DEATH, DYING AND RELIGION

AN EXAMINATION OF NON-CHRISTIAN BELIEFS AND PRACTICES

A guide for health care professionals including those working in HIV/AIDS.

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INTRODUCTION

Australia is a multicultural society, made up of people coming from different countries, cultures and religions. This diversity, is reflected in an increasingly complex religious profile and a growth in the number and size of non-Christian religious communities. Death is common to all of us, yet the way different cultures and religions view the death process differs dramatically. These different views and ideologies have led to a variety of practices and rituals related to death and the dying person, which may be critical to the peace and the comfort of the dying person and their family.

In our society, care of the dying has increasingly become a matter for professionals. While experts in their area, many health care workers may not be aware of the beliefs, related rituals, attitudes towards death and patterns of emotional response prevailing in the cultural background of their patients (Neuberger, 1987). For many immigrants and their children, religious affiliation may be synonymous with self identification (Ata, 1994). Thus a great deal of comfort can be brought to a dying patient and their family by the recognition of their particular beliefs and attention to their specific spiritual or cultural needs (Neuberger, 1987). Babacan and Obst (1998) have designed a resource kit for human service workers to aid in their understanding of different religious beliefs and practices surrounding death, that has been used as the basis for this book which has been expanded to encompass an examination of religious views on HIV/AIDS.

The onset of the HIV/AIDS epidemic since the late 1970's means that many palliative care and other health care workers will be required to care for a person dying from AIDS in the course of their profession. UNAIDS and WHO figures estimate that currently over 30 million people world wide are living with HIV infection, and that almost every country in the world is touched by the virus (UNAIDS, 1997). Such world-wide data shows that while HIV does spread differently in different populations, no country, culture, ethnicity or religion is immune to the virus.

In Australia an estimated 16 500 people have been infected with HIV/AIDS. With some 23.5 percent of the population born overseas and more than 20% of the adult population born in non-English speaking countries, Australia has a population made up of more than 130 different cultures, living within our diverse multicultural society (Cultural Perspectives, 1998).Unfortunately there is poor data on the extent of HIV/AIDS within Australia's culturally and linguistically diverse communities. Nationally, ethnicity data collection for

HIV or AIDS notification is intermittent and inconclusive (Temple-Smith & Gifford, 1996). Some "country of birth data" is collected and from such data varying estimates have been made suggesting that from 15 percent (Pallotta-Chiarolli, 1998) up to 25 percent of HIV/AIDS infected persons are from culturally diverse backgrounds (Multicultural HIV/AIDS Service, 1997).

The majority of diagnosed cases of HIV infection in Australia have been in men who became infected as a result of sexual contact with other men (Pirie, 1996). While education strategies within the gay communities have seen a decrease in the number of new infections through homosexual behaviour, a large number of men who do not identify as gay appear not to have accessed this information. These include bisexual men with female partners, many men from culturally diverse backgrounds, those with low literacy or other communication disabilities and those who use alcohol and other drugs at risk levels (Department of Community Services and Health, 1998).

Intravenous drug use is the other high risk activity in Australia leading to HIV infection. Almost all intravenous drug users report sharing injecting equipment at some time for economic, social, cultural or secrecy needs. Sharing is particularly common among ex-users who relapse, since this is often unpremeditated. Intravenous drug users are hard to reach with education and preventative messages. They do not form a homogenous group, as apart from their injection habit they may have little in common. The illegality of the behaviour helps to ensure that it often remains hidden, even from an individuals family and close friends (Department of Community Services and Health, 1998). However recent large scale education programs and availability of needle exchanges have led to a significant decrease in needle sharing.

The one group in which incidents of HIV infection are increasing is women. In many ways women are particularly vulnerable for their risk depends not only on their own actions but also on that of others, in particular their partners. The modes of transmission are the same for women as men and so their susceptibility must arise from the context in which transmission takes place. Many women lack assertiveness in interpersonal or social relations, particularly those from cultures that do not encourage women to be assertive. Women most at risk from HIV infection are female partners of bisexual men and sex workers (Department of Community Services and Health, 1998).

