



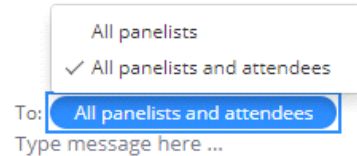
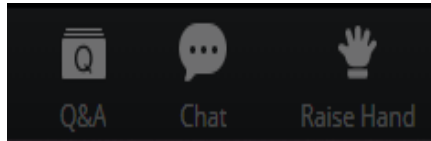
The Paradox of Protective Isolation: A Call for Trauma-Informed Care Practices to Address Treatment Experiences of Children and Youth

Dr. Jami-Leigh Sawyer

Ethics Fellow, Hamilton Health Sciences
Program for Ethics and Care Ecologies

Webinar Housekeeping

- ? Everyone will be muted except the host and moderator
- ? Ask questions through the Zoom chat box



- ? This webinar will be recorded and posted on the HHS HUB page and the Regional Ethics Network website (regionalethicsnetwork.com)
- ? An email will be sent by Sue Pantitis once the recorded has been uploaded.





We are privileged to provide care on lands that Indigenous peoples have called home for thousands of years.



Acknowledgements

▶ Co-authorship:

- Sawyer, J-L., Mishna, F., Zlotnik-Shaul, R., Bouffet, E., & Saini, M.

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Thank you to the participants of this study, without which this research would not have been possible. Thank you for sharing your time and your story, during a very vulnerable time.

Objectives

1. Explore the intersection between bioethics and trauma-informed care
2. Highlight the ethical imperative of giving voice to patients
3. Discuss the value of policies and practices to better inform and address patient treatment experiences



Introduction

Background & Rationale

Knowledge Gap:

- ▶ Very little attention has been paid to the experience of isolation from the voices of children and youth directly.

Practice Gap:

- ▶ There is a need to better understand the impact of hospital isolation and its required separation from peers during this critical developmental period to inform strategies during and post-treatment.





"NOTHING
ABOUT ME
WITHOUT ME."

Methods

Methodology: Recruitment & Sample

- ▶ Scientific Review Board and Research Ethics Board approvals were obtained from SickKids Hospital and The University of Toronto.
- ▶ Using a database maintained by the Neuro-oncology program, 30 possible participants were identified and sent recruitment packages. Of those 30:
 - 8 agreed to participate
 - 12 were never reached or had outdated contact information
 - 4 had either relapsed or died
 - Parents of 6 potential participants declined citing reasons such as “trying to live a normal life now and not wanting to go back there”, wanting to forget”, and “too much school work”



Methodology: Inclusion Criteria

1. Diagnosis of medulloblastoma;
2. Between the ages of 7-18 at the time treatment began
3. Attending/attended a regular classroom; and
4. Informed consent.



Methodology: Study Design

Interpretive Phenomenological Analysis (IPA):

- ▶ A qualitative research approach committed to the examination of how people make sense of their major life experiences
- ▶ It exposes taken for granted assumptions about knowing by reflecting on the significance of “an experience”



Methodology: Data Collection

- Individual interviews were conducted either by telephone or in-person
- Semi-structured interview guide was used
- Interviews were audio-recorded and transcribed verbatim
- Second interviews were conducted with all participants
- Patient chart review conducted

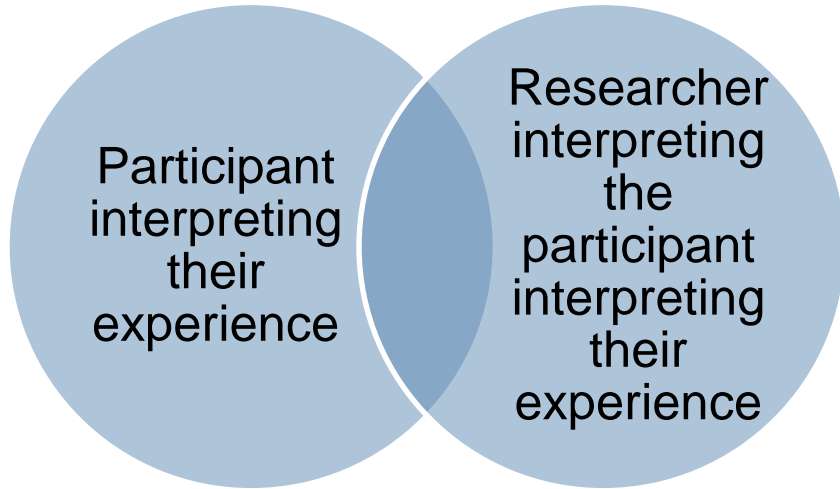


Participant Demographics

Pseudonym	Identified Gender	Age at Diagnosis	Age at Interview
Hannah	Female	7	12
Aaron	Male	14	22
Caiden	Male	9	10
Bennett	Male	7	12
Samuel	Male	14	16
Matthew	Male	7	12
Aasia	Female	8	12
Tyler	Male	10	17



