Bridging the Gap: The Paediatric Advanced Care Team (PACT) Community Outreach Nurse Practitioner Model

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**THE INNOVATION**

- The PACT Community Outreach Nurse Practitioner (NP) Model was a partnership between:
  - The SickKids Paediatric Advanced Care Team (PACT)
  - Emily’s House Children’s Hospice
  - Toronto Central Community Care Access Centre

- Based on the **Guiding Principles and Measures of Success** outlined in the Declaration of Partnership, Ontario’s “roadmap” for improving palliative care:
  - Improve access to care in the community
  - Provide more support for primary providers
  - Improve care for those in their last year of life
  - Improve quality of care by optimizing the best of what is currently available
  - Facilitate end-of-life (EOL) care outside of the hospital
  - Reduce avoidable hospitalization/ED admissions

**OUR GOALS**

- The goals of our innovation were to:
  - Improve EOL care for children across 5 Ontario Local Health Integration Networks (LHINs)
  - Build capacity and confidence among local community healthcare providers (HCPs)
  - To achieve our goals, the PACT NP Model sought to:
    - Improve transitions from hospital to home/hospice at EOL
    - Help manage problems in the community by providing support and mentorship to local HCPs
    - Overseer day-to-day care of patients admitted to Emily’s House at the EOL

**CULTURE AND CARE EXPERIENCE**

- Pediatric palliative care (PPC) is required by small numbers of children over a large geographic area
- Most community HCPs express a high level of discomfort providing PPC
- Families worry about the community’s ability to care for their dying child, resulting in:
  - Reluctance to be at home at their child’s EOL
  - Repeat and unplanned visits to tertiary care centres
- Community HCPs desire real-time support and mentorship from a PPC expert

**IMPACT STORY**

- Nearly 2/3 of participating families and HCPs believed the NP’s involvement prevented unnecessary ED visits and hospital admissions
- The NP’s mentorship and support resulted in a willingness to care for dying children among previously reluctant community HCPs
- As a result of this innovation, Dr. Rapoport was awarded the 2016 “Dr. S. Lawrence Librich Award for Palliative Medicine in the Community” by Hospice Palliative Care Ontario

**IMPACT AND RESULTS**

1. **Demographic & Contextual Features**

   - 38 children enrolled from April 2015 to Jan 2016, from all 5 target LHINs
   - 2 included from additional external LHIN
   - 82% from outside the Toronto Central LHIN (SickKids LHIN)
   - Age of patients ranged from 3 days to 17 years old
   - NP collaborated with 90 unique community HCPs
   - 458 distinct interactions
   - NP participated in 439 distinct patient/family interactions

2. **Patient & Family Experience**

   - 93% felt that having a trusted member of PACT in their home, handing over to the community HCPs entrusted with their child’s EOL care, was beneficial (N=15/17)
   - 100% felt the NP positively influenced their experience over the last month/weeks of their child’s life (N=11/11)

3. **Community Provider Experience & Capacity Building**

   - 96% (25/26) of community HCPs strongly agreed or agreed that the NP helped with the transition home
   - 86% (19/22) of community HCPs valued the NP’s ongoing involvement
   - 92% (11/12) of Emily’s House staff strongly agreed or agreed that the NP helped improve patient care

4. **Health System Performance & Utilization**

   - 100% (21/21) of the children who died during the pilot did so in their family’s identified location of preference
   - 64% (7/11) of bereaved family respondents believed the NP’s involvement prevented ED visits or hospital admissions
   - 64% (14/22) of HCP respondents believed the NP’s involvement prevented ED visits or hospital admissions

**SPREAD PLAN**

- Several aspects of the PACT NP Model suggest the potential for successful spread across Canada
  - Regional Approach – PPC in all communities requires support from experts at the regional tertiary pediatric institution
  - Utopia Problem – community HCPs everywhere lack comfort and capacity to care for dying children
  - Mentorship – infrequent PPC cases demands mentorship not just education (if you don’t use it, you lose it)
  - Flexibility – our NP worked with unique HCPs in each community, mentoring anyone willing to provide PPC
  - Technology – telemedicine may be used to extend the NP’s reach to remote areas

**LESSONS LEARNED**

- Leverage trust
  - By leveraging the existing trust in the tertiary care centre, families and HCPs feel more comfortable and confident transitioning to the community at EOL
- Education is a 2-way street
  - The NP (and the tertiary PPC team) gained valuable insights into the unique strengths and challenges existing within each local community when caring for a dying child
- Nothing beats face-to-face communication
  - The ‘warm’ handover at the transition visit between the family, the HCPs, and the NP elucidated important issues that simply were not captured on standard referral forms

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