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Maintaining distance from a necessary intrusion: A postcolonial perspective on dying at home for Chinese immigrants in Toronto, Canada

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ABSTRACT

Purpose: The purpose of this study was to describe and examine how meanings of home condition negotiations of care for Chinese immigrants with advanced cancer receiving palliative home care in Toronto, Canada.

Method: This focused ethnographic study drew on the tenets of postcolonial theory to examine the social and material circumstances associated with dying at home for Chinese immigrants. Eleven key informants were recruited, in addition to 4 cases comprised of a Chinese immigrant care recipient, primary family caregiver, and home visiting nurse. Individual, open-ended interviews were conducted with each participant, along with observations of home visits.

Results: Palliative care was not viewed strictly as an intrusion that was thrust upon the home without permission or invitation, but an insertion into the routines of the home that was necessary because care recipients recognized the need for palliative care providers to help navigate the system and negotiate dying at home. Consequently, care recipients and family caregivers also sought to minimize the intrusions of palliative care by preserving everyday routines and engaging with family and friends.

Conclusions: Although the study was focused on Chinese immigrants, the findings resonate with and speak more broadly to the contextual, systemic, social, and material circumstances associated with dying at home for immigrants with advanced cancer. Nurses providing palliative home care to immigrants may begin to critically examine assumptions of "cultural" beliefs about cancer and end-of-life care and look beyond identifying ethno-specific practices, but come to recognize how nurses are implicated in a culture of palliative care.

Introduction

Population based statistics show an overall trend towards a decline of cancer deaths in hospitals and a gradual increase in home deaths across Canada (Burge et al., 2003; Neutel et al., 2005; Wilson et al., 2009). Receipt of palliative care at home can change the meaning of home from a place of health, refuge, privacy, security, and living (Angus et al., 2005; Exley and Allen, 2007; Sorensen Marshall, 2008), to a site that also accommodates and supports dying. The home carries emotional connotations as well as vulnerabilities (Sorensen Marshall, 2008). It is a richly layered placeto understand death and dying for advanced cancer patients, and in particular, this layering of nuance may be intensified when immigrants receive palliative home care. According to Dyck and Dossa (2007), everyday practices of migrants "are not best understood as simply local, but as intricately interwoven with material resources and/or cultural knowledge located and constructed within a context of transnational connections and memories of 'home'" (p. 692). Immigrants must negotiate multiple meanings of home such as home as a place of origin, a form of shelter, and a place of belonging (Hayes, 2007), but these meanings may become unsettled when their homes are transformed to places for dying.

Immigrants may feel a sense of isolation and alienation as they try to re-build a sense of home and belonging after migration (Choudhry, 2001), and the existential anxiety associated with trying to re-claim a sense of home may be evoked again when

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receiving palliative care at home. As such, the meanings of home may be contested as a succession of outside home care providers enter to provide palliative care. There is a lack of research examining how meanings of home may change physically, socially, and spiritually over time for first generation immigrants facing terminal cancer and their caregivers when receiving home care.

Background

Chinese immigrants in Canada

Chinese immigrants make up one of the largest minority groups in Canada with over 1.2 million identifying as Chinese (Statistics Canada, 2008a). The early history of Chinese migration to Canada is characterized by institutional racism as the Canadian government passed legislations and created policies, such as the *Chinese Immigration Act, 1923*, which sought to control, limit, and stop the migration of Chinese people to Canada by charging a head tax that was not levied on other groups (Li, 1998; Liu and Norcliffe, 1996). Over the last two decades, the three main sources of Chinese immigrants to Canada have been China, Taiwan, and Hong Kong (Chui et al., 2005). Today, the Chinese diaspora in Canada is diverse with almost three-quarters of the Chinese population living in either Toronto, a large and diverse metropolitan city in Canada, or Vancouver, another large urban centre (Chui et al., 2005). Due to the long history of Chinese migrating to Toronto, Chinese communities are no longer concentrated in historic “Chinatowns”, but spread across the city, establishing multiple ethnic enclaves in suburban areas (Chui et al., 2005; Wang and Zhong, 2013).

It is important that Canada’s contentious history with Chinese immigrants not be disregarded in explorations of the present-day relations between Chinese immigrants and state regulated institutions such as home care. Past experiences of discrimination may structure health care decision-making and influence how care takes place between Chinese immigrants, their family caregivers, and home care providers. Despite the strong presence of the Chinese in Canada, little is known about what it is like for Chinese immigrants with terminal cancer to receive palliative home care.

