

Using Health Administrative Data to Understand and Improve End of Life Care Among Children With Cancer: A Population-Based Cohort and Validation Study

End of Grant Meeting Report
October 2017

Facilitators/Presenters: Sumit Gupta, Kimberley Widger

Principal Investigators: Sumit Gupta, Kimberley Widger

Co-Investigators: Adam Rapoport, Alisha Kassam, Christina Vadeboncoeur, Craig Earle, Jason Pole, Joanne Wolfe, Katherine Nelson, Rinku Sutradhar, Shayna Zelcer, Ying Liu

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Executive Summary

Despite advances in treatment of pediatric cancer, about 20% of children diagnosed with cancer will still die of their disease. Specialty pediatric palliative care (SPPC) teams are involved in the care of these children and aim to ease suffering and improve quality of life. Despite the development of SPPC teams and calls for routine incorporation of these services in oncologic care, children diagnosed with cancer carry high symptom burdens at the end of life (EOL). These symptoms may be worsened by high-intensity end of life (HI-EOL) care, such as ICU admissions and mechanical ventilation. Little is known about the current prevalence of HI-EOL in children with cancer at a population level and whether involvement of SPPC teams in care provision impacts use of HI-EOL care. Current literature is also limited on use of health administrative data to assess SPPC involvement, and patterns of referral to SPPC teams. We conducted three studies with an aim to address current gaps in the literature on EOL care for children with cancer.

Our key findings from these studies included:

1. Ontario children with cancer continue to experience HI-EOL care, with children with hematologic cancers at highest risk.
2. Less than a third of children with cancer access SPPC at least 30-days prior to death.
3. Children of lower socioeconomic status and those living at greater distance from their treatment centre are less likely to access SPPC.
4. Children who access SPPC are far less likely to experience HI-EOL care.
5. Health administrative data do not validly identify SPPC involvement.

We hosted a one-day stakeholder meeting at the Hospital for Sick Children in October 2017 to share the key findings from our three studies and gain perspectives on these findings from health care providers, researchers, parents of children living with or who died from cancer, and representatives from non-profit organizations focused on improving health care. Key recommendations for clinical care, research, and policy included:

Clinical

- Increase education for patients, families, health professionals, and policy/decision makers about available PPC options and eliminate the misconception that SPPC services are given to patients only when “nothing else is working”.
- Develop list of automatic triggers and decision-making tools to remove any potential biases in referral patterns and identify when to access SPPC.

Research

- Create regional and national PC databases to facilitate ongoing surveillance of access to SPPC and achievement of benchmarks for quality PPC indicators.
- Conduct additional research both within and outside of pediatric oncology to further explore patterns of referral to SPPC.
- Develop working groups or conduct further research to identify valid indicators of high quality SPPC and quality benchmarks.

Policy

- Examine issues related to billing (who can use PC billing codes and when can they be used) to facilitate use of administrative data to assess delivery of SPPC.
- Ensure adequate resources for SPPC to provide widespread and equitable access.

Scientific Report

Background

Despite advances in treatment of pediatric cancer, about 20% of children diagnosed with cancer will still die of their disease. Specialized pediatric palliative care (SPPC) teams are involved in the care of these children and aim to ease suffering and improve quality of life. Despite the development of SPPC teams and calls for routine incorporation of these services in oncologic care, children diagnosed with cancer carry high symptom burdens at the end of life (EOL). These symptoms may be worsened by high-intensity end of life (HI-EOL) care, such as ICU admissions and mechanical ventilation. Little is known about the current prevalence of HI-EOL in children with cancer at a population level and whether involvement of SPPC teams in care provision impacts use of HI-EOL care. Current literature is also limited on use of health administrative data to assess SPPC involvement, and patterns of referral to SPPC teams. We conducted three studies with an aim to address current gaps in the literature on EOL care for children with cancer. Below is a summary of objectives, methods, and key findings for each study:

STUDY 1: Predictors of and Trends in High-Intensity End-of-Life Care among Children with Cancer: A Population-Based Study Using Health Services Data.

