

The Living Model: An Australian model for Aboriginal palliative care service delivery with international implications

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INTRODUCTION

Research in the area of palliative care service delivery to Aboriginal peoples is still in its infancy. Service providers and health policy makers around the world are calling for research-based insights to guide practice. To make a contribution to this important initiative, this article will provide an overview of an evidence-based model developed for rural and remote Aboriginal palliative care service delivery in Australia. The model has attracted considerable interest from Canadian and international audiences, and they have provided strong feedback to the authors. These audiences indicate that the model resonates with, and provides practical insights for, those interested in Aboriginal palliative care in diverse geographical locations. Thus, this overview is intended not only to provide a thorough introduction to the model for interested readers but to go some way toward affirming our common concerns as well; it also suggests possible solutions to the challenges faced by all involved in the provision of palliative care to Aboriginal people.

THE RESEARCH

Funding for this study was provided by the Australian National Health and Medical Research Council. The data for the model development was collected using a qualitative methodology; open-ended interviews were conducted with a cross-section of participants (consumers and health professionals) throughout Australia's Northern Territory. Seventy-two (n=72) interviews were completed with a wide range of participants, including patients (n=10), carers (n=19), Aboriginal health care workers (n=11), health care workers (n=30), and interpreters (n=2). The interviews were conducted in four geographical areas in the Northern Territory: East Arnhem Land (Maningrida, Millingimbi, Elcho Island, Nhulun-

buy, Yirrkala, and Angurugu); Katherine Region (Borrooloola, Ngukurr, and Katherine); Alice Springs; and Darwin. The research questions informing the data collection included: What palliative care services are provided, and are they meeting the clients' needs? How can the services be modified to deliver a culturally appropriate, innovative, and exemplary model? What strategies are needed to develop and apply the model? Thus, the research was concerned with: What is? What works? What is needed?

The interviews were audio-recorded, transcribed verbatim, coded using the NUD*IST computer package, and thematically analyzed. The model developed from the analysis was assessed by a national peer-review panel of experts in Aboriginal health and the Northern Territory Aboriginal Reference Group.

The outcome is a living model (1) — a generic model incorporating all important factors that can be applied to the unique circumstances of each health care service working with Aboriginal people during the end-of-life trajectory. Seven principles (equity; autonomy/empowerment; trust; humane, non-judgmental care; seamless care; emphasis on living; and cultural respect) were articulated by those interviewed and affirmed by experts in Aboriginal health as foundation values to underpin the model (2). It is important to reiterate that this is not a static model to be imposed on services or communities, but rather a living, flexible model to assist with service delivery and health policy. The model is one of advocacy, to be used by those at the coal-face of Aboriginal care to ensure that they have the appropriate resources to carry out their important work (3). Due to popular demand, the full report on the study, with a detailed description and diagrammatic representation of the model, has been published in a second edition, entitled *The Living Model: A Resource Manual for Indigenous*

Palliative Care Service Delivery (3), which is available from the Web site of the International Program of Psycho-social Health Research (IPP-SHR) (www.ipp-shr.cqu.edu.au). A book of readings that bring together all of the publications from the study is presently in the process of being published, and it should be available from the same Web site later in the year.

OVERVIEW

All of the findings from the study that inform the model development are now published and available in peer-review journals. Thus, the sole purpose of this article is to provide an overview of these findings, with references to the published articles, to help readers find full and detailed discussion of the issues outlined. As the following discussion is concerned with Australian research, the word “Aboriginal” will specifically indicate “Australian Aboriginal peoples.” However, Australian aboriginality is itself a very broad category, containing many distinct language groups and subcultures.

SETTING THE STAGE

In order to understand the factors that inform the model, it is essential to have background information, documented by the study, on the Australian context for palliative care and hospice service provision to Aboriginal people.

The findings indicated that there is a lack of knowledge about hospice and palliative care among consumers and professionals involved in Aboriginal health care in rural and remote areas (4). However, there were also positive indications that once the concepts were explained, participants readily and positively embraced the palliative care philosophy and practice.

