have in me at the time, because I want to plan it out. There is a possibility my blood sugar might go low, and I’ll have to address that.”
- “There have been times that I’ve had to take breaks to stop and let my levels kind of catch back up.”

Conclusions

- The findings suggest that children with T1D in BC’s Interior are comparatively active to their peers despite barriers to PA such as hypoglycemia.
- Findings from this work may inform future work to optimize education and counselling of this important health behaviour in individuals with T1D.

Acknowledgements

This project was supported by the Centre for Chronic Disease and Management Clinical Research, QI Incubator Initiative, UBC Pritchard Graduate Fellowship, and the BC Children’s Hospital Research Institute Master’s Studentship

References

Chen Yu (Daisy) Sun
Undergraduate Student, McMaster University

Supervisor: Tamara Cohen

Comparing health outcomes of children and adolescents with obesity who attend an in-person vs. virtual multidisciplinary family-based behavioural lifestyle intervention

Abstract & Poster - https://bcchr.ca/posterday
Comparing health outcomes of children and adolescents with obesity who attend an in-person versus virtual multidisciplinary family-based behavioural lifestyle intervention

Chen Yu Sun¹; Madelaine Gierc, PhD²; Tamara R Cohen, PhD, RD³
¹Health Sciences, McMaster University ²BC Children’s Hospital Research Institute ³Food and Land System, University of British Columbia

BACKGROUND

- In Canada, 1 in 7 individuals between the ages 2 and 17 live with obesity (defined as BMI greater than the 85th percentile for one's age and sex).²
- Existing literature suggests that children with obesity are at a higher risk of developing chronic conditions, which can persist into adulthood and contribute to obesity in later life.²,³

SHAPEDOWN BC

- Clinics in BC (5): Fraser Health (2), Interior Health (1), Vancouver Coastal Health (2), Punjabi Program, Chinese Program

OBJECTIVE

- To compare the health outcomes of children and adolescents who participated in the virtual Shapedown program to pre-COVID in-person delivery.

METHOD

- **Shapedown BC** Program is a provincially funded 10-week family-based behavioural lifestyle intervention.
  - **In-Person or Virtual**
    - **Weekly educational, interactive sessions**
      - Topics: nutrition, physical activity, screen time, sleep, body image, self-esteem, family meals, and healthy family communication
  - **Intake/Baseline**
    - Anthropometric (body weight, height); Surveys (diet quality, social and demographic factors)
  - **Post-Intervention**
    - Anthropometric (body weight, height); Surveys (diet quality, social and demographic factors)

- **Study design**: Retrospective chart review of children ages six to 17 years old (n=80).
- **Matching**: Participants from the virtual intervention will be matched with those from the in-person intervention based on age, sex, BMI-z, and enrollment season at baseline.

RESULTS

- Data is currently being retrieved from the database, to be matched and analyzed accordingly.

REFERENCES

1. Shapedown BC [Internet]. Available from: http://www.bccchildrens.ca/our-services/clinics/shapedown-bc
Erica Zeng
Undergraduate Student, University of Western Ontario

Supervisor: Todd Woodward

(Profileling the fMRI derived Language-Based Network for pre- and post-surgical monitoring)

Abstract & Poster - https://bcchr.ca/posterday
In neurosurgery, pre- and post-surgical monitoring is crucial in ensuring optimal conservation and recovery of cognitive function. A key focus during this process is on the Broca’s and Wernicke’s area (BWA) as impairment of these areas can negatively impact linguistic function and quality of life[1]. Task-based fMRI has detected a left-lateralized network that simultaneously engages BWA. This study will assess this network’s activation over a range of cognitive fMRI tasks in order to establish a baseline hemodynamic response (HDR) profile of this network.

Previous works extracted functional brain networks using constrained principal component analysis for fMRI (fMRI-CPCA). Corresponding estimated HDR plots were examined to interpret the role of the Language Based network in each task. A repeated measures ANOVA analysis was used to identify significant interactions and main effects.

**RESULTS**

**Lexical Decision Task**
- 59 healthy participants completed the Lexical Decision Task, where they had to decide whether each four-letter sequence represented a real English word or not.
- Word and non-word stimuli were shown at two levels of difficulty (Easy vs. Hard) resulting in four task conditions.

**Syllable Stress Task**
- Participants (n=32 healthy controls) were shown 48 two-syllable Dutch words. There were a total of 2 conditions.
- In the phonological condition, participants had to choose where the syllable stress was located.
- In the semantic condition, participants evaluated whether the word presented was positive or negative.

**Facial Emotion Discrimination Task**
- 21 healthy participants evaluated whether a presented face reflected a particular target emotion or age.
- Significant main effect of image type (p < .001).
- Significant main effect of discrimination condition (p < .001).

**Semantic Association Task**
- Participants (n=32 healthy participants) were shown three match options for a prompt word and were asked to select the match option that most closely relates to the prompt word.

**CONCLUSION**

Activation of this network during the linguistic and emotion recognition tasks suggests that this network’s function lies in the extraction of linguistic- and emotion-based meaning. The derived task-specific HDR profiles will serve as a baseline against which a patient’s HDR profile can be compared to. This comparison will allow for the monitoring of linguistic changes in patients pre- and post-operation.

