

CURRENT REVIEWS

Chinese Community Views: Promoting Cultural Competence in Palliative Care

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INTRODUCTION

Eliciting the views of minority groups in designing and implementing cancer and palliative care services can contribute to equity in health care. Evidence suggests that minority ethnic groups make less use of cancer and specialist palliative care services than expected; the reasons for this are unclear (1,2). Failure to take up services can not be taken to mean that services are not needed. Moreover, research and policy directives have tended to combine large heterogeneous groups of people into a single category of "black and ethnic minority groups," with little recognition of the diversity of life and economic circumstances experienced by these people (3). A recent review of the literature on the palliative care needs of black and ethnic minority groups, commissioned by the UK's National Council for Hospices and Specialist Palliative Care Services (NCHSPCS), has highlighted the paucity of research on the views and needs of Chinese people (2). This report indicated that they are a relatively marginalized and under-researched group (2). The Chinese population is in need of greater attention and, as part of a current research project, the authors have examined common assumptions and stereotypes.

Chinese people resident in Western countries, especially those in the UK, are the focus of this paper. We recognise the term "Chinese people" is problematic because it represents a heterogeneous group of people who have widely different life experiences, cultural traditions, dialects, educational opportunities, and economic positions. Moreover, Chinese people have experienced different patterns of migration; some having settled in Western countries via other areas such as Singapore or Hong Kong, and some have moved directly from mainland China.

Many "Chinese people" living in Western countries will have been resident there all their lives, but the extent of acculturation can not be assumed from either length of residence or place of birth.

Chinese people may experience direct and indirect discrimination by specialist palliative care services for a number of reasons. Issues of language competence, socioeconomic deprivation, institutional discrimination, and cultural insensitivity can lead to multiple disadvantages in accessing acceptable and appropriate palliative care services. Current trends in palliative care, such as open disclosure of diagnostic information with the patient rather than the family, valuing individual autonomy, and promoting dying at home, are based on assumptions which may not be shared by the Chinese community.

The purpose of this paper is to draw upon existing evidence in the literature to explore Chinese cultural perspectives on end-of-life care. We discuss the literature on beliefs and views of the Chinese community resident in Western countries, drawing especially on the UK. A critical evaluation of the literature is presented to encourage and facilitate additional research on end-of-life issues for Chinese people. Following detailed description of key contributing factors and issues for Chinese people facing death, the paper highlights four important aspects of research in this area:

- diagnostic and prognostic information disclosure,
- preferences for family roles in decision making,
- preferences for life-sustaining treatments, and
- preferences for place of death.

Finally, the paper identifies limitations of existing studies and highlights issues for health pro-

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professionals working with Chinese communities. We aim to draw out the implications for culturally competent practice in palliative care. From this we identify assumptions made by palliative care services that may be countercultural and have unintended consequences.

A method of qualitative systematic literature reviews, described by Hawker et al. (4), provided a framework for this analysis. Using a staged approach, we undertook an initial search for published material which included the key terms "Chinese", "palliative care", "terminal care", and/or "cancer services" in relevant medical and social science databases. The identification of published literature was followed by obtaining citations found in individual articles to further publications. All papers were obtained and checked for relevance. Full copies of all papers were read, and a synthesis of our findings presented in narrative form. A more detailed presentation of this methodology is available elsewhere (4,5).

Chinese People Resident in Western Countries

Chinese people have migrated from mainland China and other parts of Far East Asia for economic and political reasons for at least two centuries. Their descendents now form sizable minority communities in many Western countries, including the USA (2.7 million in a total of 281.4 million people in 2000), Canada (1.1 million in a total of 30.1 million people in 2001), Australia (1 million Asian-born with 169,100 born in China in a total population of 18.9 million people in 2001), and New Zealand (104,583 people in a total population of 3.7 million people in 2001).

Chinese people have been resident in the UK for at least a hundred years, with a recent influx from Hong Kong during the 1990s. People of Chinese origin (208,168) make up 0.4% of the British population (6) and 5.3% of the minority ethnic population. There are two patterns of settlement among Chinese people in the UK: one is concentration around "Chinatowns" in major cities such as London and Manchester, and the other is dispersal in small towns (7). It has been argued that patterns of settlement and employment (largely in the catering trade) may have contributed to their social and political exclusion (7).