There are many practical obstacles related to palliative care service provision to Aboriginal people in rural and remote areas. These are associated with equipment, power, transport, distance, and telephone access (5). Indeed, the present provision of end-of-life care to Aboriginal people in these areas is a testament to the ingenuity and dedication of local health professionals. The study found that there is a serious lack of local, culturally appropriate palliative care services (6). The lack of publicly funded health services is compounded by the material poverty of Aboriginal people, who do not have the home resources needed for effective end-of-life care. The lack of palliative care services is exacerbated by the dearth of after-hours medical care and, for many communities, additional services such as those that would be offered by a pharmacy. As palliative care services are not available, Aboriginal people

have to rely on the acute care sector for their end-of-life care. These acute care services include: accident and emergency wards at local hospitals, health clinics, community nurses, general practitioners, respite care, and care for the aged. The solution to the problem of the lack of appropriate care is seen to be providing funding to increase the availability of local palliative care services. This option has the recorded benefit of economic viability, which increases community networks and cohesion, and it is more likely to be culturally appropriate.

For Aboriginal carers, looking after a terminally ill family member is fraught with challenges of distance, social isolation, poverty, and overcrowding, and it is complicated by the fact that their cultural perspectives and practices differ from those of mainstream health care practitioners (7). The distress associated with being a carer is exacerbated by the lack of local respite services (8). This lack was documented as having a negative impact upon the ability of carers to fulfill their caring duties, and it placed undue physical, emotional, and economic stress upon carers, patients, and their families. Furthermore, lack of access to local respite services forced rural and regional patients to relocate to metropolitan areas — away from family, community, and the land, to which Aboriginal people have strong ties. The lack of Aboriginal respite services was also found to obstruct patients’ preference (supported by their carers) to die at home, in their community. Significant hindrances were found to providing respite care to Aboriginal people — namely, beliefs about families looking after their own, resource restrictions, limited staff availability in local areas, and problems such as alcohol abuse associated with hostel use in metropolitan areas. The conclusions drawn from this study suggest the importance of tackling the obstacles to establishing local respite services close to where patients and carers live.

At present, Aboriginal people have to relocate to the major metropolitan hospitals for specialist treatment. The findings indicated that for Aboriginal people, relocation is a frightening experience (9). They have myriad fears, including: fear of leaving home, especially those who have never before left their homelands; fear of disempowerment associated with leaving behind family support networks; fear of hospital environments and high-tech treatments; fear of cultural alienation related to unfamiliar foods and ways of being; fear of travel; fear of loneliness; fear of language and communication barriers; fear of financial pressures; and fear of dying away from home. For patient escorts, as well, there are many prob-

lems associated with relocation — such as loneliness, the emotional distress of being separated from family, financial distress, and the practical problems associated with travel and accommodation (10). In view of the quite serious problems associated with relocation for Aboriginal people, there are strong indications that it should be carried out in a culturally appropriate way and avoided whenever possible.

The findings provide a clear articulation of the wish of Aboriginal people from rural and remote areas to die at home, connected to land and family (11). Cultural reasons are given for this preference, including: the strong connection with land and community, and a belief in the notion of “death country”; the significance of ensuring that the dying individual’s animal spirit is able to return to the land; the importance of passing on sacred knowledge to the appropriate family member; and the imperative of ensuring that the right member of the family network is available to provide the care. The strong wish to die at home makes it important to build local health and palliative care services and to avoid, whenever possible, relocating patients in need of end-of-life care to major metropolitan hospitals. For example, the study explored attitudes toward plans to establish a metropolis-based in-patient hospice to provide palliative care to patients and their families. The findings indicate that the most desirable location for such a hospice is the local community, not the city. Local availability of hospice care would allow patients to die within the comfort of the family network, to maintain their ties to the land, and to avoid the psychosocial problems associated with relocation to the city (4).

A key factor at the interface of traditional Aboriginal people and mainstream health care practitioners, especially for the terminally ill, is divergent perspectives on health and illness. For example, there is no Aboriginal word for “cancer,” and the Western biomedical semantic construction of the term is not widely understood (12). Additionally, for many Aboriginal people, the etiology of cancer, like the etiology of other illnesses, is embedded in beliefs about curses and payback in the spirit world for perceived misdeeds.

