Pediatric palliative care program

Effects on health system utilization and costs

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Acknowledgments

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• Support
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Conflicts of Interest

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Outline

• The program
• The objectives and research questions
• Pieces of Research
  – Review – results
  – Local Data – design/analysis/results
  – Cost Analysis
• Contributions
• Discussion
Pediatric palliative care program (PPCP)

**Total approach to care**

- Management of distressing symptoms
- Short breaks
- Care

## Life-shortening conditions (LSC)

### Category 1
Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver, kidney.

### Category 2
Conditions when premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.

### Category 3
Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.

### Category 4
Irreversible but non-progressive conditions, causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.

Multidisciplinary range of services

- Specialist short break care
- Bereavement
- Support for the entire family

- Physiotherapy
- Play therapy
- Music therapy
- Schooling

- Support, Education
  - Training to carers

- Practical help
- Advice
- Information

EOL Care
Why?

“From a national perspective, between 5% and 12% of the children who could benefit from palliative care received services from 1 of these programs before death.”(1)

Great part still died in care providers:
- 27.7% hospitalized in a general pediatric
- 12.3% critical care area
- 7.7% hospice
- 43.9% at home
- 8.4% Other/Unknow

Why?

The demand can strain tertiary care resources

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Year prior to death</th>
<th>Year of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Discharges</td>
<td>3.7</td>
<td>5.3</td>
</tr>
<tr>
<td>Days spent in hospital</td>
<td>39 days</td>
<td>48 days</td>
</tr>
</tbody>
</table>

May not be equipped to address needs beyond clinical management

Canuck Place

- Founded in 1995
- 9 beds
- 4 family suits
- Approximately 200-250 children in the program/year
- Over 2000 individual family members in house/year

- 20-25% of children with LSC in BC in the program
- Extension 10 beds, 4 family suits – Abbotsford opening 2014

www.canuckplace.org
Project Objectives

≠ patterns of utilization and cost

Children with Life-shortening Conditions

Pediatric Palliative Care Program

Tertiary Care Only/Usual Care

↓ Emergency room (ER) visits
↓ Admissions (per type)
↓ Length of stay (LOS)
↓ Lower overall costs
Research Questions

• Are there differences in admissions and cost between the 2 groups? (frequency, length, type?)
• Is this an effect of the program? (Correlation/Causation)
• What if we engage more patients in the program?
• What if we engage them earlier?
Pieces of Research

Systematic Review

Local Data Analysis

Health Economic Evaluation
Systematic Review

• Literature scoping – no SR studying health care resources use and costs in this population and program

• Children up to 22 years with a LSC enrolled in “palliative care”
  – Pieces of a program as “proxy”

• Include ECR and Observational studies
  – ↓ likelihood of finding RCT
    – nature of the population, program and ethical limitations.
    – Stigma to referral/acceptance of the program
    – Majority of the LSC’s are rare diseases - sample size.
Outcomes

• Primary outcomes
  – Health care resource utilization measured as:
    • Number of hospital admissions of any type – emergency visits, general ward, critical care, hospice;
    • Length of stay (LOS);
  – Health care costs of any nature (direct costs in hospital or hospice, indirect costs, total health care expenditures).

• Secondary outcomes – focus in the last admission
  – LOS
  – Number of invasive procedures to prolong life
Search

Databases: Medline, Embase, CINAHL, LILACS, Grey Literature, experts

- Published after 2000.
- No language limits.
- Pre-tested filters for RCT and Observational studies
  Cochrane, McMaster, SIGN
  www.sign.ac.uk/methodology/filters.html

- Weekly alerts
Results

Electronic Databases
5182 Citation(s)

Manual Search
11 Citation(s)

3765 Non-Duplicate Citations Screened

Inclusion/Exclusion Criteria Applied

3656 Articles Excluded After Title/Abstract Screen

109 Articles Retrieved

Inclusion/Exclusion Criteria Applied

96 Articles Excluded After Full Text Screen
4 Articles Excluded During Data Extraction

9 Articles Included

* 1 article last week
Results

- No RCT’s
- 10 observational studies – all retrospective

**Design**
- 4 Cohort comparison
- 4 Pre/Post studies
- 1 Case-control
- 1 Case-series

**Settings**
- 8 USA
- 1 UK
- 1 Canada

**Outcomes**
- Hospital Admissions
  - 6 articles
- LOS
  - 6 articles
- Cost
  - 7 articles
**Studies Characteristics**

**Cohort Studies**

- **Keele L et al 2013** (n=24342) - USA
  - Administrative database > 40 Hospitals
  - Died at the hospital > 5 days after admission (<18 years)
  - All causes of death
  - **Follow-up:** last admission before death
  - PC group (n=919) vs No PC (n=23423)
  - **Intervention:** Palliative Care Consultation in the last admission (measured by billing code for ICD9 - PC V66.7)

