Models of Palliative Care Delivery

Palliative Care in Canada is often associated with institutional care and traditionally Palliative Care programs have been developed within acute care hospital settings. Within the past decade, new models have evolved to meet the changing needs and expectations of those living with HIV/AIDS. Across the country there are numerous creative responses to the care needs of persons living with HIV/AIDS.

"The services available are not sufficient, both in terms of access to palliative care beds and availability of services to support care in the home"
– one voice –

Common models of care delivery include, but are not limited to:

Palliative Care Units/Beds
Free-Standing Hospice
Palliative Care Consultation Services
Community Palliative Care Programs/Services
Volunteer Hospice/Palliative Care Programs

ISSUES ARISING IN THE PROVISION OF PALLIATIVE CARE SERVICES:

Regardless of the care setting, there are a number of important issues to be considered in the development and provision of Palliative Care services. This section outlines some challenges and potential strategies.

CHALLENGES	POTENTIAL STRATEGIES
INDIVIDUAL CHOICES	
1. Individuals may choose care options which are impractical or contrary to the wishes of family or other caregivers	1. Care options must be clearly discussed with individuals early in their illness to ensure that choices are informed. To their best ability, caregivers must respect the individual's decisions
CONTINUUM OF CARE	
1. Movement across the care continuum is often fragmented	1. Care providers must talk early with individuals living with HIV/AIDS about their care options and preferences
2. There is often a lengthy waiting list to access services	2. Facilities with waiting lists must have an outreach component. Regional service registries could facilitate access to care
CARE IN RURAL VS URBAN CENTRES *The challenges identified for rural areas may also apply in some suburban areas.*	
1. Low prevalence of HIV/AIDS in rural communities may preclude development of HIV-specific Palliative Care programs	1. Services must be integrated into existing Palliative Care and hospice programs, i.e. reviewing current programs (including admission criteria), training of all staff and volunteers in HIV and related issues, reviewing fiscal and other resources to ensure appropriate allocation to meet complex care requirements

CHALLENGES	POTENTIAL STRATEGIES
2. There are often fewer resources available in rural communities	2. Hospital and community based programs must develop services collaboratively. Prevent waste of unused supplies by establishing system to recycle supplies
3. Persons living with HIV/AIDS may live outside the local community, resulting in long-distance travel for designated caregivers. Other factors include time, inclement weather safety of the caregiver	3. In some communities, it may be appropriate to develop regional teams (both professional and volunteer care teams) to most effectively service outlying areas. To ensure the individual receives required care as scheduled, and to ensure safety for staff and volunteers, appropriate backup systems and supports must be built into community programs. These may include: use of cellular phones in caregivers' cars, backup caregiver for each scheduled shift, 24-hour on-call system, etc.
4. Caregivers may have had limited exposure to HIV/AIDS, resulting in lack of HIV knowledge, discrimination and fear	4. Additional to Palliative Care education, designation of an HIV/AIDS Palliative Care consultant is a useful support to caregivers
COMMUNITY CARE CHALLENGE	
1. Many individuals living with HIV/AIDS receive care from several caregivers and agencies in the community. This can result in fragmented and/or uncoordinated care, lack of communication, "splitting", "turf wars", and less-than-optimal service to the individual	1. Designate a coordinator to work collaboratively with the individual. This simplifies lines of communication for all involved, particularly the person living with HIV/AIDS. The designated coordinator must be agreeable to the person living with HIV/AIDS and their role validated by all members of the team. Some programs have developed enhanced communication tools which are left in the individual's home for use by the individual and caregiver. It is particularly important to coordinate assessment activities through "shared" documentation to eliminate duplication and unnecessary individual assessments. When scheduling caregivers, strive for consistency of caregivers wherever possible. Regular team or teleconferencing meetings of the "care team" are essential if interdisciplinary collaboration is to be achieved
2. Many community-based Palliative Care programs do not operate 24 hours/day. This precludes many people living with HIV/AIDS from staying at home	2. To permit the option of dying at home, community-based Palliative Care programs must provide service 24 hours/day. Access to respite care is essential to any community program. Palliative quick response teams which respond to urgent needs may prevent unnecessary hospital admissions
INSTITUTIONAL CARE CHALLENGES	
1. Many Palliative Care units strive to create a home-like environment with greater emphasis on individual autonomy	1. Institutions which provide Palliative Care must strive to develop an atmosphere promoting individual autonomy, dignity and choice
2. Providing care in acute care hospitals is costly. An American study found the average per diem cost in acute care hospitals is $1,105.00 to $1,235.00 Canadian dollars[1]	2. Models of care which demonstrate quality care and cost effectiveness should receive funding priority

CHALLENGES	POTENTIAL STRATEGIES
RESOURCE ALLOCATION CHALLENGES	
1. Health care reform across Canada is shifting to community care	1. Community programs and institutions must foster and develop strategic partnerships to ensure efficient use of scarce resources, while avoiding duplication of services
2. In allocating funds, it is generally held that provision of care in the community is less costly than institutional care. Although this may be true, this view is largely subjective and unsubstantiated	2. Initiate research comparing costs associated with care provision in various settings
3. Programs must manage their limited resources and justify the economics of their activities	3. Most papers that address economic issues of Palliative Care simply compare total program costs with average hospitalization costs, and do not perform an appropriate economic analysis. If Palliative Care is to find a place in Canadian health care, more complex analyses examining economic effectiveness, benefit and even program utility must be done
QUALITY OF CARE CHALLENGES	
1. Palliative and Hospice Care programs need to be credible in Canadian health care	1. To be credible, Canadian Palliative Care programs must develop a consensus regarding practice and standards of Palliative Care. This process is ongoing through the Canadian Palliative Care Association and the Canadian Council on Health Services Accreditation
2. Programs need to continuously improve the quality of the care they provide	2. Through development of program standards of practice, and application of continuous quality improvement, programs can measure activity outcomes and continuously improve quality of care

DEVELOPING YOUR COMMUNITY'S CARE DELIVERY MODEL

Persons living with HIV/AIDS have complex Palliative Care needs which require various approaches to care delivery. Several different models have evolved across the country in response to consumer needs.

Whichever model of Palliative Care delivery you choose, it is important that it be driven by the:

1. needs of the persons living with HIV/AIDS in your community
2. response by your community to these identified needs
3. available resources and potential partnerships

Considering these factors, Palliative Care can be delivered in a setting which will best meet the identified needs of each individual and, thus, enhance quality of life.

"There is a need for coordination of care which is collaborative rather than controlling"
– one voice –

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