DEATH AND DYING IN AUSTRALIA: PERCEPTIONS OF A SUDANESE COMMUNITY

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Abstract

Introduction: The resettlement of displaced persons and refugees due to war, famine, conflicting political ideologies, racial conflict, religious beliefs, alienation due to persecution and other humanitarian issues is a universal concern, particularly for Western, developed countries that support these people. In August 2009 the Office of the United Nations High Commission for Refugees (UNHCR) identified 16 million people as refugees.

Background: Australia is a multicultural society and health care workers are faced with increasing numbers and a diversity of immigrants for whom they strive to provide quality health care. Sudanese migration from war torn Southern Sudan has been steadily increasing in various areas of Australia since 2005. The Sudanese are the fastest growing number of migrants to Australia (Australian Bureau of Statistics, ABS, 2006).

Aims: This study aims to prepare palliative care health care workers to meet the needs of the Sudanese population in relation to death, dying, bereavement and the grieving process.

Method: A qualitative interpretive approach was used with data collected from a sample population of 15 using focus group discussions. Data were then transcribed and analysed.

Conclusion: Although there are vast differences in the cultures and traditions of African countries, this study provides a snapshot of the views of a Sudanese African community in Australia about death and dying. By identifying a traditional cultural framework of care, palliative care workers can incorporate these findings into the delivery of appropriate and culturally sensitive end of life care.

Key Words: Palliative care, death, Sudanese, culture

INTRODUCTION

Palliative care is a life enhancing philosophy of care which aims to improve the quality of life for people with life limiting illnesses and to address the physical, psychosocial and spiritual needs of the patient and their families. The concept of palliative care differs according to cultures and tradition (Chater & Tsai, 2008; Hsu et al., 2005; Nunez Olarte & Guillen, 2001). Respect for individual and cultural differences is considered paramount in providing appropriate care for terminally ill patients (Chater & Tsai, 2008). Palliative Care Australia (2005) Standards endorse the need for culturally appropriate care at the end of life for all Australians.

Despite the multicultural nature of the Australian society, there are inequalities in access to health care service provision, including palliative care, for culturally and linguistically diverse (CALD) groups of people (Vydelingum, 2006). Ethnic minority groups are often excluded from access to palliative care services for various reasons, including language barriers and having little or no understanding of what palliative care can offer (Hsu et al., 2005). According to Wani (2008) and Westoby (2008) the majority of Sudanese and other Africans have difficulty understanding Western social structures and systems including the health care system and what services are available.

METHODOLOGY

A qualitative interpretive approach was used to obtain data on topics that are related to cultural competency and end of life care as outlined by Lickiss (2003). These include:

- Communication issues such as disclosure, consent and decision making;
- Concepts of disease, meaning of pain and other symptoms;
- Attitudes to medication and medical treatments;
- Customs surrounding death, burial or cremation, and bereavement;
- Spirituality, as well as religious issues and rituals.

Focus groups were conducted using open-ended questions which were formulated around these topics to generate reflection, discussion and conversation. The interviews were taped, transcribed and content analysis was used to identify dominant themes. Attention was paid to discourses which appeared as identifiable patterns or themes in the text (Minichiello, Sullivan, Greenwood & Axford, 1999).

The sample consisted of 15 participants with four focus groups of three or four participants in each. Their ages ranged from 18 to 53 years and the majority (ten) was female. All were Sudanese born who had lived in Australia for periods ranging from six months to six years. All participants identified themselves as being Christian.

Recruitment took place through the Hunter African Community Council. Information sessions took place prior to the interviews and participants were given an assurance of confidentiality and asked to sign consent forms. Counsellors and welfare officers were onsite but were not required. An interpreter fluent in both Arabic and Dinka was involved throughout all steps of the investigation from gaining consent through to reporting back to the participants on the outcomes of the research. Ethical approval was obtained from the Hunter New England Area Health Ethics Committee.