- **Fraser LK et al 2013** (n=497) – UK
  - Linked data from SPPCSs, Register of Cancer, NHS Hospital episode statistics – Yorkshire Health Authority
  - Who died from cancer (<19 years)
  - **Follow-up:** referral to death
  - Hospice group (n=132) vs Control PC (n=311)
  - **Intervention:** Specialist palliative care service carried by pediatric hospice
  - Negative binomial regression modeling – applied pre/post period for the control group based on median exposure by disease category
We chose over Poisson regression due to overdispersion, with et al included within the analysis as mentioned previously were chosen for SPPCS. As no previous literature exists on hospital admissions died without referral to SPPCS and those who had been referred and Asian; Mixed: other mixed, chinese and other ethnic group). British: Other Black) and other ethnic groups (Mixed: White and Caribbean; Black or Black British; Black African; Black or Black Asian (Asian or Asian British: Indian; Asian or Asian British: White (White: British; White: Irish; White: Other White), South combined groups to avoid very small numbers in some categories: codes were assigned their most commonly reported ethnicity group of hospital admissions (total, planned and emergency) for this time Palliative care and hospital admissions in paediatric oncology.

Table 1. Time from diagnosis to referral to specialist palliative care service by ICCC classification

<table>
<thead>
<tr>
<th>ICCC classification</th>
<th>Number of Patients</th>
<th>Median time to referral (days)</th>
<th>IQR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leukaemia</td>
<td>32</td>
<td>518</td>
<td>363 995</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>14</td>
<td>368</td>
<td>189 595</td>
</tr>
<tr>
<td>CNS</td>
<td>84</td>
<td>262</td>
<td>110 1206</td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>19</td>
<td>319</td>
<td>157 647</td>
</tr>
<tr>
<td>Retinoblastoma</td>
<td>0</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Renal</td>
<td>6</td>
<td>390</td>
<td>78 1205</td>
</tr>
<tr>
<td>Hepatic</td>
<td>3</td>
<td>122</td>
<td>49 339</td>
</tr>
<tr>
<td>Bone</td>
<td>18</td>
<td>561</td>
<td>206 678</td>
</tr>
<tr>
<td>Soft tissue</td>
<td>29</td>
<td>273</td>
<td>194 562</td>
</tr>
<tr>
<td>Germ cell</td>
<td>2</td>
<td>169</td>
<td>125 212</td>
</tr>
<tr>
<td>Other epithelial*a</td>
<td>3</td>
<td>582</td>
<td>109 824</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>

Abbreviations: CNS = central nervous system; ICCC = International Classification of Childhood Cancer; IQR = inter quartile range.
*aClassification includes: adrenocortical carcinomas, thyroid carcinomas, nasopharyngeal carcinomas, malignant melanomas and other unspecified carcinomas.
Studies Characteristics
Cohort Studies

• Dussel V et al 2009 (n=140) – USA
  – Survey of parents + retrospective chart review
  – 2 Hospital (Boston/Minesota)
  – Died from cancer (no age range)
  – **Follow-up:** Last month of life
  – Planned LOD (n=88) vs Did not planned LOD (n=52)
  – **Intervention:** Planning of location of death (LOD) determined by survey - 390 questions

• Knapp CA et al 2009 (n=1527) – USA
  – Administrative database medicaid claims, encounter, enrollment files, death certificate (Florida State)
  – Died from any cause (1-21 years)
  – **Follow-up:** Last year of life
  – Hospice users (n=85) vs Non-hospice users (n=848)
  – **Intervention:** hospice claims
  – 1/3 pediatric population, do not include private insurance, uninsured, or other public insurance
Studies Characteristics
Pre/Post Studies – No Control Group

• Postier et al 2014 *(n=425) – USA
  – Administrative database – electronic medical records, accounting system
  – Children’s Hospitals and Clinics of Minnesota’s (CHC) Homecare, Pain Medicine, Palliative Care & Integrative Medicine Programs
  – Children (1-21 years)
  – Intervention: Enrolled in the home PPC/hospice program
  – Follow-up: 12 months before/12 months after

• Arland LC et al 2013 (n=114) – USA
  – Chart review
  – Children's Hospital Colorado
  – Children (1 month - 19 years)
  – Who died from brain tumor
  – Intervention: Implementation of standardized EOL care program coordinated by the hospital
  – Follow-up: 5 years before/10 years
  – Before (n=22) vs After (n= 92)
  – Both periods included hospice providers (non-pediatric)
Studies Characteristics
Pre/Post Studies – No Control Group

