Notes from Barrie Palliative Care Session

July 6, 2016

Summary of Discussion:

Question 1: What do you think are the strengths of the current palliative care system in the community?

- So many different resources from diagnosis to treatment
- Great volunteers
- Provider training to staff, family and care providers. Education and awareness about the palliative care resources out there
- Intake of paediatric palliative
- 24/7 to nurses through the palliative care network
- Physician champions
- Dedicated and passionate people in palliative care
- Intensive case management through CCAC
- Community palliative care rounds
- Symptom relief kits in the home
- Wonderful residential hospice
- Faith community accessible to palliative care
- Enhancing partnerships in the community

Question 2: What are the opportunities to improve palliative care in this community?

- Transition, communication of primary care in palliative care
- Common communication tool would be beneficial
- Better equity in access/distribution of supports in retirement homes, inequity in the number of hours a patients receives (in home compared to retirement homes)
- Need to provide more palliative services longer and earlier
- Development of palliative care teams at the front line level
- More advanced care planning discussions early
- More support for the nursing staff and for caregivers
- Provide anti-oppressive care for diverse populations
- Need mental, emotional, and spiritual care as well as the physical care, recognizing when we need to pull in others and resources to help with the support
- Have physicians start advanced care discussions
- More communication to the community about the palliative care resources and that it is not just end of life care
- Improving coordination between LHINs and communities

Question 3: What 3 words or phrases would you use to describe your ideal vision for palliative care in this community?

- TEAMS: Timely, Empathetic, Appropriate, Measurable, Seamless
- CARE: Coordinate, Accessible, Readily Available, Equitable
- Peaceful, dignified and safe

- Standardized care, accessible, available, inclusive (of all people and disciplines to ensure choices are given and patient is provided respect and dignity)
- Living well through the dying process

Additional advice for Creating Structure

- We want you to listen
- Be transparent and inclusive
- Individualize the care needed, flexible system to adjust to patients need
- We need to go to the frontline staff to ask for advice, ask the agencies
- Hang on to the strengths that have already been developed
- Maybe communicate with us by a blog
- Need a bit of both push and pull of information
- Advisory board will be engaging patients

Submitted Worksheets

Repeated Themes:

- Question 1:
    - Having trained volunteers to work in homes and at Hospice
    - Provider training – staff, family, care providers – from palliative care network, cancer care
    - Knowledgeable multi-disciplinary team
    - 24/7 access to nurse consultants
    - Weekly community palliative rounds

- Question 2:
    - Care inclusive of all care providers (family, PSWs, neighbors – whoever is involved with that client)
    - Regional improved communication, collaboration and coordination amongst hospices and the palliative care network
    - More standardized training for PSWs
    - More communication and integration with other agencies
    - In some geographical areas still difficult to access PC physician to support

Question 1: What do you think are the strengths of the current palliative care system in this community?

- Having trained volunteers to work in homes and at Hospice
- Now educating family physicians about palliative care
- Good communication between all systems and services
- Now interact with and support people from diagnosis to bereavement
- Early intervention (because of volunteers)
- We show excellent results compared to the rest of the province
- Excellent pain management
- Large volunteer base
- Residential hospice

- Palliating people at home
- Faith leaders engaged
- Residential hospice (10 bed facility)
- Training Program on palliation for volunteers and Board members
    - Variety of sessions to ensure everyone has opportunity
- Expansion of communication bereavement groups
- Community support
- Volunteers
- Hospice education for other organization staff
    - Clients have accessed community
- Dedicated cancer palliative care unit, increased visibility
- Enhancing partnerships with the community
- Dedicated palliative staffing – high quality care provided
- More accessible to the care providers
- Awareness of services
- Provider training – staff, family, care providers – from palliative care network, cancer care
- More training for nurses and PSWs – to provide end of life care
- Symptom relief kit – training of families and staff to enable them to stay home longer. Making it more comfortable for patients and families
- Ability to make referral to palliative network nurse
- Retirement – able to keep residents to end of life if at all possible
- Volunteers play such an important role
- Sharing information of advance care planning and encouraging early intervention
- Enabling them to focus on the quality of life
- Intake of paediatric palliative for caregiver relief at HS
- Education – fundamentals of PC, ACP
- Timely access to services and at home
- 24/7 access to nurse consultants
- % increase palliative patients in hospice as opposed to Hospital
- Qualified staff to do outreach
- Interdisciplinary teams – SW, volunteers, physicians, pharmacists, etc.
- Access to pastoral services
- De-briefing often death for families
- SME's working in palliative care
- EDITH protocol
- Highly skilled, collaborative team work
- Weekly community palliative rounds
- Knowledgeable multi-disciplinary team
- Access to residential hospice beds
- Hospital/community/hospice engagement
- Access to education
- Great bereavement support
- Strengthening paediatric care

