

Adapting the Empirical Model of Compassion for Pediatric-to-Adult Healthcare Transitions

Persephone MacKinlay^{1,2}, Arella Chan^{1,3}, Dorothy Luong¹, Alene Toulany⁴, Robert Simpson⁵, Sarah Munce¹

1. Bloorview Research Institute; 2. McMaster University; 3. University of Toronto; 4. The Hospital for Sick Children (SickKids); 5. University Health Network

Background

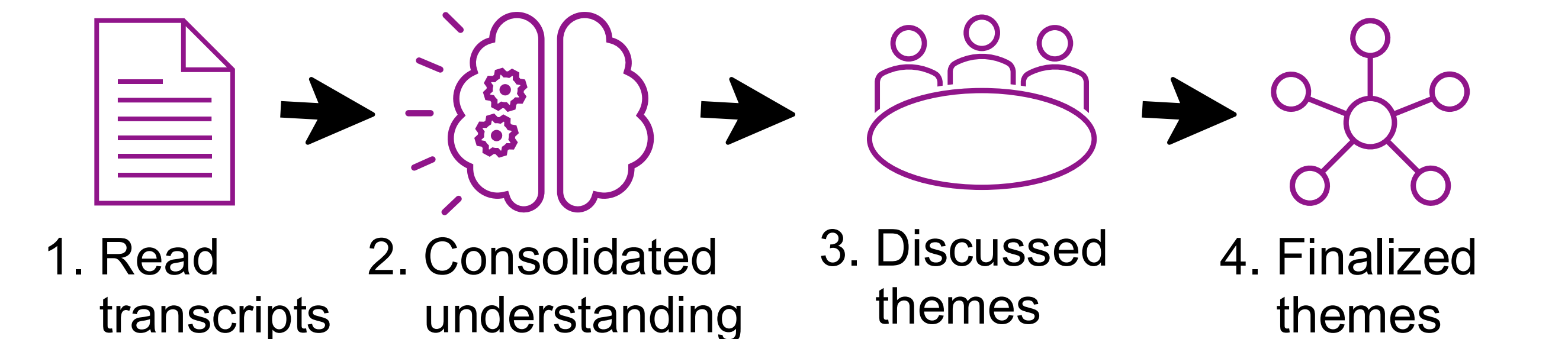
- Sinclair et al. created **first model** of compassionate healthcare from patient perspective.¹
 - Context of palliative **cancer** care.
- Healthcare transitions characterized by **fragmentation, confusion**, and **emotional burden**.²
- Transitions improved by **continuity, communication**, and **coordination**: key aspects of compassionate pediatric care.³

Research Question

What is the relevance of the first model of compassion in the context of pediatric-to-adult healthcare transitions from the perspectives of youth and their caregivers?