• Gans D et al 2012
  (n= 123) – USA – brief report
  – Database of claims (MIS/DSS claims, MEDS and CMS Net)
  – 11 counties in California
  – Children with LSC (0-20)
  – **Intervention:** Enrolled in a community based pediatric palliative care program
  – **Follow-up:** 12 months before/18 months after
  – Program counted on home care providers, hospices and contracted agencies who voluntarily decided to participate

• Pascuet E et al 2010
  (n=66) – Canada
  – Chart review
  – Roger's House Pediatric Hospice, Ontario, Canada (RH), Children’s Hospital of Eastern Ontario (CHEO)
  – Children with LSC (range not defined)
  – **Intervention:** Who had used respite at the pediatric Hospice at least once
  – **Follow-up:** 12 months before/12 months after
**Studies Characteristics**

**Case-Control***

- Ward-Smith P et al 2008 (n=18) – USA
  - Admin database - hospital-based charges
  - Children's Mercy Hospital, Kansas
  - Excluded: NICU, died < 72 hours, or enrolled in the PPCP < 30 days
  - Enrolled in the PPCP vs Not enrolled (range not defined).
  - Cases 9/133 were chosen by experts
  - criteria for matching was not stated (apparently by diagnostic), period not specified
  - **Follow-up:** 6 months before death

* the authors called a case-control but technically is a cohort comparison

**Case-series**

- Belasco JB et al 2000 (n=3) – USA
  - Chart review
  - Children's Hospital Philadelphia
  - Children Enrolled in the home based pediatric palliative care program (154 – age range not defined)
  - Criteria: to reflect medically complicated patients whose level of care at home approximately equal that in the hospital and differed only in palliative intent rather than intent to cure.
  - **Follow-up:** 1 day
  - Compared procedures in home care vs in hospital
# Summary

<table>
<thead>
<tr>
<th>Design</th>
<th>Author</th>
<th>Hosp Admissions</th>
<th>LOS</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohort</td>
<td>Keele L et al 2013</td>
<td>+</td>
<td></td>
<td>+</td>
</tr>
<tr>
<td>Cohort</td>
<td>Fraser LK et al 2013</td>
<td>?</td>
<td></td>
<td></td>
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<tr>
<td>Cohort</td>
<td>Dussel V et al 2009</td>
<td>?</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Cohort</td>
<td>Knapp CA et al 2009</td>
<td></td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Pre/Post no control</td>
<td>Postier et al 2014</td>
<td>?</td>
<td>+</td>
<td>?</td>
</tr>
<tr>
<td>Pre/Post no control</td>
<td>Arland LC et al 2013</td>
<td>+</td>
<td>+</td>
<td></td>
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<td>-</td>
<td>+</td>
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<tr>
<td>Case-Control</td>
<td>Ward-Smith P et al 2008</td>
<td>?</td>
<td></td>
<td>?</td>
</tr>
<tr>
<td>Case series</td>
<td>Belasco JB et al 2000</td>
<td></td>
<td></td>
<td>+</td>
</tr>
</tbody>
</table>
Methodological Limitations

• Threats to validity
  • Selection Bias (referral/choice of enrollment)
  • History – changes in protocols of palliative care
  • Accounting for time exposed to the program
  • Survival
  • Lack of Control (could affect in both directions)
  • Complexity of the intervention
  • Context/setting dependent
<table>
<thead>
<tr>
<th>Level</th>
<th>Evidence Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>1A</td>
<td>SR (with homogeneity*) of RCTs</td>
</tr>
<tr>
<td>1B</td>
<td>Individual RCT (with narrow Confidence Interval&quot;i&quot;)</td>
</tr>
<tr>
<td>1C</td>
<td>All or none§</td>
</tr>
<tr>
<td>2A</td>
<td>SR (with homogeneity*) of cohort studies</td>
</tr>
<tr>
<td>2B</td>
<td>Individual cohort study (including low quality RCT; e.g., &lt;80% follow-up)</td>
</tr>
<tr>
<td>2C</td>
<td>&quot;Outcomes&quot; Research; Ecological studies</td>
</tr>
<tr>
<td>3A</td>
<td>SR (with homogeneity*) of case-control studies</td>
</tr>
<tr>
<td>3B</td>
<td>Individual Case-Control Study</td>
</tr>
<tr>
<td>4</td>
<td>Case-series (and poor quality cohort and case-control studies§§)</td>
</tr>
<tr>
<td>5</td>
<td>Expert opinion without explicit critical appraisal, or based on physiology, bench research or &quot;first principles&quot;</td>
</tr>
</tbody>
</table>