For both men and women, engaging in sex work has been identified as a high risk activity. Male sex workers whose clients are also male have the highest risk of HIV infection. However it has also been shown that female sex workers that have come from high HIV prevalence countries have a particularly high risk of HIV infection (Pirie, 1996)

While endeavouring to provide quality care, a health worker involved in caring for a person dying from AIDS from a culturally diverse background may be faced with many complex and compounding issues in providing that care. AIDS does differ from other life threatening illnesses due to the wide-spread public attention, fear and misunderstanding surrounding the disease. There is also a great deal of prejudice towards the high risks groups of homosexuals, intravenous drug users and sex workers (Fusilier & Simpson, 1995). As already mentioned, different cultural and religious perspectives view the dying process in very different ways. Thus it is also of great importance for people working in the area of palliative care of terminally ill people from diverse cultural backgrounds to develop a sensitivity to cultural and religious issues surrounding death and dying. Different communities and religions may also have very different views on those suffering from HIV/AIDS in particular, which may impact on the dying person and their family. The sensitivity of the HIV/AIDS issue means that very little has been written around this subject to help those who work in the area in Australia.

This book aims to provide health care workers with an examination of death and dying from six religious perspectives incorporating many, but by no means all of Australia's diverse ethnic communities. It also aims to address specific HIV/AIDS related issues which such workers may encounter. The religions detailed in this resource are Buddhism, Hinduism, Islam, Judaism, Sikhism and Taoism. Religion rather than culture has been used to facilitate the documentation of ideologies and practices surrounding death. While this resource may not address specific cultures and not all religions, it is hoped it will be useful in caring for all terminally ill people of culturally diverse backgrounds by highlighting the issues that may need to be taken into consideration to provide quality appropriate care. The sections on HIV/AIDS related issues provide a deeper examination of the specific issues people living with HIV/AIDS from non-Christian backgrounds may face.

It is important to note that not all adherents of a particular religion will have the same practices, theological beliefs, or the same degree of observances. Within each of the religions examined here, many schools or sects exist.

Some based around cultural differences, relating to country of origin and others to the degree of orthodoxy. For the practitioner, the consequence of this diversity is that knowing someone is from a certain country or religion my not be of help in identifying that persons individual beliefs. Individuals have beliefs and practices shaped by many factors in their lives, not only religion or culture (van Kooten-Prasad, 1998). While this booklet endeavours to give a general overview of beliefs and practices of six religions and how these may impact on a terminally ill person, it is necessary to check with the individual patient and family members for details of the specific orientation, spiritual and physical needs. While a person may nominate a religious affiliation on entering a hospice or hospital, they may have very different levels of practice. What needs to be developed in the relationship with a dying person is a sensitivity towards the possible requirements of the patient, in view of their cultural or religious tradition.

HIV/AIDS SPECIFIC ISSUES

In examining HIV/AIDS specific issues a number of themes emerge affecting those of culturally and linguistically diverse backgrounds. It is important to understand these issues and how they may impact on the HIV/AIDS patients needs and responses to care.

All HIV/AIDS patients may be faced with prejudicial attitudes towards their HIV status. This may be induced by homophobic attitudes in the community or simply by a general lack of understanding of HIV/AIDS. This will often lead to a sense of isolation and marginalisation (McConachy, Grubb & Ezzy, 1997). This isolation may be intensified for those from diverse cultural backgrounds in two main ways. Family is of central importance to many cultures, with the extended family being a fundamental source of emotional, moral, social, practical and financial support. However family members may have little knowledge of HIV/AIDS and be influenced by prejudicial attitudes within the community. This may result in the HIV/AIDS patient being isolated from this close network at a time when support of family and community is most needed. To avoid such marginalisation many HIV/AIDS patients may not have disclosed their HIV status to relatives, and workers must be aware of this possibility and act according to the patient's wishes. Patients may also refuse cultural or language support services as they are concerned about confidentiality within their community (Multicultural HIV/AIDS Service, 1997).