Objectives and Methods: The objective of this retrospective study was to determine predictors of and trends in HI-EOL care in children diagnosed with cancer. Using a provincial cancer registry, a group of patients with childhood cancer who died between 2000 and 2012 in Ontario, Canada, was created and linked to population-based health administrative data housed at the Institute for Clinical Evaluative Sciences (ICES). HI-EOL care previously described in the literature comprised any of the following: intravenous chemotherapy within 14 days of death; more than one emergency department visit within 30 days of death; and more than one hospitalization or any intensive care unit admission within 30 days of death. Secondary measures included those same individual measures and measures of the most invasive EOL care (e.g, mechanical ventilation within 14 days of death).

Key findings:

- The study included 815 patients; of these, 331 (40.6%) experienced HI-EOL care.
- Children with leukemia or lymphoma were over two times more likely to experience HI-EOL care compared to other children.

Results of this study were published in *Journal of Clinical Oncology* (Kassam A, Sutradhar R, Widger K, et al: Predictors of and Trends in High-Intensity End-of-Life Care Among Children With Cancer: A Population-Based Study Using Health Services Data. *Journal of Clinical Oncology* 35:236-242, 2016)

STUDY 2: The Validity of Using Health Administrative Data to Identify the Involvement of Specialized Pediatric Palliative Care Teams in Children with Cancer in Ontario, Canada.

Objectives and Methods: The objective of this study was to determine if using population based health administrative data could reliably and validly identify the involvement of SPPC teams in the care of children with cancer. We included Ontario children with cancer who died between 2000 and 2012, received care through a pediatric institution with a SPPC team. SPPC involvement was identified using institutional clinical databases. Data for all patients were linked to population based health services administrative databases. Six algorithms were created to identify SPPC team involvement using palliative care (PC) billing codes based on the record type (physician billings vs. inpatient records vs.

both) and number of eligible codes required (≥ 1 vs. ≥ 2). Each was compared for validity against the SPPC clinical databases.

Key findings:

- The study included 572 children; 243 were in the clinical databases.
- Algorithms using only inpatient records had high specificity (80%–95%) but poor sensitivity (21%–56%).
- The algorithm with overall best performance required ≥ 2 physician billing or inpatient diagnosis codes, but was associated with only a sensitivity of 79% and specificity of 73%

Results of this study were published in *Journal of Palliative Medicine*. (Widger K, Vadeboncoeur C, Zelcer S, et al: *The Validity of Using Health Administrative Data to Identify the Involvement of Specialized Pediatric Palliative Care Teams in Children with Cancer in Ontario, Canada. J Palliat Med 20:1210-1216, 2017*)

STUDY 3: Predictors of Specialized Pediatric Palliative Care Involvement and Impact on Patterns of End-of-Life Care in Children with Cancer.

Objectives and Methods: The objectives of this study were to determine which children with cancer access SPPC and whether SPPC involvement impacted the risk of experiencing HI-EOL care. Using the same patient cohort as in Study 2, children were classified as having SPPC (present in the clinical SPPC database), general PC (PC billing codes used by adult PC Physicians, pediatric oncologists, or other physicians not associated with an SPPC team), or no PC. Our primary indicator of HI-EOL care was intensive care unit admission within 30 days of death. Secondary indicators included mechanical ventilation within 14 days of death and in-hospital death.

Key findings:

- Of the 572 children, 166 (29%) received care from a SPPC team prior to the last month of life, 100 (18%) received general PC, and 306 (53%) received no PC.
- Children with hematologic cancers, those living in the lowest income areas, and those living further from the treatment center were less likely to receive SPPC.
- Those children who received SPPC were five-fold less likely to experience an intensive care unit admission in the last month of life, while general PC had no impact.