Written Chinese is a common language with simplified and traditional versions, but there are a number of spoken dialects, Cantonese, Hakka, and Mandarin being the most common in Britain. Literacy levels of people in both written English and Chinese may be poor in less educated, older Chinese people (8). The ability to access information and communicate effec-

tively in English is likely to influence the ability to seek appropriate health services, especially with telephone-based help-lines such as NHS Direct. Literacy, and poor skills in written and spoken English may be reasons for lack of take-up of health and social care services. It has been estimated that, in England and Wales, 23% of people whose country of birth was China, Bangladesh, India, or Pakistan have little or no functional communication skills in English, and that for approximately 70%, limitations in English language competence restricts their ability to access and use health care resources (9).

Chinese Perspectives on Illness and End of Life

There is no monolithic Chinese culture. The Chinese community are a heterogeneous group drawing upon many influences, such as Confucianism, Taoism, and Buddhism; latterly, Communism and pragmatism have all had an effect on cultural values (10–12). A Confucian notion of ethics and personhood, in which personhood is seen as a relational construct which is accomplished by roles and responsibilities for others, dominate (13). Values such as loyalty, filial piety, the maintenance of social order, the superiority of men over women, self-restraint, self-respect, and self-blame are embedded in Chinese culture and have implications for health behaviour during end-of-life care. The implications of these values are that collective decision making within the family has tended to be regarded as the norm. Social cohesion is achieved through the suppression of open conflict and a submission to the collective well-being of families, rather than through the valuing of individual autonomy. Traditionally, gender-specific roles are regarded as normal, with decision making largely confined to male members of the family. Reciprocal relationships within families mean that older members and those facing the end-of-life are reliant on their children to provide care and to negotiate with health care professionals on their behalf. These dependencies are compounded for many older people by a lack of language skills and understanding of Western health care systems. Varying levels of acculturation to life in Western countries adds more complexity to understanding how particular people experience illness (14). Crabbe describes the emphasis on self-reliance and mutual help which may lead to reluctance to acknowledge health problems (15). Even those who have been brought up in the West and have adopted Western values may turn to traditional practices (16,17) in the face of life-limiting illness.

Many Chinese people in the UK see Western medicine as a short-term solution to their diseases, and prefer to rely on Chinese medicine in the long run (18). Similarly, a study conducted about the views of people living in Hong Kong indicated that they used both Western and traditional Chinese medicine (19). It was reported that traditional Chinese medicine acted "slowly" and was, therefore, believed to be better at clearing "the root of illness," while Western medicine was believed to act more quickly and was "stronger," but was associated with more side effects. Chinese people tend to regard health care as a continuing process rather than something to be done when ill, and this different viewpoint may affect the way they regard health services (8). Another research study conducted in Hong Kong indicates that acceptance of the value of Western and traditional Chinese medicine may coexist, with a preference for the use of Western biomedicine where there are clear causative explanations, and/or effective preventative or curative treatments (20). In conditions where there is little consensus on causation from a biomedical perspective, traditional Chinese therapies are regarded as appropriate. Studies show the importance of realizing that people who have adopted many Western practices may "mix and match" these with traditional Chinese ones (18,21,22).

Consideration of the ethical principles informing health care decision making highlights the problem of crosscultural conflict in end-of-life care. For example, in comparison with Western societies, individual autonomy is not traditionally valued in Chinese culture. This has implications for such issues as the disclosure of a cancer diagnosis to the patient, and the role of the family in medical decision making and treatment choices (17,14). It has been argued that open discussion of terminal illness and end-of-life issues is not regarded as appropriate in Chinese culture (23). Instead, open discussion of death is avoided, as it is perceived to be harmful and discouraging to patients, and may potentially precipitate or hasten death. This position appears similar to the rationale for nondisclosure of a cancer diagnosis, which was commonly practised in the USA and UK for much of the 20th century, but may stem from belief sets different from the "benign paternalism" which prevailed in Western medical practice before the more recent advent of "patient consumer power." Arguably, whilst the disclosure practices of Western physicians have become more open, most Chinese medical practitioners maintain a more closed approach to patients, al-

though not to their family members. Nilchaikovit et al. (24) have proposed that there are marked differences in Asian and Western notions of illness experience, which give rise, respectively, to more hierarchical or egalitarian models in relation to expectations of the doctor-patient relationship. Confucian ethics have implications for family values, the role of the family in the care of ill members, and medical decision making (13). For example, within this perspective, a doctor's role is to enhance family harmony and acknowledge the interconnectedness of family members, rather than endorse individual autonomy.