Methodology: Data Analysis



- ▶ Smith, Flowers, & Larkin's (2009) approach to IPA
- ▶ Authenticity of Findings:
 - Supervision
 - Collaboration
 - Reflexivity
 - Dependability
 - Confirmability
 - Audit trail
 - Prolonged engagement



Results

Findings

1. The paradox of protective isolation,
2. Numbing the pain, and
3. Treatment by hospital staff.



1. The Paradox of Protective Isolation

“I just felt so separate from everyone. We might have been two feet away from each other (his parents), but I wasn’t really with them...they couldn’t even touch me. I couldn’t feel their comfort”

(Samuel)



2. Numbing the Pain

*“I felt like a robot, going through the motions but not really feeling anything”
(Aaron)*



3. Treatment by Hospital Staff

“The nurses were an extended part of my family because I was there for months. It was a good relationship...they went above and beyond...they would stay with me and talk and just keep me company...I just felt very at home”

(Tyler)



Discussion

Discussion



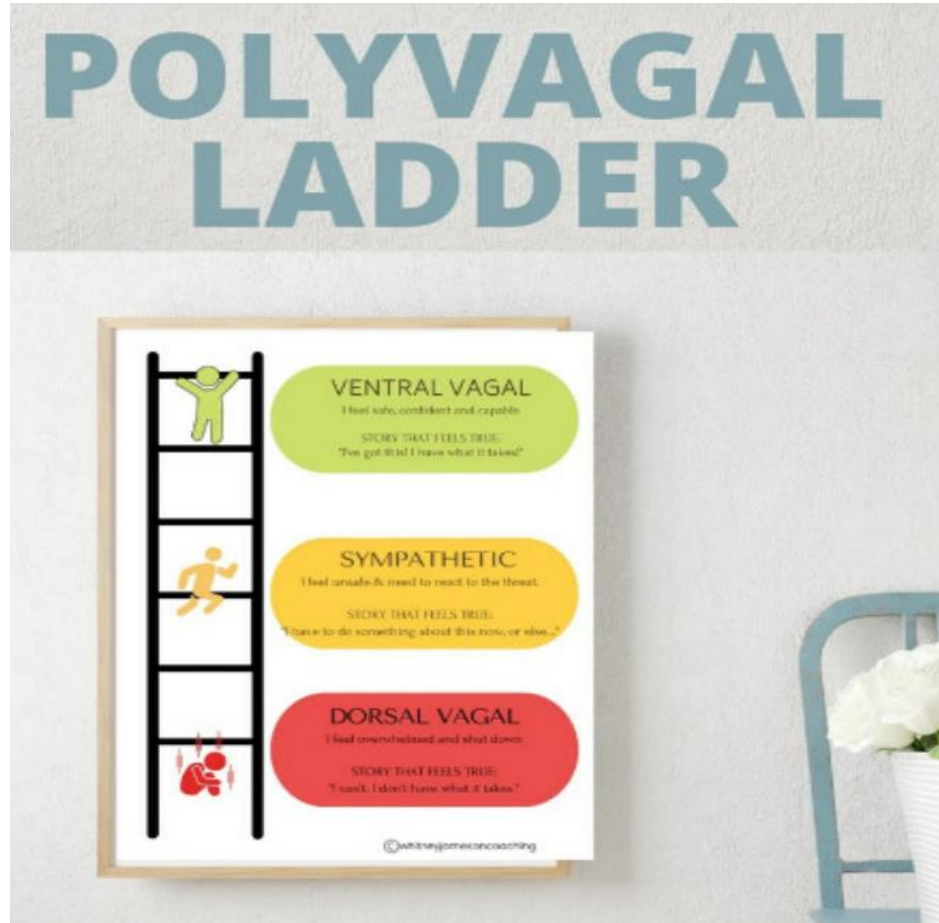
- ▶ Principle: Family Centered Care



Discussion

➤ Principles:

- Informed Consent
- Therapeutic Relationship



Overall Implications



- ▶ Self-reflection
- ▶ Learning opportunities to better understand trauma-informed care practices and application to practice
- ▶ Policy considerations
- ▶ Promote beneficence, reduce harm
- ▶ Equity considerations



Limitations

- ▶ Small sample size
- ▶ Relied on the children and youth's retrospective accounts of their treatment experience
- ▶ Although not intended to explore a trauma-informed framework, it emerged that such a framework would have proved valuable



Future Considerations



Thank You!



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