Results of this study were published in the *Journal of Clinical Oncology* (Widger K, Sutradhar R, Rapoport A, Vadeboncoeur C, Zelcer S, Kassam A, Nelson K, Liu Y, Wolfe J, Earle CC, Pole JD, Gupta S. *Predictors of specialized pediatric palliative care involvement and impact on patterns of end-of-life care in children with cancer. J Clin Oncol. In Press. Published online pre-print. doi: 10.1200/JCO.2017.75.6312 Jan 22, 2018*)

This article was selected by JCO for an invited commentary and a JCO podcast session, available at:

<http://ascopubs.org/doi/full/10.1200/JCO.2017.75.6312>

Stakeholder Meeting

A one-day stakeholder meeting was held on October 6th, 2017 in Toronto. Twenty-two participants included the study leads and co-investigators, health professionals (e.g., physicians, nurses, social worker) from four of the five pediatric cancer hospitals in Ontario (McMaster Children’s Hospital, Children’s Hospital of Eastern Ontario, London Health Sciences Centre, and Hospital for Sick Children), parents of children living with or who had died from cancer, PC researchers, and representatives from

non-profit organizations focused on improving health care both specific to children with cancer and also more broadly (see Appendices for meeting materials, list of attendees, and a participant evaluation of the meeting). During the meeting we provided background information on the definition of PPC and availability and composition of SPPC teams in Canada, use of administrative data to study end of life care, and current initiatives in adult PC research. We then presented the results of our three studies and had open discussion with participants on the clinical, research, and policy implications of our findings. The discussion is summarized in Table 1 according to key challenges, recommendations, and proposed strategies to address identified challenges within the Canadian health care system at both the micro (patient/family and providers) and macro (health system) level.

Key Recommendations

Based on the study findings and the discussion with stakeholders during the meeting we identified the following key recommendations to advance clinical care, research, and policy in pediatric oncology and PPC more broadly:

Clinical:

- Increase education for patients, families, health professionals, and policy/decision makers about available PPC options and eliminate the misconception that SPPC services are given to patients only when “nothing else is working”.
- Develop list of automatic triggers and decision-making tools to remove any potential biases in referral patterns and identify when to access SPPC.

Research:

- Create regional and national PC databases to facilitate ongoing surveillance of access to SPPC and achievement of benchmarks for quality PPC indicators.
- Conduct additional research both within and outside of pediatric oncology to further explore patterns of referral to SPPC.
- Develop working groups or conduct further research to identify valid indicators of high quality SPPC and quality benchmarks.

Policy:

- Examine issues related to billing (who can use PC billing codes and when can they be used) to facilitate use of administrative data to assess delivery of SPPC.
- Ensure adequate resources for SPPC to provide widespread and equitable access.

Table 1: Summary of challenges, recommendations and proposed strategies from the Stakeholder meeting.

Level	Challenges	Recommendations	Proposed Strategies
Micro-level (patients and providers)	<p>Patients / Families</p> <ul style="list-style-type: none"> • Population-specific needs – Wide variation in progression of various types of cancer (poor early prognosis in some hematologic cancers, transplant candidates, etc). • Cultural/ethnic background may limit interest in SPPC. • Language barriers – delivering information to families. • Access to SPPC – Lack of awareness of available SPPC services. • Expectations – Lack of understanding of the purpose/definition of SPPC (e.g., associated with end of life care rather than having a broader view of it being appropriate from the time of diagnosis). 	<ul style="list-style-type: none"> • Provide public education to increase awareness of SPPC and its definition • Enhance communication with families particularly when language / cultural / ethnic differences are present • Develop decision making guidelines and resources about when to access PC directed at families • Increase intercultural competence in staff 	<ul style="list-style-type: none"> • Offer orientation sessions for parents of children diagnosed with cancer to provide information about and explore SPPC options with opportunities for parents to ask questions. • Develop online, print, and audio/video patient/family education materials about SPPC in different languages to suit different patient populations. • Increase diversity in support staff to represent different cultural/ethnic backgrounds. • Increase access to interpreters. • Provide cultural competency workshops for staff. • Conduct Patient/family to patient/family and patient/family to physicians/staff forums, focus groups so regular feedback can be provided. • Examine other potentially vulnerable groups to assess access to SPPC (e.g. link to Citizenship and Immigration Canada to provide data on immigration status).

