

Spirituality

SPIRITUALITY AND HIV/AIDS PALLIATIVE CARE

There is profound suffering associated with HIV/AIDS. Suffering is the most significant chronic psycho/social/spiritual dynamic, both for the person with HIV/AIDS and his/her family.

Many faith traditions have a wealth of experience and tradition in understanding the dynamics of suffering, and how it can be turned into a positive experience.

Reflection, prayer, and spiritual expression can enhance the dying process for everyone.

Caregivers are encouraged to seek appropriate community resources to support them in better understanding the dynamics of human suffering.

This will help caregivers support and nurture people living with HIV/AIDS and their families.

SPIRITUALITY VS. RELIGION

Diagnosis of life threatening illness raises questions of mortality, life after death, suffering, spirituality, and religion. In Palliative Care these issues take on greater importance because of the stigmatization and judgement which still accompany HIV/AIDS.

The over-riding dynamic of spirituality is the ability it gives an individual to discern one's "otherness" within him/herself. It allows us to be conscious of something other than what we immediately see or touch. Our spiritual side challenges us to explore and answer those questions which give purpose, meaning and substance to our lives. Questions such as:

- who am I?
- what am I?
- do I have meaning?
- what is my role and purpose in this world?

Spiritual care can promote healing of past or painful relationships. It facilitates the personal psychic integration of the person living with HIV/AIDS and its accompanying chaos and destruction. For many, spirituality plays a vital daily role and provides a strong source of support. Spiritual care is an important part of caring for the whole person, and can be facilitated by a pastoral or spiritual counsellor.

- *pastoral counselling* is a systematic approach undertaken by a minister or chaplain. He/she combines psychological and clinical skills with spiritual and religious insights when working with a person on life problems and destiny
- *spiritual counselling* refers to the practice of a caregiver (including ministers or chaplains) supporting a person through interpersonal and listening skills, enabling them to discuss their spiritual dimension

Depending on the person's needs, either a pastoral or a spiritual counsellor can facilitate healing and integration.

- *spirituality* is that which pertains to the soul, spirit or incorporeal being as distinguished from the physical being or body. Spirituality can be expressed within religion but is no way limited by what we may call traditional North American religious observance
- *faith* is the belief in that for which there is no empirical or objective evidence or proof. Faith is belief in a god, system of gods, or no god (Buddhism for example favours the search for enlightenment and has no sense of god or soul) which are defined through statements of creed or dogma
- *religion* is a cultural institution. It is the public expression of a personal faith. It exists in a particular form and changes over time. Religion binds people into communities through shared symbols of ritual, myth, and ethical norms

A person's "religion" is the expression of their spirituality. Within HIV/AIDS Palliative Care, it is important that caregivers respond to unique, personal expressions of spirituality.

It is important to recognize the differences between spirituality, faith and religion. Many people living with HIV/AIDS are profoundly spiritual but not religious, nor do they observe any specific faith

Many organized religions have difficulty responding to the spiritual needs of people living with HIV/AIDS because the disease raises issues of sexuality and lifestyle which they have historically condemned. Some faiths denounce homosexuality altogether as sinful or inherently evil. Most accept homosexuality as an inherent part of the person, but believe homosexuals must never “act out” or “live” their orientation in relationships. Many persons with HIV/AIDS view this as hypocritical and do not want people nearby who cannot accept them for who and what they are. As a result, when people most need the spiritual counsel of clergy or ministers, they fear being condemned and judged by church officials.

Many faith groups condemn injection drug use and believe the user must change his/her self-destructive behaviour and seek forgiveness for the past.

RELIGIOUS ISSUES WHICH MAY CAUSE CONFLICT BETWEEN INDIVIDUALS, FAMILIES, AND CLERGY

- suicide, assisted suicide or euthanasia
- definitions of sin and its consequences
- definition of family - who is permitted to visit and make decisions regarding medical care
- who qualifies as a “believer”, and is therefore entitled to the services of the church, temple or synagogue, i.e. funerals, clergy visits
- what is meant by suffering. Why do people suffer. Suffering can be seen as a means of spiritual growth, purification, punishment, i.e. the greater the sin, the more the person must suffer

THE DYNAMICS OF SPIRITUALITY

*“Each person’s approach to spirituality is unique and needs to be respected by caregivers.”
– one voice –*

Expressing and exploring our spiritual side during times of illness or crisis help us access our interior life and acquire a sense of internal healing or wholeness. This travels far deeper than simple physical or emotional healing.