Literature Review Key Findings

The findings from the literature review have been organized into four themes.

Diagnostic and Prognostic Information Disclosure. Evidence from research conducted in a number of major cities with substantial communities of people of Chinese origin, including Hong Kong (25), New York City (26) and Sydney, Australia (27), indicate that, contrary to popular conceptions, most participants wanted to be informed of their diagnosis, prognosis, and treatment options at the same time as their family. Most Chinese people living in Hong Kong desired open disclosure to much the same extent as Western samples, but there was a trend for older people to prefer less information and less involvement in medical decision making than younger people. Likewise, a comparison of the views of 60 older Chinese people with 60 older non-Chinese people living in long-term residential care in New York City, USA, indicated few major differences, although the lack of systematic analysis of the numerous quotes made it difficult to draw conclusions (26). In an Australian study, all except one patient wished to have full disclosure about cancer to them and their family, but they preferred nondisclosure of a poor prognosis. While there is strong evidence that Chinese people wish to have open disclosure of their diagnosis, a Canadian study concluded that older Chinese people did not favour advance directives because they created negative thoughts by requiring people to contemplate their own demise (28).

Educational workshops with older Chinese people living in Calgary, Canada, were used to elicit feedback on translations of hospice information and assessment materials (29). A particular problem was the lack of suitable and equivalent Chinese words for "palliative care" and "hospice". This indicates that translation alone is not sufficient, there needs to be careful consideration

of cultural concepts and meanings in providing health care information. Australian Chinese cancer patients wanted interpreters to be available, even if the patient spoke English (27).

Preferences for Family Roles in Decision Making. Crosscultural research, conducted in Australia (30), compared the views of 371 Anglo Australians with 90 Chinese Australians and concluded that both groups wanted to be involved in decision making. A further Australian study involving Chinese cancer patients and their relatives (27) reported that families were regarded as having an important liaison role with health care workers, but they should make decisions in collaboration with patients. Another interview study of 382 older people resident in care homes and of 161 patients in geriatric wards in Hong Kong revealed that over half of them wished to be involved in medical decision making and that they did not favour decisions being made by their relatives alone (31).

Preferences for Life-Sustaining Treatments. There is some evidence that Chinese people are more likely to favour active life-sustaining medical interventions than are other groups. Comparison research between Anglo Australians and Chinese Australians (30) indicated that Chinese people were more likely to desire intensive care, but fewer wanted euthanasia. An interview study of older people resident in care homes and of patients in geriatric wards in Hong Kong (31) revealed that most of the participants were keen to have life-supporting medical interventions, such as cardiopulmonary resuscitation (CPR), although this declined by 20% once they were made aware of the poor outcomes. Females over 80 years of age who had no spouse were less likely to favour CPR.

Preferences for Place of Death. Preferences for facilitating choice of place of death have taken a central role in palliative care provision in the UK (32). Evidence from the literature on Chinese community preferences is mixed, and largely dependent upon environmental factors. Poor housing conditions in Hong Kong and the lack of community nursing services mean that dying in hospital is preferred (33). In comparison, Taiwanese culture places a high value on dying at home (34), even to the extent that moribund patients were artificially ventilated prior to transfer home so that they could "breathe their last breath" at home (35). Data collected from Anglo Australians and Chinese Australians indicate that just under half of both groups wanted a "natural" (hospice) death rather than be admitted to an acute care hospital (30), which sug-

gests that, where palliative care services and hospices are well-established and readily available, they are acceptable to most Chinese people. There is little evidence about the preferences about place of death of Chinese community members living in the UK and North America.

DISCUSSION

Anecdotal evidence often suggests that Chinese people are fearful of death and reluctant to talk about it (an inauspicious topic), unassertive and unwilling to express their views (conformist), and have strong preferences for family information giving and decision making. Evidence from this literature review has started to challenge these assumptions. A recognition of and advocacy for the views and preferences of minority populations is a common feature of many health care organizations in multicultural societies. There is little doubt that an acknowledgement of diversity in preferences and experiences of illness can bring substantial benefits to patients and health care providers. This paper goes some way to highlighting the evidence from research conducted with Chinese people living in a number of countries.