Secondly many people from culturally diverse backgrounds who have contracted HIV/AIDS through homosexual behaviour may not identify as gay or as a positive person, which may prevent them from accessing available HIV support services or linking in any way with these communities (McConachy, Grubb & Ezzy, 1997). They may also experience a feeling of loss of their own identity especially their ethnic or religious identity when diagnosed with HIV due to factors such as non-acceptance (Multicultural HIV/AIDS Service, 1997). Thus many are in a position where they are receiving no support from either their own family or community, nor from the HIV community leaving them in a very isolated position.

Another issue important to all people living with HIV/AIDS is that of treatment. Everyone has the right to know and understand all treatment options and make their own informed choices (McConachy, Grubb & Ezzy, 1997). For many people of culturally diverse backgrounds, the doctor is viewed as the absolute authority in relation to health decisions. Given poor access to other sources of understandable information, patients will often simply do what the doctor says and will not ask about alternative treatments or state their needs (Multicultural HIV/AIDS Service, 1997). It is important that workers ensure that those in their care have access to information on treatments that they can understand and are able to make their own choices based on their personal, cultural or religious needs and beliefs.

Language barriers are always a major issue for those of culturally and linguistically diverse backgrounds (Cultural Perspectives, 1998). Language barriers can prevent a patient from expressing their needs clearly, making a person a passive recipient of care, rather than taking an active role by articulating what they require from such care. This situation may be especially intensified for HIV/AIDS patients where isolation, a sense of culpability and many other issues may impact on their communication even further. Workers in this situation should attempt to help the person in their care to feel comfortable about communicating their requirements.

It is also important to understand that a patient from a different cultural background may approach the concept of illness itself very differently. For example in some cultures there is a perception that talking about an illness leads to further illness, differing greatly from our dominant form of response to illness, which encourages the patient to talk about their illness in order to come to terms with the fact that they have a terminal illness (Multicultural HIV/AIDS Service, 1997).

While some embrace it and others deny it, spirituality holds an important place in the consciousness of humanity. Facing death is one of the most powerful incentives to re-examine our spirituality. In essence, spirituality is about relationships: Relationships with the depth of oneself; with the intimate otherness of those close to us; and our personal relationship with our own concept of the creator. HIV/AIDS profoundly affects all these relationships (Bouma, 1996). We must remember that society makes a framework for the conceptualisation of a disease, which determines to a large extent how that disease is approached. The framework in which HIV/AIDS has been placed impacts greatly on the those infected; their spirituality, their family and friends (Cadwallader, 1996).

Lastly, the practicalities of death itself may also be impacted upon by misunderstanding and the conceptualisation of HIV/AIDS. The practicalities of the management of the deceased are largely the responsibility of Funeral Directors. Here again we may see the compounding of HIV/AIDS issues and those associated with belonging to a non-Christian religion. Firstly, the stigmatisation of HIV/AIDS as a communicable disease may lead to difficulties with the handling of the deceased person by the funeral director. Essentially this can be seen as rejection even after death. This can be greatly distressing for the deceased's family and friends. When the deceased also requires specific practices or rituals due to their family's or their own religious beliefs, the issue of preparation for, and burial of a person from a non-Christian background who has died from AIDS can become one of great difficulty. Families will often be unaware of their rights, and are in no emotional state to insist on specific treatment when they face obstacles of prejudice and misunderstanding. Workers can be of great assistance to families in helping them communicate their needs to funeral directors. A resource booklet on Infection Control Information for Funeral Directors, designed specifically to counter misconceptions that funeral directors may have relating to AIDS is available from The Queensland AIDS Council.

OVERVIEW OF HOW CULTURE AND RELIGION MAY IMPACT ON VIEWS OF DEATH, DYING AND GRIEVING

Each culture has its own approach to dealing with death and dying. These are normally more or less standardised, involving a core of understandings, spiritual beliefs, rituals, expectations and etiquette which then impact on an individual's own way of approaching death. The dominant western culture is no different having it's own particular cultural approach to death. A common

reaction to finding that our own culturally inherited categories do not fit the realities of others is to consider the "others" ways to be uneducated, superstitious, less developed or in some other way faulty. However in trying to offer understanding and assistance to people from cultures that differ from our own, an understanding that our own view is but one reality and not "the" reality, superior to that of those we want to understand and help is the first step. The preferred course is to become adept at learning, respecting and dealing with other's reality (Parkes, Laungani, & Young, 1997).