Similarly, the provision of clinical care can be impacted by cultural factors. For example, to understand the problems of pain management, it is important that one first appreciate many of the cultural practices and beliefs of Aboriginal people (13). Findings from the study show that Aboriginal people may have a higher pain threshold and are less likely to complain; this is particularly so for men, who think that they will appear weak if they express their pain. Key factors impacting

on pain management are cultural concerns about blame and payback. There is also a fear of Western medicine stemming from a lack of understanding of clinical notions of pain relief; fear of the administration, side effects, and ramifications of medications; and fear that Western pain medications will speed up the dying process and inhibit the passing on of traditional knowledge and secrets during the end-of-life period. Strategies posited for ensuring effective pain management include: developing trust; having doctors administer pain medication in a timely fashion; offering emotional support; providing information to decrease fear; giving the right information to the right person; and strengthening health services provision.

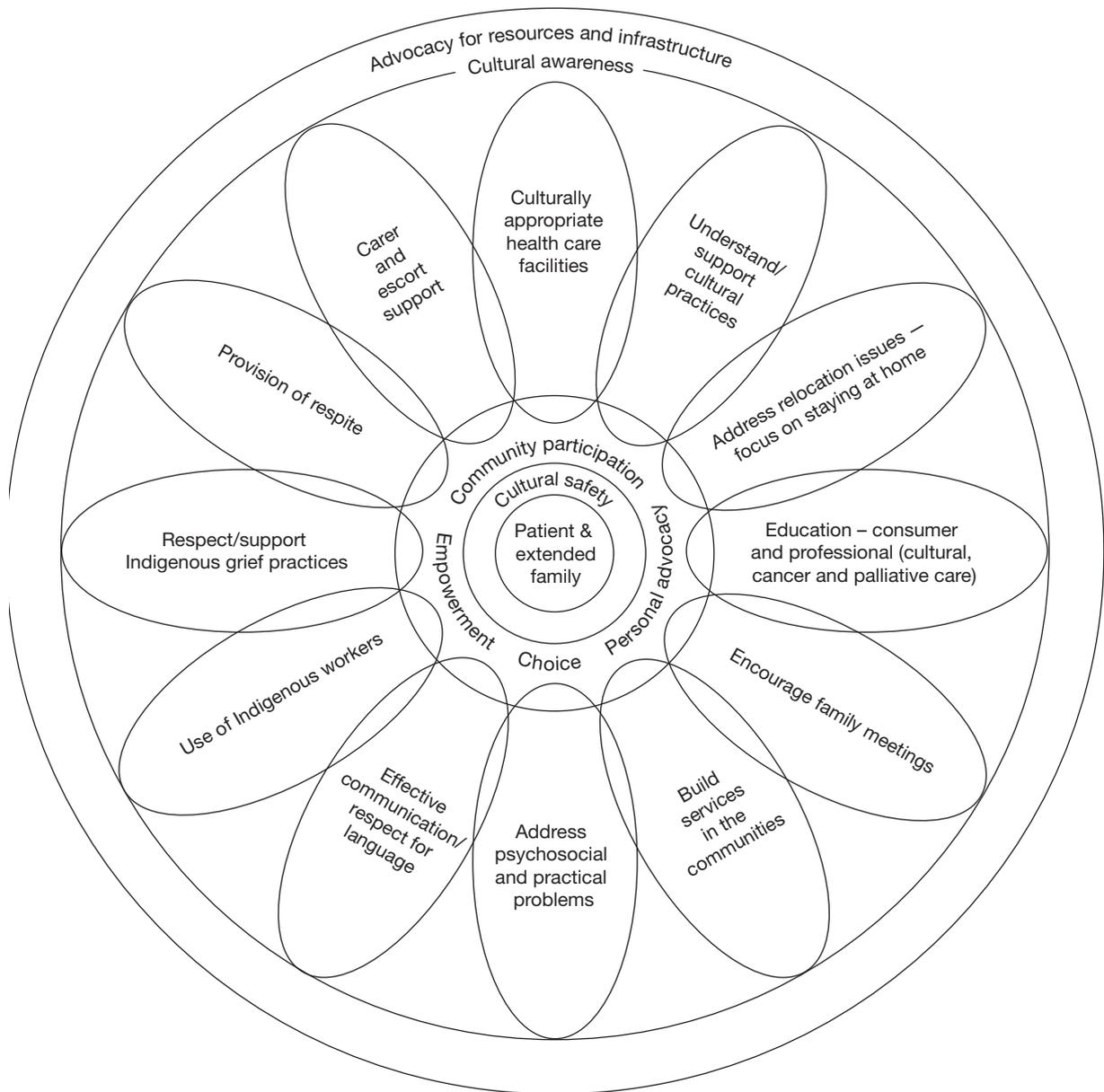
THE LIVING MODEL

The model for palliative care that was developed to address the many challenges faced by Aboriginal people in rural and remote areas has at its core the notion of the patient within the context of the extended family. For Aboriginal people, kinship and the extended family network — rather than the autonomous individual, as in the Western model — should be central in the delivery of palliative care (14). In consideration of the history of oppression — along with the hegemony of Western biomedicine — notions of cultural safety and empowerment are also prioritized as concentric rings at the centre of the model. The model is intended to serve as a practical itemization of factors for practitioners to use in their advocacy work. It is comprised of 12 interlocking ovals that outline key processes in the provision of effective palliative care to Aboriginal people (see Figure 1). These include: employing Aboriginal health workers; ensuring effective communication/respect for language; addressing psychosocial and practical problems; building services in the communities; encouraging family meetings; organizing educational activities, both consumer and professional (related to cultural factors, cancer, and palliative care); addressing relocation issues, with a focus on staying home; understanding and supporting cultural practices; developing culturally appropriate health care facilities; offering carer and escort support; and providing respite. All of these activities are contained in a circle of cultural awareness, and they inform the process of advocacy for resources and infrastructure.

