One Voice

> *“Three weeks, two dead — two*
> *more lost from the magic*
> *circle. To put it another way,*
> *two more rocks flung at the*
> *vast glass house of the world’s*
> *complacency – falling short as*
> *usual. But the numbers of the*
> *disappeared are relative, at*
> *best, and buried in the*
> *thicket of lies called statistics.*
> *As Randall Jarrell said*
> *succinctly, counting bodies*
> *of another war:*
>
> *‘We died on the wrong page*
> *of the almanac...*
> *When we died they said,*
> *Our casualties were low.*
>
> *As for my own losses,*
> *the pile of bodies is hardly*
> *countable anymore*
> *– except in the heart –*
> *because the dead outnumber*
> *the living now.’”*
>
> *– Paul Monette* [1]

> *“...the measure of our response*
> *to AIDS*
> *is the measure of the*
> *humanity of our society...”*
>
> *- Dr. David Roy* [2]

“The great tragedy of the AIDS epidemic lies in our unwillingness – individually or collectively – to face death. Instead, we have chosen to look for someone or something to blame, thereby diminishing the meaning of our deaths.

The lives and stories in all our communities bear witness to what we are living through, and can bring meaning to our deaths. Caregivers must tell the stories of those they have known, those who worked hard at living...and dying.

Stories often answer the questions, “What brings you here?”, “How are you feeling?”. The caregiver must initially recognize and understand the true function of these narrative efforts. They explain our life events, sustain and/or project certain images of us, justify our behaviour, illustrate how we handle the crises and transitions created by our illness.

Through our stories, you can help us find answers in our search for meaning. Help us work together to alleviate our suffering, without excessive drugs making us unaware of our environment. Stories will help us deal with multiple losses in our lives, which incite fear that we will be the one left behind, with no one to care when those close to us have all died or walked away. In our isolation and fear, we need to be assured that services will be available to care for us when our time comes.

Our stories must be stated loudly – on behalf of those who died slowly, bit by bit, consciously accepting their inevitable dependence – assuring those who loved and wanted to care for them that such dying is not undignified. Recognize and support us through our deliberations around ending our lives at the moment of our choice, rather than facing the possibility of unbearable pain and suffering.

Through our stories, hear our concerns for our families, partners and friends. Help our parents – caught in their own web of aging, community and generation – to understand our grief and their own. Bridging disparate realities eases our isolation, enabling those around us to help us live safely in whatever place we choose to call home.

Listen closely to our stories and you will understand our desire for empowerment, for control over who we are and how we live our lives. In turn, you will help us be proud of who and what we are.

Help us share our stories so that others may know of a caring, compassionate and courageous way of living and dying.”

Anonymous

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What is HIV/AIDS?

INTRODUCTION TO HIV DISEASE

> *Without fear, HIV would be just another disease.*
>
> Author Unknown

HIV disease is caused by a retrovirus which infects lymphocytes and other cells with CD4 receptors. The primary effects of HIV infection are two fold. One is a progressive deterioration of immune system function, which leads to increased susceptibility to infections caused by viruses, bacteria, fungi, and protozoa, and also to certain malignancies. The other is progressive deterioration of the nervous system, mental deterioration, seizures, and sensory and motor changes.[1]

CD4 cell count is the term used to define the marker on specific lymphocyte subpopulations. These CD4 lymphocytes are responsible for the coordination of the immune system response. Declining CD4 cell counts are indicators of the degree of immune system compromise.[1]

The course of the disease is highly variable for any particular individual. Table 1, (next page) illustrates illness progression over time, and associated clinical management. Shaded areas identify clinical issues where consultation with more experienced colleagues could be considered.

Historically, HIV disease has largely affected gay or bisexual men or recipients of HIV infected blood and blood products. Today, more women are living with HIV infection than previously, as they increasingly become infected through heterosexual transmission or other risk behaviours. Women and children present with different symptoms than men and their experiences of HIV/AIDS are diverse. At the same time, the number of adults and children infected through HIV infected blood and blood products is decreasing. Diagnosis of an HIV+ child remains an indirect test of the HIV serostatus of the biologic family and the potential for multiple infected family members.