	Level	Challenges	Recommendations	Proposed Strategies
Micro-level (patients and providers)	Providers	<ul style="list-style-type: none"> • Is HI-EOL care equivalent to poor quality care? Ambiguity around definition and indicators of high quality PPC provision. • Which patients should be referred to SPPC? Lack of standards or benchmarks to guide practice. • Low referral to SPPC in certain types of patients (e.g hematologic cancer, low income, living further away) but cause unknown. 	<ul style="list-style-type: none"> • Re-examine indicators for HI-EOL care and applicability to pediatric population • Define indicators of quality of PPC with gold standards/benchmarks • Define triggers for SPPC referral (Set minimum standards for proportion of children who should be referred to SPPC) 	<ul style="list-style-type: none"> • Convene expert opinion/working group to: <ul style="list-style-type: none"> - define quality PPC and associated indicators with benchmarks - identify benchmarks for SPPC access • Create goals of care document which also include documentation of whether or not goals were achieved. (To be used for clinical and research purposes). • Develop clinical algorithms to determine when a referral to SPPC services should be offered to a family. • Monitor SPPC referral patterns to examine changes over time to guide policy and decision making. • Conduct research on patient populations with low SPPC referral patterns (e.g hematologic cancer) to identify potential causes. • Examine similar HI-EOL care indicators outside pediatric oncology population.

	Level	Challenges	Recommendations	Proposed Strategies
Macro-level	Systems pathways	<ul style="list-style-type: none"> • Traditional interpretation of palliative care as equivalent to “end of life” care perpetuated by OHIP billing system. • Various limitations in OHIP billing codes for PC – <ul style="list-style-type: none"> - use only by primary provider - rejection of PC codes if patient later admitted to ICU - anyone can use PC codes in Ontario - No PC codes available to document bereavement support, etc. • PC services provided by non-physicians particularly at community level (e.g., nurses, LHIN, interlink, etc) who may be providing a substantial portion of PC are not captured in any system therefore access is unknown. • Provision of PC limited by geography with very limited PC resources at some centres. 	<ul style="list-style-type: none"> • Revisit schedule of benefits (differentiate general from specialized PC in billing codes) • Create a model care that allows for general PC providers and SPPC teams to work together - synergize PC and SPPC efforts. • Further research needed on PC and SPPC access to identify gaps. • Routine surveillance of general PC and SPPC provision. 	<ul style="list-style-type: none"> • Revise PC and SPPC billing codes with attention to who uses them and when they can be used to address differences in specialist vs generalist PPC provision and to avoid dichotomy between cure directed care vs comfort directed care. • Provide education at all levels (public, health care providers, decision/policy makers) to change paradigms for PPC – PPC is not focused on end of life. • Conduct research on access to PC and SPPC to guide policy, identify gaps and disparities at provincial vs. national level. • Conduct pragmatic research on benefits of PC, patient outcomes and cost-effectiveness- to guide policy. • Create hospital-based databases to consistently document SPPC provision but also have provision of SPPC documented on a population level (CYP-C, POGONIS) to facilitate ongoing examination of patient outcomes and gaps in care. • Conduct research on variations in PPC availability and models of care across regions, population characteristics and patient outcomes – differences could be used for future policy discussions to improve PPC and identify disparities.

Appendices

Appendix 1: Invitation Letter for stakeholder meeting.

Using Health Administrative Data to Understand and Improve End-of Life Care Among Children with Cancer

Dear Colleagues,

We have recently led a team of investigators in conducting a study aiming at characterizing and understanding end-of-life care in children with cancer by linking population-based clinical and health services databases. The study was funded by Garron Family Cancer Centre (GFCC) and the main objectives were 1) to identify which children with cancer were most likely to receive high intensity therapy at the end-of-life, 2) to see if health administrative data (e.g. physician billings) could identify which children were receiving specialty pediatric palliative care (SPPC) services, and 3) to identify which children were most likely to receive SPPC services and whether such services impacted on the intensity of end-of-life care. Our study team included researchers, pediatric oncologists, and palliative care providers from across Ontario and beyond. The results for the first and second objectives have been published in scientific journals and we have started disseminating our findings for the third objective.