In many societies death rituals are far more elaborate and extended than is common in Australian society. Many of these rituals may seem pointless or even abhorrent to an outsider. However these rituals may have enormous religious, social and personal significance for the dying person and their family, reflecting the values, beliefs and social structures of their culture (van Kooten-Prasad, 1998). Not engaging in rituals important to the culture may leave people at a loss to understand and accept death or to find a sense of closure. Yet it is important to be aware that many people from a particular culture or religion may not necessarily be knowledgeable about their own cultural rituals and may wish the assistance of a ritual's specialist, as many in the West look to a priest to oversee the appropriate death rituals. For those of diverse cultural or religious backgrounds living in Australia there may be many barriers to performing customary rituals, such as the stringent rules and regulations surrounding death and burial. This is particularly so if the death occurs in a hospital rather than at home (Parkes, Laungani, & Young, 1997). The following comments illustrate how such regulations may impact on funeral practices:- "One cannot place the body at home before the funeral. It is very upsetting for Vietnamese mourners" ; " We prefer an open cremation like in India, not instant hidden burning between walls" (Ata, 1994).

In many cultures different kinds of deaths are understood differently and dealt with differently. The meaning of death, the rituals called for, the emotions felt, the extent to which others are involved, how the body is disposed of, the bereaved's relationship with the dying or deceased may vary greatly depending on such factors as, whether the death was suicide, a drowning, if the deceased is a child, a woman who has died in childbirth, or a violent death. Thus even if one knows about how a typical death is dealt with by a particular religion or culture, one may not be prepared for the specific rituals and beliefs surrounding certain types of death (Parkes, Laungani, & Young, 1997).This is of important consideration when dealing with a person dying from AIDS as this may invoke distinct rituals or beliefs.

It is not uncommon for there to be generational differences in dealing with death. The older generation may be more observant of rituals than the younger generation who have been more influenced by western values. An outsider thus also needs to be sensitive to the varying needs and expectations, standards and practices of religious adherents from different generations. In this light it is also important to note that often it is a member of the younger generation who acts as the informant about an older patients culture or religious needs (Parkes, Laungani, & Young, 1997).

While many very useful models of the death and dying process have been developed to help those involved in caring for terminally ill people, it is important for health care workers to realise that these models may not fit those whose cultural background or religion views death in a very different way to that suggested by the model. The nature of AIDS may also impact on the application of such models. One of the most utilised models of the dying process is the five stages of Kubler- Ross (1969), which suggests that the dying person passes through phases of denial of the condition, anger and resentment, bargaining for more time, depression at the impending loss, and finally peaceful acceptance. While such models have added greatly to our understanding of the dying process, they are frequently steeped in uniquely western attitudes and values. They represent possible responses to terminal illness rather than universal truths. Models like Kubler-Ross's do not necessarily increase our understanding of the way in which people from other religious orientations and cultural backgrounds approach death. A practising Buddhist who has meditated on death and impermanence may hold an attitude of such complete acceptance towards their impending death that their experience of terminal illness is not recognisable within any of the prevailing models. A person dying from AIDS may have passed through these stages at notification of being HIV positive and may now face different issues.

For a western practitioner, such standard ways of supporting dying or bereaved people are as much culturally embedded as the ways that other cultures deal with such issues. It is risky to assume that the supporting actions commonly used here are appropriate. Talking is a standard western way of dealing with grief and reaching acceptance. While this is completely appropriate and helpful for many, for some talk about death is seen to bring more death into a family, for others mentioning the name of the deceased is thought to prevent their spirit from leaving. The possibilities are innumerable. A helper therefore needs to know what sort of talk is appropriate for the person they are working with (Parkes, Laungani, & Young, 1997).

In general there are a few simple but key guidelines that can help in working with those from a different belief system to our own.