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TABLE 1: Clinical management by CD4 lymphocyte cell count

DEGREE OF IMMUNODEFICIENCY BY CD4 CELL COUNTS (PER MM^3)	ASSOCIATED SYMPTOMS AND ILLNESSES	CLINICAL FOLLOW-UP	MANAGEMENT				
		FREQUENCY OF FOLLOW-UP (MONTHS AND WHEN SYMPTOMATIC)	FREQUENCY OF CD4 TESTING (MONTHS)	ANTIRETROVIRALS	PROPHYLAXIS		
					PCP	TOXO	MAC
Over 1,000 virtually normal		q 6–12	q 6–12				
500 mild	*Herpes simplex,* Generalized lymphadenopathy, Shingles, recurrent bacterial pneumonia, Candida vaginitis.	q 3–6	q 3	Consider antiretrovirals and recommend if symptomatic.			
300 moderate	ITP, Thrush Tuberculosis	q3	q3	Recommend antiretrovirals			
200 moderate – severe	PCP, Toxoplasmosis, Esophageal candidiasis	q1	q3		YES	YES	
100 severe 0	Wasting, Lymphoma, Cryptococcosis, M. avium complex, CMV.	q1 or more frequently	As required				YES

* Table reprinted with the permission of the Society of Obstetricians and Gynecologists of Canada

The Interrelationship of Palliative Care & HIV/AIDS

HIV/AIDS has challenged Palliative Care. The complex dynamics of the disease process, the treatments, the social circumstances, including stigmatization, have all brought new dimensions to the provision of Palliative Care. Historically, most Canadian Palliative Care and hospice programs/services did not respond quickly to meet the needs of persons living and dying with HIV/AIDS. Over time, a few specialized programs have developed, particularly in centres with large numbers of persons living with HIV/AIDS. Today there remain large gaps in the Palliative Care resources available to persons living with HIV/AIDS across Canada.

WHAT IS PALLIATIVE CARE?

Illness often starts silently and most people only become aware that they have a problem either when symptoms start or when they receive information (laboratory or x-ray results) that suggests or confirms a diagnosis. Figures 1 and 2 illustrate the continuum of Palliative Care and how various Palliative Care programs fit into the trajectories experienced by the person living with any life-threatening illness, his or her family and those who care for them. All who participate are affected by illness and death, and become the focus of the attention of Palliative Care.

> *We now accept that dying of AIDS is qualitatively different from dying of other illnesses. Not only is there an excess burden on young people, but dying of AIDS remains a highly stigmatizing and socially isolating experience for the individual and his/her caregivers*

While symptom control and support may be needed prior to knowing the diagnosis, disease-specific therapies are likely to play an important role soon afterwards. As the degree of disease, distress, discomfort and dysfunction waxes and wanes over time, there is a varying need for:

- disease-specific therapy (anti-retrovirals, anti-microbials, chemotherapy and surgery), and
- therapy focused on providing comfort, including symptom control, and support

During the last days of a person's life, therapies that provide comfort and support are usually more important, though disease-specific therapies may continue until death, i.e. anti-retrovirals, anti-microbials for CMV.

DEFINITION OF PALLIATIVE CARE[1]

Palliative Care as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with life-threatening illness. During periods of illness and bereavement, Palliative Care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practices. Palliative Care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.

Palliative Care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family and caregivers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.

While many caregivers may be able to deliver some of the therapies that provide comfort and support, the services of a specialized Palliative Care Program may be required as the degree of distress, discomfort and dysfunction increases.

Integral to effective Palliative Care is the provision of opportunity and support for caregivers to work through their own emotions and grief related to the care they are providing.

FIGURE 1[1]