Death is often portrayed as a taboo topic within the Chinese community, and thus, there is an expectation that dying at home may not be the preferred option (Braun and Nichols, 1997; Mjelde-Mossey and Chan, 2007; Payne et al., 2005; Yick and Gupta, 2002; Woo, 1999). These perceptions about Chinese beliefs of death and dying fail to recognize the heterogeneity within the Chinese immigrant population, the historical context of Chinese immigration, and how migration and long-term re-settlement may influence Chinese immigrants’ health beliefs and behaviour. Hence, examining the palliative home care experiences of Chinese immigrants is a complex endeavour because it means not only studying how beliefs can influence their views of the dying process, but also taking into consideration the geopolitical context of migration.

Health care and palliative home care in Canada

Canada has a publicly financed and administered health care system based on a single-payer system (Health Canada, 2011). Since the 1990’s, a shift in care to the home has been characterized by fiscal constraints, cost-efficiency, decline in the economy, and cost-saving attempts (Williams, 1996). Growing demand for home care has been attributed to the changes in demographic and life expectancy rates of Canadians, and is related to a larger movement of non-urgent care from hospitals to community (Abelson et al., 2004; Deber, 2003; Lilly et al., 2010; Masucci et al., 2010). In Canada, approximately 230,000 people die annually (Statistics Canada, 2008b). Only 5% of dying Canadians receives integrated interdisciplinary palliative care (Chochinov, 2001; Standing Senate Committee, 2000). Thus, both fiscal restraints and the “aging in place” strategy have contributed to the trend towards home-based palliative care (Guerriere et al., 2010; Masucci et al., 2010).

Theory

Postcolonialism and cultural categorizations

A postcolonial framework was adopted as a critical lens to help deepen analysis of how Chinese immigrants with advanced cancer, their family caregivers, and home care providers navigate the provision of palliative home care. For immigrants, dealing with terminal cancer may be layered and intimately connected with changing meanings of home, past experiences of migration, efforts to create a sense of belonging in their adopted countries, and stereotypical representations of death and dying beliefs. Postcolonial theory is concerned with notions of home, belonging, displacement, historical context, and the boundaries between nationhood and self (Loomba, 2005). As indicated, the historical context of migration is relevant for examining the experiences of immigrants, and in particular Chinese immigrants in Canada because of legislations and policies that greatly restricted the social and political rights of Chinese immigrants (Li, 1998).

Cultural categorizations develop through the privileging of certain social groups and their knowledge over culturally different and subordinate “Others” (Ashcroft et al., 2007). Persistent and insidious binary divisions, enforced through the discourse of East and West, insider and outsider, organize constructions of social categories, often based on race (Ashcroft et al., 2007; Said, 1979/2003). These categories are juxtaposed as favourable and unfavourable stereotypes that may act to reinforce the superiority of the Canadian medical model over other models of health care. Postcolonial scholars in health care critically examine the meaning of culture in health care (or the perceived lack of culture of health care providers), and how marginalizing forces, such as cultural categorizations, limit ethnic groups’ access to health care (Anderson, 2000; Reimer Kirkham and Anderson, 2002; Mohammed, 2006; Puzan, 2003; Racine, 2003). Anderson et al. (2003) state that a postcolonial lens challenges health care providers to look beyond exotic belief systems associated with ethnocultural groups and to begin treating each individual as a distinct entity. Cultural categories used in health care are not neutral in that categorizations tend to normalize Western biomedical beliefs and problematize health beliefs and practices that are “different”, thus positioning “cultural” health beliefs and practices as inferior.

Cancer and colonization

The concept of colonization is closely linked with postcolonial theory. Colonization is associated with imperialism and imperialist endeavours, and thus, elicits negative and traumatic images of historical processes of invasion and domination of countries and citizens (Loomba, 2005; Tuhiwai Smith, 1999). But the concept is used with caution as it is recognized that it would be harsh to speak about palliative home care in a similar light. Although the violent and traumatic histories of colonization are acknowledged, in Frank’s (1995) book, *The Wounded Storyteller: Body, Illness, and Ethics*, he described how his sick body became colonized by medicine through the processes of surgical and pharmacological treatment. Similarly, the term colonization is used as an analogy and metaphor to describe how a care recipient’s body is invaded by cancerous cells. Malignant, foreign cells come to displace what was once normal, healthy tissue; thus, the body becomes colonized by cancer.