FINDINGS

Cultural attitudes and views differed within the focus groups according to age, education, whether entry to Australia was from refugee or migrant status, time spent away from Sudan prior to coming to Australia as well as tribal differences and the districts in Sudan from which the participants had migrated.

The main themes and discourses were categorised under five main headings:

1. Communication Issues Including Disclosure and Consent

From the interviews the consensus was that bad news was to be withheld from patients and families until the community leaders could gather around to support and protect the people receiving the information. The participants in this project identified community leaders as being elders (elected by the community), church ministers, welfare officers and African support workers.
Bad news is not given without the protection and support of the community due to the risk of self-harm. The Sudanese are very demonstrative in their grief and could hurt themselves as they throw themselves on the ground or against walls and furniture. They have been known to cut or burn themselves. One participant related the story of her cousin, who on being told of her father’s death, repeatedly banged her head on the wall, then threw herself on the ground hitting her head, sustaining a fatal head injury.

Gathered community members protect the family for three days, in which they will do all the cooking to prevent the bereaved from burning themselves. Initially, furniture is removed from the family home and mattresses are arranged on the floor. Grieving families are never left alone. Men and women gather together but sleep in different rooms.

The role of the community is to comfort and calm the grieving family. People are openly expressive in their emotions of grief, demonstrated by crying, screaming and wailing, often uncontrollably.

If you have a friend or someone die you have to be ready for her because every time she will be sad and cry or something. You need to calm her down, you have to be with them, to comfort them.

Traditionally, males are the dominant decision makers within the Sudanese family unit. But in most Sudanese communities in Australia there are a large number of widows. If they do not have an adult son, the community leader takes on that responsibility.

… if someone has a husband is good but most of us they don’t have a husband.

Death and dying are not discussed openly; this includes with the terminally ill and elderly.

This will make them sad and they will maybe die.

Children are traditionally ‘protected’ from death but participants in this study point out that children have had much exposure to death in recent years due to war.

You can give them [children] nightmares or something they don’t feel comfortable because they cry, they may feel deep sadness of someone dying, that is not good for them, that is hurting them.

People are generally scared of dying, and as death and dying are taboo subjects they are rarely discussed.

We don’t talk about death. No one talks about death when you die.

By contrast, the younger participants (under 30 years of age), whilst acknowledging their older counterparts’ concerns in the delivery of bad news, wanted to be fully informed of all health care issues regarding themselves and their families. They did not want the involvement of the community in their health care decision making. They did not want to hear bad news second hand from elders in the community. Although it is customary to display their grief and react physically, they said they were able to ‘control themselves’.

2. Concept of Disease and Illness

When discussing disease and illness, there appears to be a culture of blame. Prior to the war, participants identified the major cause of death in Sudan as being old age or childhood deaths.

Death before war is not common.

Children have a higher survival rate if they are breast fed and deaths in children were blamed on mothers not breastfeeding long enough.

Breast fed babies are not sick and do not need medicine and do not die so often.

Participants identified breast feeding as a preventative to cancer and HIV, as well as a natural contraception. There is a perception that women who do not breast feed will get cancer, particularly breast cancer.

According to the participants, cancer was relatively unheard of before the war. One participant vaguely remembers an aunt in the village dying of cancer attributed to her aunt having no children and therefore not breast feeding.

You know when we come here they just find the cancer the most famous disease.

Before the war people died of “old age” (60 years+). Now the blame for the cause of death is placed on pollutants in the air from the bombing in Sudan.

3. Attitudes Towards Medical Treatment

In Sudan there was a reliance on natural herbs and plants for medicinal purposes, which are not available in Australia. The participants had a perception that in Australia medicine is sophisticated and treatment can cure almost everything. In saying that, they expressed disappointment in their experience of the Australian health care system. They related stories of relatives and friends that have not been cured of headaches and miscarriages and the treatment actually made them even sicker.