Observations from medical anthropology indicate that people can believe simultaneously in biomedical concepts, folk and traditional Chinese medicine, and beliefs in the explanation of illness causation (20,27). There is mixed evidence about the influence of ethnicity on preferences for medical interventions near the end of life expressed in advance directives in the USA, with one study (36) indicating no effects of ethnicity, and another study (37) reporting that Asians were more likely to prefer less aggressive treatments.

Crain (26) cautions that "while a group's cultural beliefs must be explored, understood and respected, it must also be remembered that groups are made up of persons with individual differences and experiences that result in varied value systems" (p 9). Gunaratnam (38) has argued against the use of "checklist" approaches in dealing with cultural diversity in palliative care. Our review of the published evidence has found little support for common cultural stereotypes of Chinese end-of-life views. Our analysis of the literature indicates that the majority of Chinese minority populations in Western countries appear to hold views of end-of-life preferences, in terms of disclosure and treatment choices, similar to those of others living in these countries. There is more ambivalence about preferences for more intensive medical interventions near the end of life and this requires more

research. Further, little is understood about the relationship between Chinese older people's underpinning belief systems, and their treatment and care preferences. These issues are being addressed in ongoing research by the authors. Much less research attention has been directed to exploring the preferences of Chinese patients, although there is evidence that many of them value Western and traditional Chinese medicine, and do not regard them as incompatible.

The literature review has examined the views of Chinese healthy and patient populations. Eliciting the views of "healthy" members of the Chinese community offers the opportunity to understand what attitudes to end of life are held, and how preferences for treatment and care are expressed. Focusing on healthy people has other advantages, including providing professionals with a resource of culturally relevant information; it may also be less ethically difficult than conducting research with people (patients) who are already ill. In addition, it has the advantage of obtaining views from those who are not seeking services and, therefore, data are collected at less emotive times. However, the disadvantage is that people may have relatively little experience of particular illnesses or end-of-life care situations and, therefore, the topic may not be salient to them.¹

Chinese people who do not speak the language of their country of residence are at a disadvantage. A comparative study of crosscultural competence in palliative care professionals in Western Australia indicates that language differences are regarded as more problematic for Asian people (39). The availability and use of interpreters requires successful coordination of resources and skills by practitioners and, often, forward planning. Evidence from cancer patients indicates that interpreters should be offered even when it appears that the patient can speak English (27). However, health professionals may regard interpreters with some ambivalence, as they cannot establish direct communication with the patient. This may be particularly significant when dealing with end-of-life care issues. The preparation of information materials in Chinese may help, but some words such as "palliative care" are difficult concepts to translate. In addition, our analysis has indicated that professional-patient communication with Chinese patients needs to take account of differing understandings and values placed on individual autonomy versus collective family decision making.

Cultural competence encompasses a set of values, behaviours, attitudes, knowledge, and skills which allow professionals to offer patient

care which is respectful and inclusive of diverse cultural backgrounds (29). Papadopoulos et al. (40) have argued that there are problems with the notion of "cultural sensitivity" and that there should be greater recognition of "cultural competence" in health care.

Issues for Health Professionals

What might be the implications for culturally competent palliative care? In our view, it requires a recognition of individual experience and beliefs which can not be known by assumptions derived from attributions about larger cultural groups. Even within this paper, we have tried to emphasize the diversity of views captured within the label "Chinese." Still less can these perspectives be assumed to transfer from studies of other, more dominant, black and ethnic minority groups. Culturally competent palliative care should incorporate knowledge of local minority communities; recognition of one's own cultural assumptions and position; and the communication skills, time, and motivation to explore the preferences, values, and beliefs of individual patients and their families. It might, therefore, be helpful for palliative care practitioners to explore, in a nonjudgmental way, what concurrent treatments—including traditional Chinese medicine—patients are using. Likewise, explanations of treatment options should be presented in such a way as to be respectful of illness concepts and beliefs. Other aspects of palliative care, such as psychological and spiritual support, require further investigation if practitioners are to achieve cultural competence with Chinese patients. Further research is needed to inform the development of such practice.

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¹ Although early findings from the authors' ongoing research suggest this is not the case.

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