Spiritual exploration provides a new sense of hopefulness, peace and understanding. This hopefulness is not for physical healing, but for honest expression of love given and received. The transition can be a time of real transformation from social preoccupation with materialism to a deeper realization of the value of relationships and accepting people simply for who they are. It provides an opportunity to experience the transcendence of humanity.

This search for internal healing can be reflected through questions such as:

- do I take an active role in my healing?
- what is my attitude towards life? Is it positive, negative, apathetic?
- what does healing mean to me at this point in my life?
- what is my attitude towards my death?

For some persons living with HIV/AIDS, there is a spiritual “return to childhood” that takes place, often in parallel with a return to their hometown to be cared for by friends and family. In returning, the person may re-encounter childhood spiritual/religious influences. This can either be rewarding and comforting, or a source of intense pain and disagreement with family members —especially if the person’s beliefs have diverged from those of their family or community of origin. The latter case may require the counsellor to serve as facilitator, supporting the individual in meeting their needs, while assisting the family to reach a workable position that does not deprive them of the support and comfort provided by their beliefs

METHODS OF EXPRESSING/ FACILITATING SPIRITUAL CARE

- will I be forgiven? Do I forgive the people in my life? Can I forgive myself?
- do I enjoy inner peace and strength?
- do I accept and love myself? (very important in HIV/AIDS)
- am I loved? Do I experience love unconditionally from the deepest power of the universe?

Questions such as these touch on intensely private thoughts and feelings. They impact on the very core of our self-perception. They are questions which help us articulate an understanding of our soul, spirit, or sense of being.

When facilitating any reflective process, the spiritual counsellor must deeply respect the person. Answers must be received as a gift and nurtured to conclusions which promote personal integrity and self-worth. To force someone into a “socially acceptable” box or norm can be highly destructive. Each person’s spiritual expression is unique and must be seen as such.

In the last days of life, the person may experience friends and family who have died previously or even persons of spiritual significance “coming to them”. It is important to offer support in exploring these connections (see *Last Hours of Living*).

We are all spiritual counsellors. Paid or volunteer caregiver, nurse or chaplain, we all have the ability to speak honestly about our own sense of spirituality. Effective spiritual or pastoral counselling facilitates the individual’s personal expression, while guarding against forced social norms of religious expression.

BASIC REMINDERS FOR SPIRITUAL EXPRESSION

- we all have a spiritual dimension. Whether or not we recognize and nourish it is our choice, not the choice of the caregivers or family
- spirituality affects all aspects of our life: psychological, emotional, physical, social
- spirituality involves understanding how we live and choose to die
- our environment can affect our spirituality deeply. For some, a noisy cluttered room may hinder spiritual reflection, while a quiet restful room may assist a person’s spiritual exploration and expression

FAMILIAR FORMS OF SPIRITUAL EXPRESSION

Meditation and prayer	There is an extensive history of prayer and meditation within established faith traditions. The individual and/or family who already live their faith and exercise their tradition will benefit from structured prayer and facilitated times of meditation. However, some religious families may feel uncertain or unsure of how to express their faith within secular health care facilities. They would benefit from gentle encouragement by staff to express their faith, and may need added privacy. Alternatively, they may take greater comfort from prayer groups, so occasionally meeting rooms or lounges may need to be offered for family/group services.
Ritual and sacrament	At important moments in life, ritual and sacrament can soften the blow of approaching death and/or create an environment of spiritual healing. Laying on of hands, anointing, or intercessory prayer can help.
Clergy	Most faith traditions recognize or licence certain people to act on behalf of that community, exercising authority and conducting appropriate rituals. Whether called clergy, minister, shaman, rabbi, or elder, they work to promote spiritual healing. It is important to know the wishes of the individual regarding the presence of such a person. Family may desire the "clergy to come" but the individual may resist due to past experiences of alienation and condemnation.