We don’t have like treatment and medicine all this things.

Medicines is safer in Africa.

In Sudan there are local clinics in the villages and hospitals in larger towns and in certain rural regions treatment is still paid for in ‘cows’. The participants in this study have never heard of palliative care.

The participants were surprised to discover residential aged care homes existed in Australia. In Sudan to care for the elderly is seen as a privilege and a blessing. The elderly are hospitalised only at “the very end” of life for terminal care. There is a belief that where a person dies is where the spirit remains. Some people do not want the spirit to linger around the home as this may cause fear. They welcomed the idea of a hospice for terminal care.

With medical and end of life discussions, all participants stated that they would unquestionably do what the doctor said. There is a reliance on the family doctor to know what is best.

We do all what doctor says.

Participants said they would continue with artificial hydration, mechanical ventilation and other treatments if that is what the doctor ‘wanted’ even if the treatment was ‘useless’. Some participants stated that they thought it was breaking the law if you went against a doctor’s instructions. When discussing keeping people alive by mechanical means (machines), participants viewed turning the machine off as killing, despite treatment being futile. These views were shared by all participants regardless of age.

….when you turn off a machine that is keeping someone alive, that mean you killing the person. So if you killing the patient that is
criminal mean you have to bring you in justice.

4. Customs Surrounding Death, Dying and Bereavement

The discussion around this topic differed according to the age of the deceased. When an older person dies (60 years and over) there is a celebration: everyone brings either a goat or a chicken and a celebration feast is held. When older people die it is a celebration of a long life rather than a time for crying and sadness.

The tribe will sing and dance and pray and thank God for a long life.

However, when a younger person dies it is a time of great sadness. The bereaved mourners tend to scream and to cry. There is an increased risk of self harm in those close to the deceased, they tend to throw themselves around, injuring themselves. There is an increased risk of suicide. Black clothes are worn in mourning, except by some tribes or areas in Sudan where the widow wears white. Widows are expected to mourn the death of a husband for 12 months, after which a community member will remove the mourning clothing. For a parent or sibling, the expected time for grieving is 40 days.

5. Spiritual and Religious Issues

All the participants in this study identified themselves as Christians. One female participant (from the younger group) said she had converted to Christianity since leaving Sudan, but was afraid to tell her parents who are Muslim. The main religions in Sudan are Christian and Muslim. There is hostility between members of the two religions in Sudan, but all participants say this does not happen in Australia.

Among the participants there was is a sense of great faith in God and they found great strength in prayer and trust in God and the Bible, saying God had given them courage at times of adversity. When faced with death and illness, prayer helps.

It’s not in our hands, it’s in God’s hand.

If you are sick and can’t get better – pray.

There are different prayers for different occasions. The participants described prayers as being sad or happy prayers. Prayers for the dead are either happy or sad according to the age of the deceased.

We do pray a lot and we thank God.

The participants acknowledged that they pray to thank God for bringing them to Australia. The importance of religion, prayer and belief in God was stressed by all participants regardless of age.

DISCUSSION

Due to the reaction of the Sudanese to bad news, their overwhelming grief reaction and risk of self harm, it is important to establish who should receive that information. The participants who were entrenched in their traditional culture were more likely to need support from their community leaders, particularly if there was not a dominant male in the family. This is relevant and it is important to health care professionals to identify these people to enable information to be given in a timely and culturally sensitive manner.

According to Gillack (2009) conflicting cultural values and cultural aspects on truth telling and honesty are dilemmas frequently encountered by Australian nurses in Australia as a multicultural society (Gillack, 2009). Gillack (2009) and Royak-Schaler et al. (2006) say that families are trying to protect the patient as it is a cultural belief that patients will become depressed, downhearted or even suicidal if they knew the truth. Within the Sudanese community, this protection is extended to the bereaved as well as the sick, the elderly and the very young.