WHAT WORKS

The study not only documented the challenges as outlined in the background to the model development, but it also actively sought descriptions of processes that facilitated palliative care service delivery to Aboriginal people. These descriptions

Figure 1 / Living Model: A Model for Indigenous Palliative Care



directly informed the model. The following discussion summarizes the findings.

Effective communication with Aboriginal people is especially important, because Aboriginal beliefs about health and sickness differ greatly from Western views (15). The central concept informing communication with Aboriginal people is that the right story must be told to the right person: that is, full and culturally appropriate information (properly translated, with the opportunity given for feedback to ensure comprehension) must be communicated to a person selected in recognition of the importance of family and community relationships. Acknowledging Aboriginal people's relationship rules and communi-

cating through family meetings are practices that demonstrate respect for Aboriginal cultural processes of information sharing (16). Aboriginal people can become angry when such processes are ignored or misunderstood. Respecting the need to share the story broadly with the appropriate people in the extended family and the community through family meetings is noted as vitally important in health care, and it is especially important during the dying trajectory. Complex cultural relationship rules determine who should and who should not be directly involved in providing physical care (13).

The findings point to the great diversity of languages spoken by Aboriginal peoples in the

Northern Territory and highlight the fact that Aboriginal peoples in that area either do not speak English or speak it as a second language (17). Fear is the key emotion associated with the communication problems that arise at the interface of Aboriginal people and those who speak *balanda* (Western) languages. This is especially so for the elderly and for people from the remote communities and homelands, as they are less likely to speak English. While it is noted that Aboriginal people appreciate attempts to bridge language barriers, the findings also point to the difficulties encountered in trying to understand a language in which the actual meanings of words are open to interpretation. The findings indicate that speaking in traditional language is emotionally significant for Aboriginal people during the intense end-of-life period. The health professionals interviewed reported that they find traditional language extremely helpful when discussing serious matters. The core recommendation for bridging the language divide is to use Aboriginal interpreters in the communities.

