

Using Qualitative Methodology and Theory to Examine  
Preferences for Place of Death of Terminally Ill Chinese Canadians

Lisa Seto, RN, PhD student

Lawrence S. Bloomberg Faculty of Nursing

University of Toronto

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Recently there has been growing interest in where individuals want to receive end-of-life care. Many studies in countries, such as the UK, Australia, US, and Canada have found an increasing trend toward dying in the home, rather than in hospitals. In a review of the literature on preferences for place of death, most studies indicate that patients wish to die at home. In fact, results from these studies generally range between 49%- 100% of respondents expressing a preference for a home death (Higginson & Sen-Gupta, 2000). Dying at home has been constructed as the ideal place to receive end-of-life care. Indeed, it is considered the “gold standard” of palliative care (Dudgeon & Kristjanson, 1995). Recent studies on place of death among cancer patients in Canada show that increasingly, more patients are dying in the home (Burge, Lawson, & Johnson, 2003; Neutel, Bishop, Harper, & Gaudette, 2005). There is little knowledge about the ethnicity of those who prefer to die at home, and how cultural beliefs may contribute to the reasons individuals prefer to receive palliative end-of-life care at home or hospital.

Although Canada is considered one of the most ethnoculturally diverse nations in the world, there remain few studies examining preferences for place of death among different ethnic groups, and in particular, immigrant populations. One reason for this gap in the literature is that the term “culture” is highly contentious. Many studies that examine palliative end-of-life care and ethnicity take a traditional approach to defining the concept. These studies generally prescribe ways to provide care based on the assumption that culture is “pre-existing, discovered among a group of people, and can be written about in an allegedly neutral way” (Mohammed, 2006, p. 99). A static, neutral view of culture tends to reinforce differences between groups of people and obscures major differences within cultural groups that result from experiences of immigration and acculturation. Health care providers that accept such conceptualizations of

culture may fail to see the complexity of cultural health beliefs. The purpose of the intended thesis work that informs this paper is to: a) examine how preferences for place of death are depicted among Chinese Canadian immigrants diagnosed with terminal cancer and their family caregivers, and b) explore how Chinese Canadian immigrants and their family caregivers negotiate care with health care providers to organize palliative end-of-life care in the home. An ethnographic study will be conducted and will draw on the tenets of postcolonial theory to examine the contextual and systemic issues of palliative end-of-life home care for Chinese immigrants. This paper will discuss why qualitative methodologies should be used to explore preference for place of death among Chinese Canadians, and also how theory is used to guide the qualitative research process. In particular, the paper will examine how using a postcolonial framework can help direct the research question, method, and analysis; as well as, provide an alternate way of conceptualizing culture through the concept of hybridity.

### Background

There are over one million Chinese people living in Canada, making them the largest visible minority group in Canada (Statistics Canada, 2003). Approximately one hundred thousand (101,810) Chinese Canadians are over the age of 65 (Statistics Canada, 2003). Some of these Chinese Canadians are recent immigrants or may be second, third generation immigrants. As this population continues to diversify and grow, and as the number of elderly Chinese Canadians increases, sensitive topics such as palliation and end-of-life care are becoming especially important to research. It is increasingly important for health care providers to gain an understanding of how palliative end-of-life care can support a good death among immigrant populations. Within the literature, there has been much written about the cultural and health

beliefs of Chinese people. The Chinese belief system is often described as being influenced by the teachings of Confucianism, Taoism, Buddhism, local folklore, and superstition (Yick & Gupta, 2002; Woo, 1999). Chinese cultural values are often associated with filial piety, the importance of the family unit, and emphasize hierarchical familial relationships (Yick & Gupta, 2002). Many articles describe Chinese attitudes toward death as a taboo subject not to be spoken of because it is considered back luck and foreboding (Braun, 1997; Woo, 1999; Yick & Gupta, 2002). While not explicit in the literature, Chinese families may feel pressured to care for a dying family member at home which may not be compatible with personal beliefs. For instance, Chinese families may not want to have a family member die in the home because it may bring bad luck to those that continue to live in the home after the patient has died. Anecdotally, the literature has shown that most Chinese patients may want to receive palliative care in the home, but for the last moments of life, may wish to be transferred to the hospital where the actual death is to take place (McGrath, Vun, & McLeod, 2001).

Palliative end-of-life care emphasizes supportive rather than curative measures at the moment of a life-threatening illness to the end-of-life (WHO, 2007). The World Health Organization (WHO) defines palliative care as

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (2007)

To date, there is little information about the experiences of Chinese immigrants once they are diagnosed with a terminal illness, and what follows that results in whether they receive palliation in the home. It is also important to remember that the Chinese immigrant population itself is

heterogeneous. Cultural differences within the Chinese immigrant population may depend on where and when individuals migrated. There may be generational and regional (urban/rural) differences and differences in dialect based on area of origin. Stereotypes can erroneously propagate assumptions that all Chinese people share the same values and beliefs. Therefore, a conceptualization of culture as a fluid and dynamic process would generate a better understanding of the complexities of culture, migration, health beliefs, and choice in the context of palliative end-of-life home care. By using qualitative methodology to explore preference for place of death among terminally ill Chinese patients, the individual, contextual, and structural factors that influence preference can be elucidated.

### Using Qualitative Methods

While quantitative studies are able to provide a numerical representation of preferences for place of death, they are not able to provide an in-depth description of the reasons for participants' preferences. Simplistically stated, quantitative research generally involves quantifying phenomena with a relatively large sample of people (Esterberg, 2002); such that quantitative researchers work with few variables but many cases (Creswell, 1998). Quantitative research is also deductive; its aim is to test theories and hypotheses (Mitchell & Cody, 1992).