- Do not stereotype a person on the basis of their culture or religion. As has been pointed out there are many variations in beliefs and practices depending on personal circumstances. Rather, use any knowledge of beliefs and practices to help further understanding of individuals.
- Develop an awareness of ones own ethnocentrism and how this may impact on providing appropriate care to those of different cultural backgrounds to ourselves.
- Learn more about a particular belief system and related practices and use that new knowledge to help in understanding an individual's needs. This includes not only what to do but also what not to do, simple things that can cause great distress such as crossing legs during rituals, touching or pointing feet.
- Most importantly is simply to develop a sincere openness to other's realities.

This book aims to provide a general guide to the beliefs and practices of different religions as they may impact upon the treatment and care of dying persons. Each section provides a brief overview of the general beliefs of each religion; the specific beliefs and attitudes surrounding death and the afterlife; practical concerns in relation to the appropriate procedures prior to and after death; and a specific section on HIV/AIDS related issues. Prior to death, the manner of notification of the condition, the role of the family, spiritual needs such as prayer or meditation, physical needs such as diet and issues of modesty, and attitudes towards medical procedures are outlined. After death information is provided regarding last rites, the handling of the body, prohibited medical procedures, and funeral and mourning procedures.

Overall this guide simply seeks to encourage staff to increase their awareness of cross cultural issues in order to enhance the provision of care and comfort of those in their care. Following each section, a list of religious organisations and their contact details is provided should further information be required. However, the final authority on spiritual, religious and in fact all of a dying person's needs must of course always remain with the person themselves.

Quick Reference Chart

Religion	Buddhism	Hinduism	Sikhism	Taoism	Islam	Judaism
Major Regions of Practice Although may be found in many other countries	China, Tibet, Vietnam Burma, Laos Thailand, Cambodia Sri Lanka Taiwan, Japan, Malaysia, Singapore	India Malaysia Fiji Singapore Africa Sri Lanka	India Pakistan Malaysia Singapore Fiji	China Hong Kong Japan Taiwan Malaysia Singapore Vietnam Laos Cambodia	Middle East Africa, Fiji Malaysia Indonesia Indian Sub Continent South Africa Former Yugoslavia Afghanistan	Israel Europe America Africa
Attitudes Towards Death	Strong acceptance: Reincarnation	Strong acceptance: Reincarnation	Not to be feared: Reincarnation	Not to be feared: The return to Tao	Acceptance of Allah's will	Various attitudes towards death
Medical Procedures	Pain relieving drugs may not be wanted	No religious objections	No religious objections	Possible objections to autopsies and pain relief	Objections to autopsies, euthanasia and organ donation	Objections to euthanasia autopsies and some organ donation
Dietary Needs	Many vegetarians. Fasting on special days	Many vegetarians Some strict, no eggs, dairy products. May want to fast as part of practice	No halal meat Most no pork or beef No alcohol, tobacco.	Mainly vegetarian Fasting recommended for the ill	No pork products and specially halal prepared meat No alcohol. Ramadan: Fasting may be required	Kosher food - no pork or shellfish and meat and dairy separate Fasting may be part of practice

Religion	Buddhism	Hinduism	Sikhism	Taoism	Islam	Judaism
Washing	No special rituals	Bath in running water. Wash before eating and prayer	Bath in running water. Wash before eating and prayer	No special rituals	Cleanliness extremely important. Washing with running water before prayer	No special rituals
Religious Practices	Meditation Maybe a small shrine	Prayer and Meditation, small shrine	Prayer and meditation. Wearing of 5 K's	Mediation	Prayer towards Mecca five times a day	Prayer and observance of the Sabbath
Handling of Deceased Body	Leave undisturbed as long as possible.	Do not wash, touch with disposable gloves	Touch with disposable gloves. Must not remove 5 K's	No special requirements	Only same sex Muslims otherwise touch with disposable gloves. Body believed to feel pain after death	Do not wash. Wrap in plain sheet. Contact Chevra Kadisha (Burial Society)
Burial Practice	Mainly cremation, some burial	Cremation as soon as possible	Cremation as soon as possible	Burial after one week	Burial within 24 hours	Burial as soon as possible