**REFERENCES**
Serena Zhang
Undergraduate Student, University of British Columbia

Supervisor: Kevin C. Harris

READYorNot™ Feasibility Trial: Assessing the Efficacy of an App-Based Transition Intervention in Adolescents with Congenital Heart Disease

Abstract & Poster - https://bcchr.ca/posterday
READYorNot™ Feasibility Trial: Assessing the Efficacy of an App-Based Transition Intervention in Adolescents with Congenital Heart Disease

Serena Zhang¹, Bianca Fukakusa¹, Najah Adreak¹, Simran Gill¹, Venessa Thorsen¹, Kevin C. Harris¹
¹Children’s Heart Centre, BC Children’s Hospital; Department of Pediatrics, University of British Columbia

BACKGROUND

Many adolescents with congenital heart disease (CHD) face challenges continuing regular cardiology follow-up into adulthood¹-³.

E-Health transitions in care (TiC) interventions have the potential to offer cost-effective, accessible, and long-term support for young adults.

METHODS

INTERVENTION TIMELINE

Baseline Assessments:
- Transition Readiness Assessment Questionnaire (TRAQ)
- MyHeart Scale
- General Self-Efficacy (GSE) Score

Intervention
Randomization to app or nurse group
App group: 30 minute session with nurse + access to the app for 18 months
Nurse group: 1 hour TiC intervention with nurse

1 Month Post-Enrolment
Repeated measures: TRAQ, MyHeart Scale, GSE

Optional Qualitative Interview (3-6 months)

6 Months Post-Enrolment
Repeated measures

12 Months Post-Enrolment
Repeated measures

18 Months Post-Enrolment
Repeated measures

OBJECTIVE

To compare the efficacy of the MyREADY Transition™ CHD app with a 1-on-1 nurse-led TiC intervention in improving self-management skills.

EXPECTED OUTCOMES

Primary outcomes
The app group participants will see greater improvement in self-management skills over 18 months compared to the nurse-led intervention, as measured using the TRAQ.

Secondary outcomes
The app will result in:
1. Superior CHD knowledge
2. Superior self-efficacy
3. Shorter time to first Adult CHD (ACHD) clinic appointment
4. A valuable and engaging experience
5. Cost savings relative to the nurse-led intervention

ACKNOWLEDGEMENTS

I would like to acknowledge the study participants and their families, as well as the staff of the Children’s Heart Centre for their support and contributions to this project.

REFERENCES


METHODS

Inclusion criteria
- 16-17 years old
- Have moderate to complex CHD
- Patients at outpatient cardiology clinics at one of four hospitals across Canada

serena.zhang@bcchr.ca
Athena Li
Undergraduate Student, University of British Columbia

Supervisor: Vilte Barakauskas

Review of Quality Indicators in Pediatric Lab and Future Steps Towards Better Pediatric Care

Abstract & Poster - https://bcchr.ca/posterday
ABSTRACT

To objectively measure and manage lab quality, labs need to define their service goals and objectives. Clinical quantitative quality requirements in the form of quality indicators (QI) are then established to meet set goals. Starting from 2008, the International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) established the Working Group on “Laboratory Errors and Patient Safety” (WG-LEPS project) to define specifications for QI’s across labs independent from the size of organization and type of activities, the complexity of processes undertaken and the different degrees of knowledge and ability of the staff. The final goal is to establish a Model of Quality Indicators (MQI) that can provide labs with a way to monitor processes, improve performance and decrease error rates. However, established MQIs so far do not generally differentiate between adult or pediatric labs. This review seeks to explore and search through any existing literature on QI’s in pediatric labs and other quality assessment methods in pediatric healthcare. Search parameters will focus on the Quality Indicators consisting of the 10 key core lab indicators recommended by the Laboratory Medicine and Pathobiology (LMP) Quality Council and population set to neonates (0-28 days), infants (<28 days to 1 year) and pediatrics. Then a general search for quality assessment in pediatric healthcare will be conducted to gather information about this gap in knowledge of lab QI’s in pediatrics.

OBJECTIVES

1. Are there any literature on quality indicators or quality assessment for pediatrics lab?

2. How should we go about developing more specific quality indicators and assessment for pediatric labs?

METHODOLOGY

# Query Results from 24 Jul 2023

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RESULTS

33 articles selected for further review

Out of 33 articles distribution of countries is as follows: US (13), EU (7), China (6), UK (2), Korea (1), Peru (1), India (1), Australia (1), International (1)

RECOMMENDATIONS

- 3 out of the 33 articles will be read in full
- Two articles found about quality assessment in pediatric care in general
- Both quantitative and qualitative quality indicators should be considered especially in a pediatric setting
- Quality management of specific areas should be placed more into focus with pediatric care in mind (ex. Focus on point of care/take home kits quality assessment and quality indicators)

ACKNOWLEDGEMENTS

Thank you to Dr. Vilte Barakauskas for supervising this review.