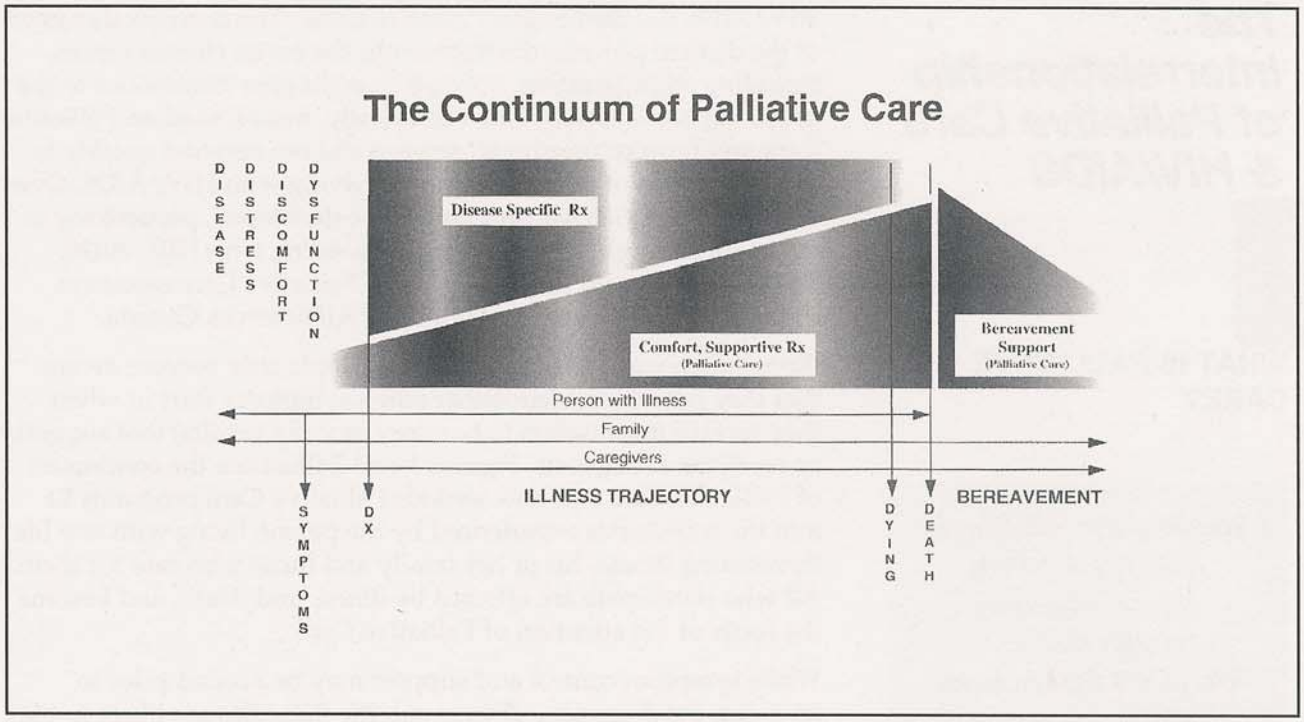
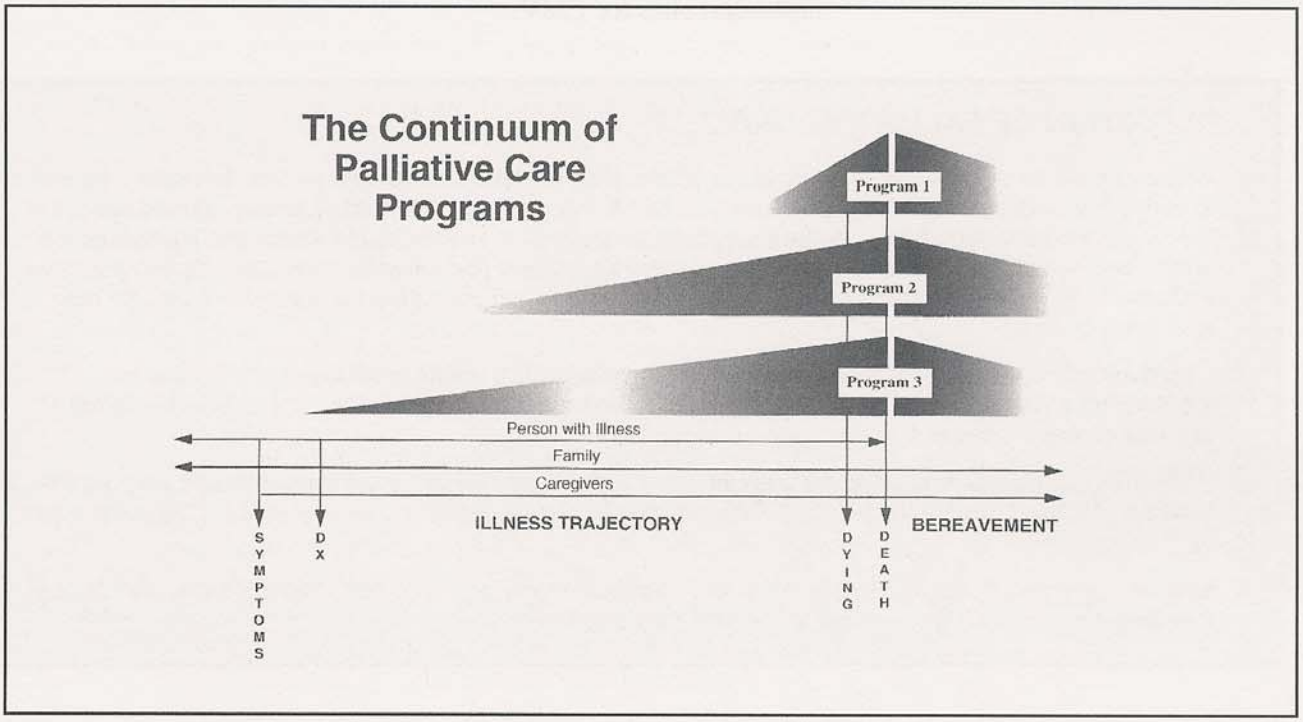