- EDITH/SRK
- Hospice Simcoe ranks 2nd in the Voices Survey for Residential Hospice in Ontario
- Dedicated people that are passionate about palliative care and service provision
- Dedicated leadership – cancer care, FHT, NSM HPCN, Hospice Simcoe
- Recognize need for change and linkage of service providers
- Good mechanism to ensure all patients have palliative physician
- EDITH protocol/SRK
- Intensive case management through CCAC
- Multi-disciplinary PC rounds – 2nd Tuesday RVH (standardized)
- Access to good palliative care education
- 24/7 on call nurse consultant NSM HPCN
- Residential Hospice access (# of beds)
- Volunteers and informal PC providers
- Development of a stronger palliative care approach in LTC and developing in retirement homes and across all sectors
- Improved flow of communication
- Earlier identification of PC (still room for improvement)
- Strength of paediatric palliative care – developing physician support
- Hospice
- Pain management program (network)
- Volunteers
- Community support
- Physician champions
- Recognition of government support
- Good training/education
- Support provided to the long term care community
- Nurse practitioners

Question 2: What are the opportunities to improve palliative care in this community?

- Opportunities for doctors to become comfortable in discussing palliative care with their patients
- More communication to the community about services, and that palliative care is not just end of life care
- Improve coordination between communities when discharging from one to another
- Get the word out about Advanced care Planning
- Opportunity to provide anti-oppressive care
    - More inclusivity to different cultures/diverse populations
- Use social media to assist in fundraising
- People working in silos – not a smooth transition of care (getting better)
- Could be seen more as a priority for physical health of a person rather than social, emotional, mental, spiritual (sometimes spiritual isn't even considered)
- Communication to public regarding ability to provide culturally sensitive/safe and diverse care (care accessible to all)

- Remove stigma of palliative care/death
- Care inclusive of all care providers (family, PSWs, neighbors – whoever is involved with that client)
- Respite care for caregivers
- Clearer communication/education about the dying process earlier in the process
- Government to consider wage increases for palliative / community
- Regional improved communication, collaboration and coordination amongst hospices and the palliative care network
- Improved communication between care providers. Ex. Patient dies, PSW shows up to provide care, agency not informed of death
- Increase the number of hospice beds for the increasing population in the area
- Look at existing beds available within the community
- PSWs that are trained and they are the ones dealing with end of life clients
- More support for nurses and staff in retirement/LTC in order for them to stay longer at home – reduce caregiver burnout
- More standardized training for PSWs
- More advance care planning
- LTC "private room"
- Potential shortage of hospice beds
- Intake vs. availability (assessment)
- Shortage of care in community (ie. OSMH closure palliative floor)
- Funds for creation of more hospices
- Move volunteers (weekends, after-hours, etc.)
- Monthly/quarterly nursing debrief/de-compression
- Review PPS – Qualifications to enter Hospice/palliative care
- Longer duration of palliative services in community
- More government funding for palliative home care
- Increase in Physicians willing to do house-calls
- Need for alternative pain relief besides palliative sedation
- Waste of medication/coordination of medication dispensed in home
- Lack of primary care services involvement
- Lack of awareness of services
- Re-structure paperwork to make it easier to have access to palliative care
- Share a common record
- Equal access to education (paid for)
- Develop palliative care teams at the provider level – Residential Hospice as the 'Hub' of P.C.
- Certain demographical areas still lack palliative physician support – Innisfil, Angus, Coldwater
- Possible to have MD champions
- NPs should work for a direct service provider ie. Hospice
- Decrease duplication/increase efficiency of already available support (ie. NSM HPCN 24 hr consult available and hospice nurse also available)
- Increase EOL (days-weeks) support in the home – Increase respite

- Clarity of roles – CCAC/NSM HPCN/Visiting Nurse, decrease duration – (hospice Simcoe could be the sole service provider)
- Retirement home supports at EOL – disconnect/unequal services
- Better equity of supports in retirement homes and certain other living environment (in RH do not have PC CCAC case manager)
- Lack of communication and trust in care providers assessment due to 'process', need own assessment
- Services provided not always geared to need, but to 'guidelines'
- Some primary care providers still not aware of who to contact
- Prognosis discussion not always done well
- In some geographical areas still difficult to access PC physician to support
- Care in emergency – lack of knowledge/education or unaware of goals of care
- PC provided in nursing clinics – lack of privacy, consistency can be difficult for patients to access
- Patients end up in emergency due to inability to have care streamlined (ie. Blood transfusions)
- Holiday/after-hours 'Access to Care'
- Lack of education with some PC providers and public
- Gap in availability of care for patients that are not able to stay on own but not necessarily EOL
- Lack of respite care/support to prevent care provider burnout
- Lack of understanding/supports for non-malignant diagnosis
- Not good outcome measures as to quality of PC given/received
- More funding
- Strengthen the communication when patients transition from primary care to palliative care
- More public awareness
    - Discussion of advanced care planning
    - What resources are available
- More communication and integration with other agencies
- Improved technology
- Common communication tool

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- Peaceful, dignified and safe
- Standardized care, accessible, available, inclusive (of all people and disciplines to ensure choices are given and patient is provided respect and dignity)
- TIME: Timely, Integrated, Multidisciplinary, Efficient
- Communication, access, collaboration, client/family centered care
- Compassion, equality, continuity
- Your life journey supported by all
- Living well through the dying process
- Seamless transition

- Patient focus regardless of other influences