Those undertaking to obtain Aboriginal consent for medical procedures should consider the differences in perspective on illness and healing. They must obtain consent from the right person in the right relationship to the patient and maintain a focus on the extended family and community network; they must appreciate different notions of time; and they must remain mindful of practical obstacles and language barriers to obtaining consent and of different approaches to balancing the harms and benefits of treatment (14).

There are significant cultural differences between the two groups — the dominant Anglo-Australians and the Aboriginal Australians — particularly in the way each deals with death (18). It is thus extremely important for health care professionals to be fully informed about Aboriginal spiritual beliefs associated with death and dying. Many Aboriginal perspectives on serious illness and dying blend Christian and traditional beliefs. Traditional healing, the medicine man, and the preferred place of death are also important spiritual considerations for Aboriginal people.

There are a number of Aboriginal cultural practices related to caring for the deceased that need to be respected (19). The findings indicate the importance to Aboriginal people of viewing the body and the bereavement practice of group wailing, which can be accompanied by self-mutilation and the removal of clothing. There are many cultural practices through which traditional Aboriginal people deal with the emotional pain of bereavement, including sharing grief among large family and community networks; crying, wailing, sing-

ing, and storytelling; and confronting blame (20). Special ceremonies are conducted when the body is returned home, and there are strong relationship-based practices that dictate who should handle the body. Of great significance in many Aboriginal cultures are certain traditional end-of-life practices: the smoking ceremony, a ritual conducted in the deceased's living space to drive away the spirit of the deceased; the practice of painting all living spaces inhabited by the deceased with ochre, or putting up flags to drive away the deceased's spirit and to notify the community that this is the house of a deceased person; and the death ceremony, which includes keeping the deceased in the home, painting the bodies of the mourners, and bringing kinship communities together to share food, song, and dance (21).

In view of all of these major cultural, linguistic, ceremonial, and spiritual differences, the model emphasizes the importance of employing Aboriginal health workers (AHWs) to provide palliative care (22). Due to the alienation created by such differences, participants reported that Aboriginal people would prefer to be cared for by members of their own community. It is important to ensure that during the sensitive and distressing end-of-life period, terminally ill Aboriginal people have the assistance of an AHW — someone with whom they can communicate in the spoken and unspoken language of their people and negotiate Aboriginal knowledge and cultural belief systems. While highlighting the valuable role of AHWs in providing palliative care for Aboriginal people, the findings emphasize that the lack of such workers deserves serious attention. In the findings, myriad employment issues associated with AHWs are explored, including: staff turnover and the need for sustainability; the lack of individuals to employ from the local community; and the dearth of culturally appropriate support for AHWs.

Along with affirming the importance of addressing cultural differences, the study findings affirm that successful outcomes are derived from generic factors associated with palliative care philosophy and practice (23).

CONCLUSION

The living model is a humble first step toward creating a conceptual map for addressing the many challenges associated with the provision of palliative care and hospice services to Aboriginal peoples in Australia. The model has been requested by practitioners involved in the care of Aboriginal peoples around the world. Their ongoing feedback affirms the basic worldwide commonality of factors such as: the importance of

cultural, spiritual, and ceremonial differences; the ways in which Aboriginal perspectives on health and illness differ from those of mainstream medicine; the centrality of language; the significance of Aboriginal people's connection with the land; the difficulties they encounter due to relocation; the lack of local services; the importance of kinship and family networks; the practical obstacles to service provision; concerns about pain management; the importance of culturally appropriate communication; the need for respect for cultural practices associate with grief; and the import role to be played by Aboriginal health workers.

We hope that this summary of the model will provide an effective and useful overview of issues related to providing palliative care services to Aboriginal peoples in Australia and help to identify points of similarity with Aboriginal peoples elsewhere. The living model is offered to all involved in the care of terminally ill Aboriginal people, their families, and their communities so that they can benefit, as we did, from the wisdom and extensive experience of our many study participants. These people generously gave their time and insight to enrich our understanding of how best to care for Aboriginal people during the difficult time of dying and bereavement.

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