Figure 2 illustrates 3 different Palliative Care program models. Program 1 might be an inpatient Palliative Care unit where stay is only a few days. Program 2 might be a community based program or an inpatient consultation service which gets involved much earlier and remains involved. Program 3 might be an HIV clinic or a community nursing service that gets involved very early, and plays a varying role over time.

FIGURE 2[1]



PHILOSOPY OF PALLIATIVE CARE[1]

Palliative Care is based on the belief that:

- when living with a life-threatening illness, and especially when dying, every individual has the right to participate in informed discussion about health care resource options, and to choose the best possible option to maximize the quality of his/her life
- Palliative Care strives to meet physical, psychological, social, and spiritual needs of individuals and families, with sensitivity to personal, cultural and religious values, beliefs and practices. This includes supportive interventions at the direction of the individual, whether or not the individual is receiving anti-disease therapy
- care should be delivered in a person focused, family centered environment
- it is the individual's right to access information and services from an interdisciplinary team of appropriately trained professionals and volunteers, who receive continuing Palliative Care education and evaluation

PRINCIPLES OF PALLIATIVE CARE[1]

The principles of Palliative Care include:

1. **Holistic Care:** meets physical, psychological, social, and spiritual expectations and needs of the person and his/her family with sensitivity to personal, cultural and religious values, beliefs and practices
2. **Unit of Care:** the individual and his/her family
3. **Information is a Right**: it is the individual's right to be informed about his/her disease, potential treatments and outcomes, appropriate resources and options. It is the family and caregiver's right to be informed about the disease, potential treatments and outcomes, appropriate resources and options, respecting the individual's right to confidentiality
4. **Choice is a Right:** decisions are made by the individual and family in collaboration with caregivers, respecting the level of participation desired by the individual and family. The individual's and family's choices for care, settings of care and information sharing are respected within the limits of available resources
5. **Access to Care and Information:** individuals and families have timely access to information and services provided by Palliative Care when they need and are prepared to accept them. Information and care is provided in a language they can understand. Essential Palliative Care services are available 24 hours/day, 7 days/week
6. **Equal Availability of Services without Discrimination:** services are equally available to all regardless of age, gender, national and ethnic origin, geographical location, race, colour, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, or family status
7. **Ethics and Confidentiality:** care is provided in accordance with principles of ethics, including confidentiality
8. **Interdisciplinary Team:** care is provided by an interdisciplinary team of caregivers working collaboratively with the individual and family
9. **Continuity of Care:** a coordinated, continuous plan of care incorporating minimal duplication is maintained across all settings of care, from admission of the individual to bereavement support for the family

All who provide therapies that comfort and support through the illness trajectory and into the bereavement period should strive to achieve the standard of practice implied by the philosophy and principles of Palliative Care shown above.