We believe strongly that engaging stakeholders (families, clinicians, policymakers, researchers) is key in translating research into meaningful practical results and ensuring that we are focusing on the issues that are most pressing and have applications in real-world situations.

We therefore invite you for a one-day interactive workshop/meeting to share with you summary of key findings from our study, highlight findings from the study that could potentially have clinical and policy implications and get your input on whether any actions should be taken based on our findings, in either the clinical or policy realms. We also hope to hear from you on what future research questions/directions should be pursued, thus enabling us to set priorities as a team.

For those based outside of Toronto, we are pleased to be able to support your travel expenses as well as one night accommodation.

Below you can find more details about the meeting and a brief agenda for the meeting is attached. Please do not hesitate to contact us should you need further information.

Sincerely,

Sumit Gupta MD PhD
Staff Oncologist, Division of Hematology/Oncology
The Hospital for Sick Children
Sumit.gupta@sickkids.ca

Kimberley Widger RN PhD CHPCN(C)
Assistant Professor, Lawrence S. Bloomberg Faculty of Nursing,
University of Toronto
kim.widger@utoronto.ca

Appendix 2: 1-day stakeholder Meeting Agenda held at Peter Gilgan Centre for Research and Learning (PGCRL).

9:30—10:00	Breakfast	CRL Gallery (2 nd floor)
10:00—10:15	Introductions, Objectives and Agenda	CRL Gallery (2 nd floor)
10:15—10:45	Introduction to Pediatric Palliative Care	CRL Gallery (2 nd floor)
10:45—11:15	Introduction to Research Using Administrative Data	CRL Gallery (2 nd floor)
11:15—11:30	Morning Coffee Break	CRL Gallery (2 nd floor)
11:30—12:15	Research Paper 1 – Trends in High-Intensity End-of-Life Care	CRL Gallery (2 nd floor)
12:15—12:45	Research Paper 2 – Using Administrative Data to Identify Which Children Receive Palliative Care	CRL Gallery (2 nd floor)
12:45—1:30	Lunch	CRL Gallery (2 nd floor)
1:30—1:45	Initiatives in Adult Palliative Care – Research and Ministry	CRL Gallery (2 nd floor)
1:45—2:30	Research Paper 3 – Impact of Pediatric Palliative Care	CRL Gallery (2 nd floor)
2:30—3:30	Small Group Breakout Sessions	CRL Event Room 2a & 2b (2 nd floor)
3:30—3:45	Afternoon Coffee Break	CRL Gallery (2 nd floor)
3:45—4:45	Full Group Discussion	CRL Gallery (2 nd floor)
4:45—5:00	Discussion on Additional Stakeholders, Next Steps	CRL Gallery (2 nd floor)

Appendix 3: Stakeholder meeting list of attendees.