Retrospective Matched Cohort Study

**Case:** deceased in the hospice

**Control:** deceased in the hospital – not referred to the program

Up to 3 years

**Primary**
- Length of Stay (LOS)
- Admissions
- ER visits
- Cost

**Secondary**
- EOL admission
  - LOS
  - Invasive Procedures

**Children deceased from a LSC 2008-2012**

Matched
- ICD Code
- Age at Death

**Impact – Shifting in Patient Enrolment/Setting**
Possible Pathways – Usual care
Possible Pathways - Program
## Non-Cancer Patients

<table>
<thead>
<tr>
<th>Pair</th>
<th>Age CPCH Group</th>
<th>Age BCCH Group</th>
<th>ICD</th>
<th>Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0 years, 1 months, 28 days</td>
<td>0 years, 2 months, 12 days</td>
<td>Q20</td>
<td>Congenital malformations of cardiac chambers and connections</td>
</tr>
<tr>
<td>2</td>
<td>9 years, 3 months, 29 days</td>
<td>9 years, 8 months, 27 days</td>
<td>E71</td>
<td>Disorders of branched-chain amino-acid metabolism and fatty-acid metabolism</td>
</tr>
<tr>
<td>3</td>
<td>0 years, 0 months, 17 days</td>
<td>0 years, 0 months, 7 days</td>
<td>P52</td>
<td>Intracranial nontraumatic haemorrhage of fetus and newborn</td>
</tr>
<tr>
<td>4</td>
<td>0 years, 0 months, 4 days</td>
<td>0 years, 0 months, 4 days</td>
<td>Q23</td>
<td>Congenital malformations of aortic and mitral valves</td>
</tr>
<tr>
<td>5</td>
<td>0 years, 2 months, 27 days</td>
<td>0 years, 2 months, 9 days</td>
<td>G93</td>
<td>Other disorders of brain</td>
</tr>
<tr>
<td>6</td>
<td>0 years, 2 months, 2 days</td>
<td>0 years, 1 months, 25 days</td>
<td>P91</td>
<td>Other disturbances of cerebral status of newborn</td>
</tr>
</tbody>
</table>
## Cancer Patients

<table>
<thead>
<tr>
<th>Pair</th>
<th>CPCH Group</th>
<th>BCCH Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Stage 4 neuroblastoma 10 years, 4 months, 27 days</td>
<td>Neuroblastoma 13 years, 0 months, 9 days</td>
</tr>
<tr>
<td>8</td>
<td>Relapsed ALL 18 years, 7 months, 24 days</td>
<td>ALL 14 years, 7 months, 5 days</td>
</tr>
<tr>
<td>9</td>
<td>Medulloblastoma 7 years, 1 months, 30 days</td>
<td>Medulloblastoma 6 years, 10 months, 4 days</td>
</tr>
<tr>
<td>10</td>
<td>Metastatic osteogenic sarcoma 15 years, 3 months, 29 days</td>
<td>Bone tumors 22 years, 0 months, 2 days</td>
</tr>
<tr>
<td>11</td>
<td>Osteosarcoma 13 years, 8 months, 7 days</td>
<td>Bone tumors 10 years, 10 months, 24 days</td>
</tr>
<tr>
<td>12</td>
<td>Brain Tumor 5 years, 2 months, 6 days</td>
<td>Astrocytoma 19 years, 10 months, 5 days</td>
</tr>
</tbody>
</table>
Matching Process

• Challenges/Limitations
  – ICD code
  – Age flexibility
    • Case < 1 year: Control up to 3 months older/younger;
    • Case 1 - 2 years: Control up to 6 months older/younger;
    • Case > 2 years: Control up to 12 months older/younger.

• Criteria changed for cancer
  – Died in the same period
  – By disease
  – Partially considering age
  – Shorter diagnostic-death period for comparison

• Preliminary Conclusions
  – Selection Bias
  – Need for a clinical tool to classify eligibility
  – Close partnership CPCH/BCCH
Data Retrieve

• CPCH
  – Average cost/day/type
  – Chart review

• BCCH database
  – PHSA data retrieving
  – Number of hospital admissions per type
  – LOS per type
  – Average cost per day/type
  – Chart review
Data Analysis

• Limitations
  – Small sample size – statistical inferences and power, other confounding factors
  – Differences in follow-up times across pairs

• Modified paired t-test (correlated data) – if normally distributed
  • $\Delta$ LOS/month (scalling to the differences in the follow-up within and across pairs)
• Wilcoxon signed-rank test – if not normally distributed
• McNemar’s test (drugs, mechanical ventilation, CPR)
Economic Evaluation

• Descriptive Cost-Analysis
• Assure Comparable Cost Comparison
• Δ Cost / type admission / day
• Δ Cost / shifting health care setting
Learning/Contribution

- Systematic review
- Need for standardized measures for outcomes
- More accurate local cost-comparison
- Suggest differences population
- Common sense/clinical impression not always confirmed by research investigation
Thank you!

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