THE CHALLENGE FOR PALLIATIVE CARE

The challenges facing Palliative Care as a result of HIV/AIDS include:

EVOLVING THE CONCEPTUALIZATION OF PALLIATIVE CARE

Palliative Care evolved from the management of persons living with cancer. It developed from the ideology that cancer could be beaten: that treatment usually starts with a period of active and aggressive therapy, followed by a cure or period of remission, and ultimately by a transition to Palliative Care. In many ways, the original perception of Palliative Care, and when to access services, is an impediment to care and the development of care delivery models for HIV/AIDS.

"We have been fighting forever. We don't like to admit we are going to die, and some of us have difficulty accepting palliative care as it is delivered today"
– one voice –

The current trend is to involve the broad range of Palliative Care services when the individual is first diagnosed with a life-threatening illness. These interventions can range from simply providing information about Palliative Care services to working with those with HIV/AIDS and their families on advance planning or anticipatory grief issues.

This shift in conceptualization of Palliative Care has now been adopted nationally and internationally.[2,3] It is one of the important insights that HIV/AIDS has given to the delivery of health care. However, the conceptualization of Palliative Care continues to evolve due to the tensions inherent in balancing investigation, diagnosis and treatment versus measures directed solely at palliative comfort.

MULTIPLE PROBLEMS/COMPLEXITY OF CARE

The second challenge to Palliative Care is the dynamic nature of HIV/AIDS treatment.

- persons living with HIV/AIDS are surviving longer and are experiencing more problems as a result of treatment advances:
  - under optimal circumstances, survival with a diagnosis of AIDS has increased to 23-30 months, of which up to 50% of these days may be associated with the need for Palliative Care[4]
  - multiple simultaneous opportunistic infections and/or cancers, as well as multiple complex symptom control and psycho-social issues[5]
  - complex inter-relationships of the problems and their therapies
- new treatment options have shifted care from inpatient settings to either outpatient clinics or the person's home:
  - approximately 10% of persons living with HIV/AIDS avoid hospitalization or require only a brief admission immediately prior to death
  - the average cumulative hospitalization has remained at 30-40 days (range 0-200 days), in spite of the significant increase in length of survival[4]

SOCIO-ECONOMIC IMPACTS OF THE DISEASE

"I'm afraid that my family, my friends and society will abandon me"
– one voice –

Further adding to this complexity are the variety and diversity of the psycho-social issues faced by those with HIV/AIDS, their families and friends.

Judgments are often made about a person's lifestyle that result in physical and social isolation. Financial losses may accrue as a result of job loss and, as the disease progresses, Palliative Care issues can be compounded by lack of housing, poor nutrition and inability to afford treatment.[6] Multiple experimental and newly approved medications, many of which may need to continue up to, or close to, death are often expensive and unique to HIV/AIDS, and may not be covered by provincial health plans.

Stigmatization and social isolation occur at unprecedented levels in HIV/AIDS Palliative Care and challenge caregivers to seek out or define new service options and partnerships.

> *In AIDS care there may be no clear transition between active treatment and Palliative Care. Active aggressive treatment often continues right up to death.*[7]

ROLLER COASTER OF HIV/AIDS

With all of these changes in the disease and its treatment, many persons, their families and caregivers are experiencing the roller coaster of HIV/AIDS:

- unpredictability of HIV/AIDS progression: declining health alternating with periods of stability
- swings in physical and emotional well-being due to the unpredictability of the disease
- chronic uncertainty about the meaning and potential outcome of each event and intervention

SERVICE AVAILABILITY

The rate and nature of the progression of the disease, social circumstances and the poverty which may come with HIV/AIDS all interact to challenge our ability to deliver comprehensive compassionate care to individuals.

The experience of Palliative Care in HIV/AIDS in Canada is by no means homogeneous. The specifics of Palliative Care for any particular individual in any community will vary according to programs available, and the density and complexity of the local caseload.

To meet the challenge, new Palliative Care initiatives will have to be developed that are sensitive to the evolving needs of those living with HIV/AIDS.

CONCLUSION

The services that are available, and the way they are provided, will affect the quality and quantity of life for these living with HIV/AIDS, and the utilization of health care services. Adequate funding to ensure cost effective delivery of Palliative Care will avoid the use of high cost institutional alternatives. Palliative Care must respond to the continuing challenges of HIV/AIDS.

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