#	Attendee	Affiliation	Email
1	Ute Bartels	The Hospital for Sick Children	ute.bartels@sickkids.ca
2	Clare Cheng	Canadian Institute of Health Information	CCheng@cihi.ca
3	Craig Earle	Institute of Clinical Evaluative Sciences	craig.earle@ices.on.ca
4	Hande Elmaagacli	The Hospital for Sick Children	handearaz@gmail.com
5	Paul Gibson	London Health Sciences Centre	Paul.Gibson@lhsc.on.ca
6	Esther Green	Canadian Partnership Against Cancer	esther.green@partnershipagainstcancer.ca
7	Paul Grundy	Canadian Partnership Against Cancer	Paul.Grundy@partnershipagainstcancer.ca
8	Sumit Gupta	The Hospital for Sick Children	sumit.gupta@sickkids.ca
9	Susan Kuczynski	Ontario Parents Advocating for Children with Cancer	Liaison@opacc.org
10	Sonia Lucchetta	The Hospital for Sick Children	sonia.lucchetta@sickkids.ca
11	Dave Lysecki	McMaster Children's Hospital	lyseckdl@mcmaster.ca
12	Doug Maynard	Canadian Association of Pediatric Health Centres	dmaynard@caphc.org
13	Lisa Pearlman	London Health Sciences Centre	Lisa.Pearlman@lhsc.on.ca
14	Jason Pole	Pediatric Oncology Group of Ontario	jpole@pogo.ca
15	Adam Rapoport	The Hospital for Sick Children	adam.rapoport@sickkids.ca
16	Milane Segal	The Hospital for Sick Children	milane@rogers.com
17	Peter Tanuseputro	Ottawa Hospital Research Institute	ptanuseputro@ohri.ca
18	Chris Vadeboncouer	Children's Hospital of Eastern Ontario	Vadeboncoeur@cheo.on.ca
19	Kim Widger	University of Toronto	kim.widger@utoronto.ca
20	Joanne Wolfe	Dana-Farber Cancer Institute at Harvard	Joanne_Wolfe@dfci.harvard.edu
21	Leah Young	C17 Council, Alberta Health Services	Leah.Young2@albertahealthservices.ca
22	Weeda Zabih	The Hospital for Sick Children	Weeda.zabih@sickkids.ca

Appendix 4: Summary of Stakeholder meeting evaluation.

Criteria	Mean rating out of 7*
Content and format of meeting package materials was clear	6.8
Length of meeting was appropriate	6.5
Venue was suitable and comfortable	6.5
Agenda topic progression was logical	6.8
Presentations contributed to my understanding	6.7
Break-out group sessions were relevant and thought-provoking	6.7
Break-out group discussions generated useful ideas	6.9
Full group discussion generated useful ideas	6.8
Overall satisfaction	6.8

* Response options ranged from 1=Strongly Disagree to 7=Strongly Agree

Constructive comments/suggestions related to any of the above:

- Great idea to have an end of grant meeting. Helpful to plan next steps.
- Very useful – makes grant outcomes easily translated into activity.
- Overall nice talk – “what is palliative care?” Maybe overkill.
- Appreciative of the opportunity to participate. Didn’t address issues of communication between teams – palliative care and oncology.
- Excellent meeting: many insights shared on the data aspects. The most important discussion was on Action – what are the next steps.
- Agenda and details of the meeting were very late being sent out (5 days before) unless I missed a critical email.
- 1. Education on palliative care from time of diagnosis (use videos). Develop a “palliative care” plan to capture preferences. Change the conversation with clinicians – PC begins at time of diagnosis. 2. When desired, don’t stop curative care and HI ELC. These serve to extend life and provide comfort. This is not mutually exclusive to palliative care. 3. Change the definition of palliative care from a billing perspective. 4. Collect and capture the data that is meaningful directly to provide ongoing insights into the success of palliative care provided.

Name/describe one thing you liked most about the meeting, and why?

- Excellent multidisciplinary discussion/perspectives.
- Interactive nature of the discussions.
- Great Ideas! Everyone committed. Parents' perspectives.
- Opportunity to interact with those I may not normally interact with.
- For a diverse group, very inclusive conversation.
- Good discussion regarding funding.
- Involvement of different people from different regions and professions created broader views on the subject.
- To hear from a variety of stakeholders.
- Kim and Sumit leadership today was evident and really helped to facilitate the discussion.
- General openness to new ideas and perspectives.
- Opportunity to share ideas.

Name/describe one thing you liked least about the meeting, and how it could be improved.

- Potentially ** moderation of discussions could help get more of the feedback that you may be looking for.
- Would have been interesting to hear from CCAC representatives to hear about their experience providing palliative care in the community. Smaller room – would have been helpful.
- Sometimes ideas are “stopped” prematurely due to constraints such as resources. We should challenge ourselves to think creatively about how to overcome obstacles, to reach our goals.
- Really nothing.
- Nothing.