

Interest/Networking Groups Report 2009

In general the networking interest groups were well attended and all the groups that reported wished to see the forum continue next year with some changes as to timing, etc. as listed.

Rural

This group made suggestions to the conference planning for next year about both the venue for the networking sessions and the content for the conference itself. They felt that the networking groups should not be in the evening as it made for too long a day. They felt that more panel discussions on specific issues, with representation from varying perspectives to discuss their experiences/points of view, (i.e. rural, urban, First Nations, etc) would be desirable. They also would like to somehow encourage more abstracts from rural providers.

This group's two priority issues they wished to bring to the attention of OPCA were:

1. The need for more mentoring and education for rural family physicians on palliative care.
2. More flexibility in policies and regulations to reflect the needs and realities of rural areas.

Nursing

Facilitator – Cathy Joy

This group felt strongly that they get a copy of the report or feedback from this forum and suggested that the yahoo palliative care internet group might be used to facilitate the process. They also found the timing of the sessions made the day too long and suggested perhaps 5 – 6, before supper might be more appropriate

Their top 2 new priorities were:

1. One Voice – One Vision - complete and clarify consensus of 1 voice + 1 vision – and market it! To the Public, ourselves, schools – everywhere!
2. Competency and capacity building – work on competencies for all nurses in all sectors (thus resulting in increased capacity).

They also wanted to finish and keep the momentum on Symptom Response kits, common referral forms, the Expected Death at Home Protocol, and Advanced Clinical Practice work.

Other issues discussed were: Resources both in nursing and all sectors (i.e. pay equity, QOL issues, 24/7 outreach, etc.), CCAC program and access consistency provincially (i.e. RFP's), and a provincial repository to house tools, research projects done and being worked on (maybe nationally)

Paediatric

Facilitator: Marion Rattray

This group also thought the session would be better held earlier in the day and suggested breakfast or lunch meeting as a preferred time. They also felt it might be valuable to hold the sessions in one room

with tables assigned to specific groups and an ability to rotate between groups.

They listed three priority issues, which were:

1. Palliative care being recognized as a speciality (including paediatric palliative care).
2. Children need a voice, we need to advocate on behalf of dying children who need palliative care.
3. Paediatric palliative care is not the same as adult palliative care. The needs of children and their families are more labour intensive than the adult palliative care patient.

The group had great discussion around challenges and successes.

Challenges

- Advance the profile of paediatric palliative care – children do die!
- Clarification of PAS and euthanasia, palliative sedation
- Advocacy on behalf of those who have no voice
- More research required when adult meds used for children
- increased care demands of palliative child equals burden on family (financial, psychosocial...)
- Dying equals failure of health care system therefore palliative care is futile treatment.
- Need for more awareness about types illness and death in children (not all children die of cancer - only 20% of population). Need for more equality of services and supports for all dying children

- Parents are experts on the care of their child but “we know the care of dying children”.
- Fragility and unpredictability of course of paediatric life limiting illness
- Family centered care is core principle
- Research net work for paediatric palliative care in Ontario

Success

- Hospice for paediatrics a success
- Research ongoing
- Respect of parental role in care of dying children
- Long term relationship with child and family
- Bereavement of parents and siblings
- Bereavement beings @ diagnosis – even with early pregnancy loss, perinatal and antenatal support imperative

Aboriginal

Facilitator: Sharon Preston

This group also preferred a different time for the session. They felt that there should be a workshop specifically with the focus on aboriginal communities to describe the issues and ask: “do all communities have the same issues or are there differences? “. It should be facilitated by a First Nation’s person and all communities should be contacted and attendance promoted.

End of Life Care Networks

The number one priority for this group was the need to do an inventory of resources. There were many concerns discussed around retention of Directors and thus the sustainability of Networks. Challenges here included short contracts and benefits. There was discussion around the varying degrees of supportive at the LHIN and/or CCAC levels with some of the Networks struggling. It was felt that there was definitely a need to be creative.

The second priority identified was a Provincial Advocacy strategy utilizing known PEOLN advocates at a political level.

Rehabilitation/Complimentary Therapy

There were unfortunately some venue challenges for this group and only one practitioner was able to give feedback. He wanted to highlight a complimentary therapy that has potential for pain reduction, the Feldenkrais method. It has empirically been shown to help recover significant functionality and decrease in chronic pain. He had worked with individuals with stage 4 cancers, others with a diagnosis of MS, and a spouse who was burned out after several years of caring for a husband before his death.

He is interested in exploring the potential for Feldenkrais lessons to improve quality of life for people requiring palliative care perhaps in a residential hospice in the Mississauga/Oakville/Burlington area

His contact information is available if interested.

Volunteers

This group indicated that they would like the interest group forum to continue and had no issues with the format or timing. They listed the following two priority areas.

1. Education:
Workshop on explaining HAO training programs (i.e. bricks & mortar hospices)
Could this be online?
Where are we with this (training programs)? – particularly when dealing with new volunteer groups (Baby Boomers and Generation X & Y)
2. Professional Staff and Volunteer Relations:
Standards and guidelines for volunteer service and recognition for hospice volunteers in LTC & Hospital situations.

Psychosocial/Spiritual

This group also wanted the forum to continue and listed the following three priority issues:

1. Consent: for example patients or clients are asked if they “want” to see a Social Worker or chaplain but we do not ask if they want to see a nurse or physician or pharmacist. Social Work or Chaplain should be able to go in and meet with the patient and assess them, then the patient can decide on ongoing involvement/therapy.
2. Terminology: only seeing religiosity of the role not the spiritual, meaning-finding aspect of the role. Seeing the person not just the disease or nursing task to be done.

3. Clarifying competencies for Spiritual Care Providers (i.e. Scotland has 4 levels of competencies). Marie Curie Hospice
→fit with CCO model being developed.

Concluding comments

This was a learning year for the interest group forum with the new collaboration for the conference and there was very good input from the individual groups that will be taken into consideration when planning for the next conference.

Thank you to all the facilitators of the groups and participants. We look forward to interacting with everyone next year.