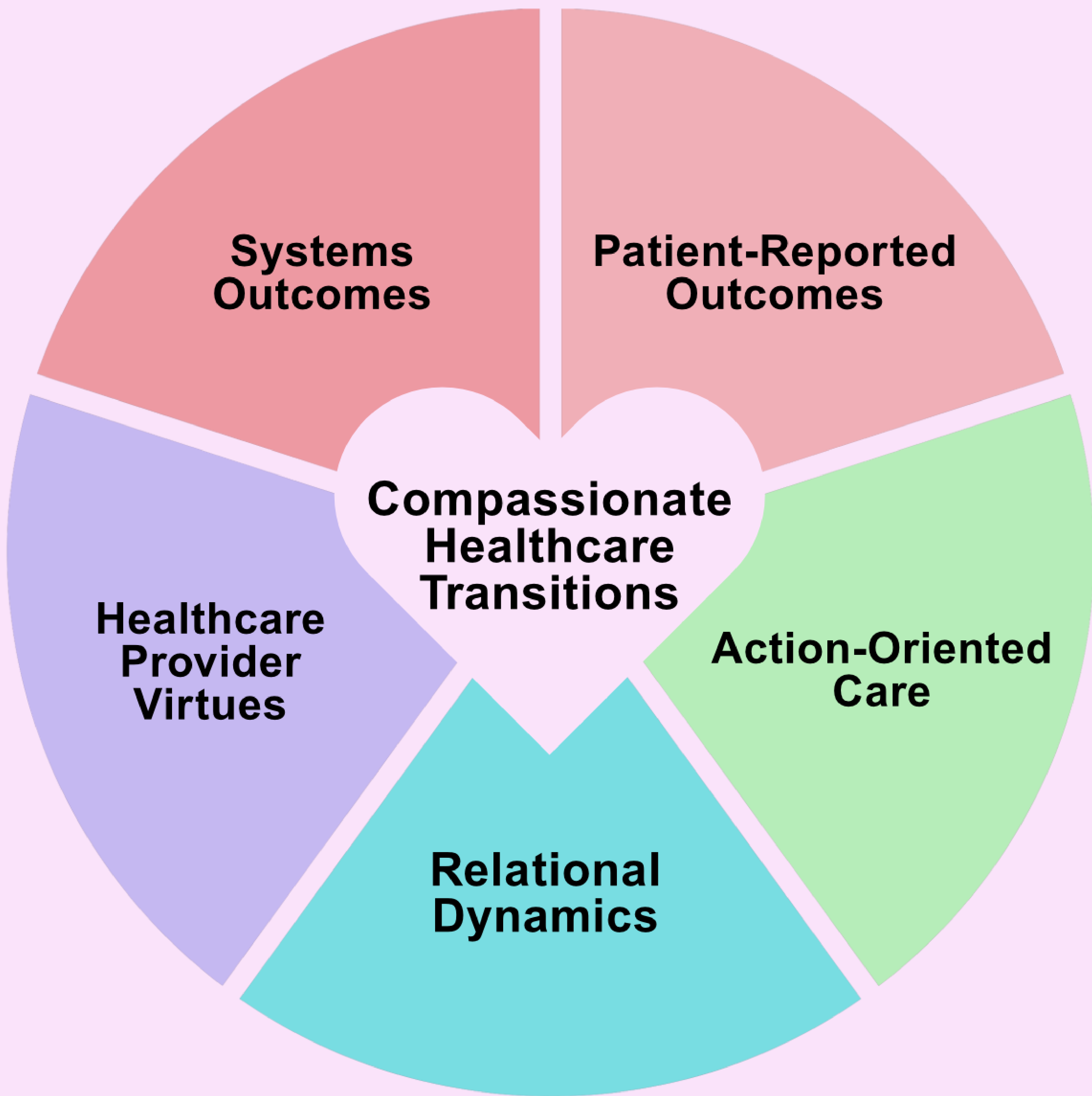
Methods & Analyses

- Secondary analysis** of interviews:
- **12 youth** aged 18 - 30 and **5 caregivers**
 - Asked to define compassionate care and its facilitators
- Followed Braun & Clarke’s **reflexive thematic analysis**:
- Coded **inductively** using Sinclair et al.’s model
 - Coded **deductively** to reflect context of transitions



| Sinclair et al.’s Model: | | | |
|--------------------------|--------------------|---------------------------|--|
| Domains | Themes | Domains | Themes |
| Virtues | Genuineness | Seeking to Understand | Seeking to Understand the person |
| | Love | | Seeking to Understand the Person’s Needs |
| | Openness | Relational Communicating | Demeanor |
| | Honest | | Affect |
| | Authenticity | | Behaviours |
| | Care | | Engagement |
| | Understanding | Attending to Needs | Compassion Related Needs |
| | Tolerance | | Timely |
| | Kindness | | Action |
| Relational Space | Acceptance | Patient Reported Outcomes | Alleviates Suffering |
| | Patient Awareness | | Enhances Wellbeing |
| | Engaged Caregiving | | Enhances Care |
| Virtuous Response | Knowing the Person | | |
| | Person as Priority | | |
| | Beneficence | | |

New model of compassionate healthcare for youth to adult transitions emphasizes flexibility and systemic factors.



Results

| Adapted Model: | |
|-----------------------------|--|
| Domains | Themes |
| Healthcare Provider Virtues | Attentive Presence |
| | Respectful |
| | Knowledgeable |
| | Flexible |
| | Openness |
| | Transparency |
| | Beneficence |
| Relational Dynamics | Seeking to Understand |
| | Building Rapport |
| | Communication |
| Action-Oriented Care | Support |
| | Timely |
| Patient-Reported Outcomes | Alleviates Suffering |
| | Enhances Wellbeing |
| | Enhances Skill Development |
| Systems Outcomes | Structural Barriers |
| | Culturally & Developmentally Sensitive |

Key Features of Adapted Model:

- Compassion addresses **goals** and **needs**
- Emphasizes importance of continuity and flexibility of care

Adaptions to Sinclair et al.’s Model:

- Modified Virtues: Respectful, Transparency, Beneficence
- New Virtues: Attentive Presence, Knowledgeable, Flexible
- Modified Domains: Relational Dynamics, Action-Oriented Care
- New Domain: Systems Outcomes

Conclusions

- Compassionate care must:
- Be understood in **context**, not isolation
 - Include systemic factors to capture **structural barriers**
 - Be flexible, action-oriented, and goal-driven

Relevance to Clients & Families

Model informs targeted **interventions** and **contextualizes** healthcare transition **quality indicators**.

Key References

1. Sinclair S, McClement S, Raffin-Bouchal S, Hack TF, Hagen NA, McConnell S et al. Compassion in health care: An empirical model. Journal of Pain and Symptom Management. 2016;51(2), 193–203.

2. Kokorelias KM, Lee TJ, Bayley M, Seto E, Toulany A, Nelson MLA et al. "I have eight different files at eight different places": Perspectives of youths and their family caregivers on transitioning from pediatric to adult rehabilitation and community services. Journal of Clinical Medicine. 2023; 12(4), 1693.

3. Sinclair S, Kondejewski J, Schulte F, Letourneau N, Kuhn S, Raffin-Bouchal S et al. Compassion in pediatric healthcare: A scoping review. Journal of Pediatric Nursing. 2020;51: 57-66.

