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The experience of Chinese immigrant women in caring for a terminally ill family member in Australia

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Summary The Chinese community, a heterogeneous, highly visible non-English speaking ethnic group in Australia, remains mostly hidden and underrepresented in palliative care service delivery along with participation in health research despite being the fastest growing such group in the country. There is a lack of Australian research information concerning the impact of migration on the caregiving experience of women carers within the Chinese cultural framework and the Australian palliative care context. This paper aims to explore the influence of Chinese cultural norms and immigration on the experience of immigrant women of Chinese ancestry caring for a terminally ill family member at home in Sydney. This study also seeks to identify factors that may present access barriers to palliative care support services. A qualitative approach was used in this study. Data were collected from semi-structured interviews with five home-based Chinese women carers and were analysed using thematic analysis. Findings identified that the participants found being a carer is a lonely and isolating experience. Sources of isolation and loneliness included social isolation experienced as a solitary carer without meaningful family and social relationships; loss of familiar cultural understandings and family values; and emotional isolators expressed in response to the physical and emotional role commitment and other constraints. The study results suggest the need for palliative care educational programmes designed to help nurses to understand the impact of cultural background within the palliative care context. Results also indicate that health care professionals should provide culturally appropriate and competent palliative care services, sensitive to the diverse socio-cultural influences and individual needs of Chinese migrants.
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Introduction

Mounting recognition of the contribution, complexity and burden associated with the caring role has captured international (Fast, Eales, & Keating, 2001; Koffman & Higginson, 2003) and Australian (McGrath, Vun, & McLeod, 2001; Zapart, Kenny, Hall, Servis, & Wiley, 2007) research attention. Recent Australian palliative care research has focused on the challenges and unmet needs of predominantly female Australian home-based primary carers of a terminally ill relative (Aoun, Kristjanson, Currow, & Hudson, 2005; Hudson, Thomas, Trauer, Remedios, & Clarke, 2011).

In palliative care, in Australia, caring for people with disability is predominantly undertaken by women. About 71% of primary carers are women; two-thirds are wives and 20% daughters or daughters-in-law (McIntyre, 1999; Palliative Care Australia (PCA), 2004). Primary carers provide the main and sustained assistance with core activities that include communication, self-care, mobility, transport and housework (Australian Bureau of Statistics (ABS), 2011). The most frequent stated reasons for being primary carers include; family responsibility, emotional obligation, provide better care, and no-one else willing or available to take on the responsibility (ABS, 2003).

Australian studies have found that Australian women carers suffer profound distress and powerlessness whilst watching a loved one suffer (Grbich, Parker, & Maddocks, 2001; Zapart et al., 2007). The carers in these studies experienced great physical and intense emotional stress related to the physical tasks of care of the dying relative, the emotional supportive care needed, inadequate emotional and social support, lack of formal support information and financial difficulties. During 2009, there were over 770,000 primary carers (ABS, 2011) including an estimated 186,000 carers with culturally and linguistically diverse (CALD) backgrounds living in New South Wales inclusive of Chinese immigrants (ABS, 2003). The Chinese speaking population is the largest non-English speaking community language group. In Sydney, 292,338 individuals identified themselves as having Chinese ancestry, including Chinese migrants from mainland China, Hong Kong, Malaysia, Vietnam, Singapore, Taiwan and Indonesia (ABS, 2007). This heterogeneous group has different political and cultural backgrounds and individual needs (Martin, 1999). The diversity of the Chinese in Australia is reflected in their complex migration patterns and histories, languages, politics, education, social and economic characteristics and religious and cultural influences (Khoo, 2011).

Traditional Chinese cultural beliefs about death, dying and end of life issues have been deeply influenced mainly by three blended Chinese philosophical and religious concepts, namely Confucianism, Buddhism and Taoism (Hsu, O'Connor, & Lee, 2009; Mjelde-Mossey & Chan, 2007) (see Table 1). Culture deeply influences perceptions of, and helps make sense of, illness, health and suffering (Surbone, 2004; Surbone, Kagawa-Singer, Terret, & Baider, 2007) and dying (Kagawa-Singer & Blackhall, 2001) and how individuals respond to change, deal with stressors, and ultimately cope (Abramson, Trejo, & Lai, 2002). Local folk beliefs commonly exist in death attitudes and practices, including the influences of different deities, hungry ghosts, evil spirits, geomancy and astrology (Park, 2009; Yeo et al., 2005; Yick & Gupta, 2002). Ancestor reverence, an enduring belief, has permeated traditional Chinese religions (Mjelde-Mossey & Chan, 2007; Park, 2009) and promotes continuing bonds with the deceased and the afterlife, influencing the lives of generations of families (Hsu et al., 2009; Yick & Gupta, 2002). For some Chinese, dying at home has a significant cultural meaning as it is a way of sustaining bonds with ancestors (Tang, 2000). Paying proper respect to ancestors through offerings, rituals and prayers is believed to invoke their blessings on the descendents (Hsu et al., 2009; Yick & Gupta, 2002) and to combat terminal illness (Chui, Donoghue, & Chenoweth, 2005).

However, Chinese culture is not static but a dynamic process influenced by migration and life experiences, socioeconomic status, language, gender, and religious belief (Waddell & McNamara, 1997). These factors shape the diversity of perspectives and responses of Chinese individuals to illness, dying and death and palliative care (Huang, Meiser, Butow, & Goldstein, 1999; Payne, Chapman, Holloway, Seymour, & Chau, 2005). An individual tailored approach with awareness of the diversity within the Chinese community is essential for healthcare providers to respond to the specific needs of the Chinese individual (Waddell & McNamara, 1997; Yu, 2009).

Migration, culture and caregiving

Confucianism profoundly influences Chinese world views, cultural norms, behaviours and value systems (Kwan, 2002), that often are different from, and at distinct variance with, those found in Western traditions (Meng, Zhang, & Jiang, 2011; Mjelde-Mossey & Walz, 2006). Filial piety, the fundamental concept of care in Confucianism (Koh & Koh, 2008) prioritises self-sacrifice, harmony with all others, importance of the family name, respect for parents, obligation, and devotion to family (Chen, 2001; Lai, 2010;Wong, 2006). As well, the primacy given to duties and responsibilities to others (Chen, Jo, & Donnell, 2004; Kim, Yang, Atkinson, Wolfe, & Hong, 2001), and taking care of a dying relative (Chan, Lam, Chun, Dai, & Leung, 1999; Mok, Chan, Chan, & Yeung, 2003) are strong elements of filial piety in Confucius's core teachings (see Table 2). Furthermore, in traditional Chinese societies Confucian values and societal expectations have defined women as the primary carers (Holroyd, 2005; Zhan & Montgomery, 2003) whose duty is to provide unconditional care for family members particularly during illness (Holroyd, 2003). Females have been ''raised to accept responsibility'' of caring for family members as a ''cultural and moral mandate'' (Jones, 1995, p. 394).

Recent researchers assert that despite social and cultural changes in East Asian countries, traditional gender roles for women still prevail within the family and society in general (Pascall & Sung, 2007; Wu, 2007). Notably, these gendered cultural norms form a controlling cultural force (Granrose, 2005) and are still practised by immigrant Chinese women overseas who fulfil the role of primary carer (Leung & McDonald, 2007; Spitzer, Neufeld, Harrison, Hughes, & Stewart, 2003), despite diversity in terms of geographic location, language, religion, and socio-economic status. However, filial piety can be a source of intense anxiety when caregiving obligations conflict with individual

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