

Alberta & Territories (NWT/Yukon/Nunavut)

Putting Progress into Action Workshop

Small group Discussions

June 16, 2004

Gaps

Patient and Family Care

Continuity of care

 Duplication

 Communication from shift to shift, from service sectors

Navigation of clients through the system

Fragmented care

Need coordinated access

 Linkage both ways

 Should be 7 days a week and 24hrs a day

Remote areas- recruitment and retention

Training of family caregivers – in some cases families are trained to provide complex care at home but home care professionals are not

Criteria for admission varies across service sectors and regions

Criteria does not necessarily reflect needs of patients (ie do not fit into criteria)

Cultural differences on what is palliative care- must ensure palliative care meets the needs of what is believed to be appropriate to the individual and family

Need to educate communities, health care professionals, support staff and indifferent settings (ie acute, home care, long term care- have different educational needs based on services they provide)

Too much focus on disease

Strategies to educate different health care professionals

Level of education of health care professionals (is support aides) differ

Patient must understand their condition (ie control of disease vs cure of disease)

Physicians rely on support services (is nurses, social workers, etc.. to help coordinate care and manage care)

Caregiver support

Lack of someone taking responsibility to coordinate care

Still focus on curative, disease management, prolonging life

Education on personal directives

Attitudinal education and comfort around own mortality and death and dying

Regions need to have palliative care programs

Start linkages at Cancer clinics

Need to also link non-cancer group where appropriate

Flexibility on interpretation of policy (care should be based on need not policy)

Education

Sustainability of educational programs to informal caregivers
Rural vs urban – ie David Thompson has no education program
Lack of Volunteers
Mentorship programs
Ensuring core competencies within core curriculums
Recruitment and retention for rural areas (including salary replacements and coverage for those who leave the region to receive further education)
Levels of educational opportunities (ie finding the most appropriate venue to receive education)
Filter up education , community, colleges, etc.
Cost of transportation

What works

- Calgary 2 day training for volunteers
- Hospice Victoria training for volunteers
- Undergrad – Faculty of Nursing program at U of C
- Telehealth
- UNA contract – 3 days paid educational leave
- Yukon is developing an educational strategy
- Corporate support
- ACHRN

Opportunities

- Telehealth
- Link with educational institutions
- Pallium and other palliative care opportunities available
- Intersectoral perspective

Research

Impact of research on front line workers and managers workload
Lack of dedicated HR for research
Networking
Sharing of info – integration
Ethiivs review process
Lack of clearing house- where is the vision of education and research
Lack of research in rural palliative care
Strengthen qualitative and quantitative aspect of palliative care research

What works

- Yukon model
- ACHRN
- Supportive CEO and senior management

Advocacy

Rural

- Decrease public awareness
- Small number of advocates
- Need public awareness in order to mandate
- Strong associations needed
- Underserved areas such as small cultural groups (colonies) rural especially
- Clients and families are not able to advocate or do not know how to do so or not aware (we need our own TV show)
- PPS transitions book
- Need slogan “cancer can be cured – can not capture palliative care
Eg “till death do you part” (BC)

Management/Administration

- Public policy
 - Access
 - Minimal data
- Determine what are core services
- Population health (start there vs later eg LTC)
- Primary health care focus (social model), link with others
- Who administers care
- Palliative care as a separate service- how to identify
- Access to services
- Lack of common definitions
- Palliative care expertise vs access to regular services
- Inventory of available services in the province
- Palliative Care defines – when start – diagnosis, pain and management issues, when?, when should system and resource be available for services to commence

How do we reach the decision-makers?

- Workshops on how to influence the decision makers
- Toolkit on advocacy
- Federal projects on how to influence the decision makers
- Research and documentation/data to communicate how programs will save dollars
- Gather and show data, present data to CEO and Boards
- Develop the business case
- Balance quantity and quality outcome based case
- Need face to face contact with decision-makers
- Utilize family experience
- Listen to the staff, find out their thoughts around palliative care services and present that to decision-makers

Cancer board reports- share the info and raise awareness
Cabinet Ministry (Sharon Carstairs- or others that have been personally affected)
Movie star with palliative disease
Business orientation (utilization, save \$ later by helping now, speak language of administrators)
Moral persuasion (how society treats disadvantaged and dying)
Pallium workshops
Health Councils (regional)
Accreditation standards

What kind of supports can Pallium Provide?

Education component to physicians and RN's
Presentation to Board
Council of CEO's and continuing care council leaders
Sessions like today are helpful
Interest to provide palliative care but need supports and resources to do so
Advocacy toolkit
Clearing House
Link Educational Activities
Regional weekend courses
Connecting sectors and people
Television
Public service announcements
International Activity
Define core elements (nursing hours, 24/7, hospital, ER-measurable cues)
Too many small groups- need to link AIDS, ALS, etc- coalition had started but ended
 National model but need a provincial model, need coordination provincially,
Alberta Strategic Alliance Strategy
Need multi-level approach
Nurse help line
Western Canada telehealth
Forum of what has been successful across provinces (ie best practice in palliative care services)
2005 conference – incorporate pallium sponsored panel
Professional journal publication on core services
Workshop on advocacy strategies