Nunez Olarte and Guillen (2001) suggest that a global trend in people wanting to know the truth is occurring. Young adult patients are more likely to want further information and open discussion. This trend in truth telling is emerging in various countries such as Italy, Greece, Japan, Latin America and the Philippines (Nunez Olarte & Guillen, 2001). This study also supports the theory that the younger, more educated participants wanted full disclosure but acknowledged that this may not be the case for their parents or grandparents.

Health care decision making in Australia is based on the ethical principle of autonomy, with full disclosure and information given to health care consumers. In this study, the participants (even those in the younger age bracket) indicated a reliance or trust in medical practitioners to know what is best for them and to make medical decisions on their behalf. It appears from this study that they accepted and expected medical care which could be construed to be paternalistic.

The culture of blame pertaining to disease and illness may influence the way health issues are viewed by the Sudanese population here in Australia. People may experience feelings of guilt and of being at fault. This can manifest in psycho-spiritual issues impacting on their health status. Cancer was relatively unheard of in their country of origin, but here in Australia it is well publicised in health promotion campaigns. This reinforces the idea of blame due to modern lifestyles and pollutants. Their perceptions of modern technology as being able to cure everything may have ramifications in the transition between active treatment and palliative care where the focus is on comfort rather than cure.

From the focus group interviews it was evident that palliative care was an unfamiliar concept. Traditionally death and grief are managed by the community or tribe with designated leaders and support is not sought externally. This may be a barrier for people of Sudanese extraction in accessing palliative care services, although the concept of hospice for end of life care was welcomed. The belief that the spirit of the deceased stays at the place of death makes the choice of where to die extremely important. Some participants fear spirits staying in their home whereas others found it comforting to have the spirits of loved ones around them.

Grief and mourning are displayed openly and loudly and are much more public and communal than in Western societies. The grieving family is cared for by the community. The emphasis is on protection and support for the bereaved, with religious rituals and customs enabling mourning.

For the respect and dignity of all people, regardless of their country of origin, health care professionals need to recognise the diversity of cultures. Despite cultural backgrounds, for appropriate cultural competency in health care delivery such care must be individualised. Discussion needs to take place between health care professionals and whether it is with a community elder or male family member or the patients themselves to establish cultural aspects of care.
LIMITATIONS OF THE STUDY

Limitations of the study primarily evolved around recruitment. Recruitment proved difficult as palliative care was not a priority in this population, therefore sample size was small. Despite this data saturation was achieved. However these results may not be transferable to generalize about the wider Sudanese population.

It is acknowledged that there is great diversity in cultural attitudes and norms within Sudan. All the participants in this study were from South Sudan and all were Christians. While this project has provided insight into attitudes and cultural norms for this particular part of Sudanese society, other groups and in particular Muslims in the North Sudan, may have very different ideas, customs and norms in relation to death and dying.

CONCLUSION

As there is little research in this area and with the increasing rate of migration from African countries to Australia, future research is warranted. This study highlights the need for palliative care services and health care workers to provide individual consultation and sensitive discussion with the appropriate person/s while acknowledging that specific cultural aspects will apply to all people from that population.

This study supports other studies that indicate a global trend towards the Westernisation of ethical principles where younger people value the principles of autonomy and informed decision making in regards to health care. Despite this trend, there is still a patriarchal view held by the participants that the doctor knows best and will make decisions in the best interest of their patients. Alarmingly, participants in this study shared the view that it was illegal not to follow a doctor’s orders. This has implications for the treating medical officers who have to make decisions on behalf of their patients; and for families and patients who believe they have no choices in these matters. Advance care planning is being widely promoted in health care. This study highlights the difficulties of such advanced planning due to cultural barriers.

As a community, Sudanese people come together and support one another at times of loss and grief. To be open and demonstrative in mourning, to display grief are considered natural behaviours and are encouraged. The wider community extends their support to the family to ensure they are protected, comforted and cared for. This approach to community care has much to offer.

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