SOME NON-TRADITIONAL FORMS OF SPIRITUAL EXPRESSION

Dream Work	We process and integrate many life experiences through our dream world. Accessing and reflecting upon dreams in a disciplined way enhances self knowledge and clarifies spiritual issues. (Be aware of dream-suppressing side effects from drugs.)
Ritual	Personalised ritual can be one of the most powerful and effective forms of facilitating spiritual/pastoral care. Encourage the person to design and create their own ritual using important symbols and meaningful objects from their life. There is tremendous creativity and expression of ritual within the HIV/AIDS community. The chaos of this disease, the youthful age of its casualties, and the minority status of its population have given birth to unique rituals and personal symbols which speak of life, love, and life after death. Ritual speaks of the truth that the human spirit cannot be vanquished by disease, alienation or stigma. To be truly effective, spiritual/pastoral counselling must respect, encourage, and support expression of individual spirituality.
Peer Support	Sharing your experience and life story with another is generally understood to be an initial step towards inner healing. Peer support groups create safe environments for expressing pain, fear, love, and spiritual anguish due to HIV/AIDS. They can play a vital role in promoting health and assisting people infected and affected by HIV/AIDS to cope with the disease. Spiritual/pastoral counsellors may facilitate such groups using creative listening skills taught to them through prayer and meditation.

QUALIFICATIONS FOR HIV/AIDS PASTORAL CARE

It is important that the individual's wishes are always followed, even if he/she is too ill to communicate. Therefore, ask the person as early as possible:

- *what are his/her wishes?*
- *what does he/she want to happen at the bedside before death and at the time of death?*
- *which rituals are important and which rituals should not happen?*

Good pastoral/spiritual care involves the nurture, promotion and growth of the person's sense of spiritual identity, not the imposition of what the chaplain, pastoral counsellor or family may think is "right"

Not everyone is suited to HIV/AIDS pastoral care or spiritual counselling. Many professional caregivers are uncomfortable with discussing issues of faith and spirituality, owing to their own experience or lack of belief. No one should be forced into the role of pastoral or spiritual counsellor. However, persons living with HIV/AIDS will often "pick" someone with whom they wish to discuss spiritual concerns. Many times this will not be the chaplain. Often staff or volunteers are picked first because they appear less threatening or because the person living with HIV/AIDS knows them better than the chaplain.

At institutions run by religious organizations, or where religious symbols are widely evident, it may be presumed by the individual that all caregivers share these religious beliefs. It can impede counselling if the person does not share these beliefs. In this setting, the counsellor may need to establish his/her "neutrality" to foster trust and openness.

Some health care facilities will not have chaplains on staff or available. Then it is necessary to access community resources. Identify persons familiar with Palliative Care and HIV/AIDS, who can respond quickly to pastoral or spiritual care issues as they arise.

Whoever the spiritual/pastoral resource person may be, these are skills necessary to HIV/AIDS Palliative Care:

- familiarity with issues of sexuality, sexual orientation, drug use
- flexibility
- no imposition of spiritual beliefs
- non-judgemental acceptance
- openness to non-traditional forms of spiritual expression
- "gay positive" attitude
- ability to access non-Christian and Christian community faith resources
- ability to facilitate and lead non-traditional services in various settings

Many educational programs offered across the country deal with issues of drug use, homophobia, and HIV/AIDS specific issues. Such training should be considered essential for those who are entering the HIV/AIDS Palliative Care field. Some hospital chaplaincy training centres offer field placement opportunities in HIV/AIDS clinics or Palliative Care facilities.

SUGGESTED READING

Woodward J. Embracing the chaos: theological responses to AIDS. London, UK: SPCK, 1990.

Feinstein D, Mayo P. Rituals for living and dying: from life's wounds to spiritual awakening. San Francisco, CA: Harper, 1990.

Smith WJ. AIDS: living and dying with hope; issues in pastoral care. New York, NY: Paulist Press, 1988.

Callanan M, Kelly P. Final gifts. New York, NY: Poseidon Press, 1992.

Kramer K. Death dreams. New York, NY: Paulist Press, 1993.