On the other hand, qualitative research “produces findings that are not arrived at by statistical procedures or other means of quantification” (Strauss & Corbin, 1998, p. 10), and work with fewer cases but many variables (Creswell, 1998). Qualitative research is either inductive where existing theory is absent (i.e. using grounded theory produces theory) or abductive where the process is guided by theory (Mitchell & Cody, 1992). Denzin & Lincoln (1994), notable proponents of qualitative research, define it as

... multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts – that describe routine and problematic moments and meaning in individuals' lives (p. 2)

Most definitions of qualitative research highlight similar characteristics: data is collected in the natural setting, the researcher is the key instrument of data collection, outcome as process rather than product, analysis of data is inductive, and focus is on participants' perspectives and their meanings (Creswell, 1998; Denzin & Lincoln, 1994).

There are three major components of qualitative research: data, procedures, and writing. Interviews, observation, documents, and records are all considered data. Qualitative researchers use different procedures to interpret and organize data; specifically, coding as a means of analysis (Strauss & Corbin, 1998). Qualitative findings are presented in written or verbal formats generally. There are several different qualitative methods, but the three most commonly used in health research remain grounded theory, ethnography, and phenomenology (Mitchell & Cody, 1992). Researchers choose to conduct qualitative research for many different reasons. Morse and Richards (2002) provide five common reasons for using qualitative research: 1) to understand an area where there is little known or previous research is inadequate; 2) to make sense of complex situations, where there are multiple contexts and the phenomena continues to shift or change; 3) to learn from participants about the meaning of experiences and how they interpret it; 4) to construct a theory or theoretical framework that reflects reality, i.e. grounded

theory; and 5) to understand a phenomena in-depth. Using qualitative methods is conducive to exploring preference for place of death among Chinese Canadian immigrants because there is currently no empirical data on the preferences among this particular population. There are a multitude of variables to consider when examining preference for place of death. Dying at home is already laden with complex issues, such as preference of the terminally ill patient versus that of the family caregiver, and delivery of professional care in the home by an “outsider”, such as nurses, physicians, and other members of a palliative care team. As well, preference for place may change over time for the patient. In the case of Chinese Canadian immigrants, issues of migration and acculturation make the situation even more complex. There are multiple perspectives and contexts to consider when providing palliative end-of-life care in the home, in particular the relationships between the terminally ill patient, family caregiver, and health care providers. Qualitative data, such as interviews and observational data, would best re-present the experiences and meanings of dying at home for this population.

The foundations of the proposed thesis will be based on the methodological tenets of ethnography which aims to examine social phenomena, and describe and interpret social aspects of daily life (Hammersley & Atkinson, 2007). The researcher examines the “meanings of behaviour, language, and interactions of the culture-sharing group” (Creswell, 1998, p. 58) and how they make sense of the social world (Hammersley & Atkinson, 2007). Ethnographers seek to gain an emic or insider’s perspective and to learn from participants (Morse and Fields, 1995). Health ethnographies are specifically concerned with understanding the interaction between contextual influences on health behaviour and experiences. Ethnographers seek to understand the health beliefs and practices of a cultural or social group so that practitioners can develop an understanding of health and illness behaviours (Morse and Fields, 1995). Health ethnographies

may be considered more focused than classical ethnographies because there is a sense of the research problem before entering fieldwork (Morse and Field, 1995). Reflexivity is an important part of ethnography which reminds researchers that they are part of the social world they study and that their values and beliefs orient them to the research problem a particular way (Hammersley & Atkinson, 2007).

As well, qualitative research provides not only a means of merely describing a phenomenon, but also involves the scrutiny of social phenomena (Esterberg, 2002). Qualitative researchers must try to understand social life in novel ways, and at the same time be attune to the researcher's own subjectivities. Thus, qualitative researchers may look to existing theory to help look at phenomena in a new way, and to also understand their own subjectivities. This is important because death, dying, and palliation are sensitive issues which researchers may hold strong feelings. Using theory to acknowledge their own subjectivities will help guide the researcher so that he or she may be more open to participant experiences and preferences.

### Theory in Qualitative Research

All theory comes from a philosophical paradigm or worldview (Mitchell & Cody, 1992). Theory has many definitions but Sandelowski (1993) broadly defines it to include the disciplinary paradigms in the arts, sciences, and humanities that direct or inform both the inquiry process, including the presentation of findings, and the abstract schemas (ie concepts, conceptual models, and frameworks) describing, organizing, and interpreting the target phenomena that constitute the subjects/objects of individual research projects in a substantive area (p. 214)

Research paradigms are a set of beliefs and practices that guide inquiry and provide a lens for interpreting substantive issues within a discipline (Weaver & Olson, 2006). The four major classifications of paradigms include positivist, postpositivist, interpretive/constructionist, and critical-social theory (Weaver & Olson, 2006). Each paradigm is differentiated by their epistemological and ontological stances. In qualitative research, epistemology refers to the nature of knowledge and the relationship between the researcher and the participant (Sandelowski, 1993). Ontology refers to the nature of reality; qualitative researchers believe there are multiple realities and that they are subjective (Creswell, 1998).

Morse (1992) speaks about the four ways theory is used in qualitative research: 1) as a theoretical basis for the research; 2) as a mold for data (this creates serious threats to validity); 3) to investigate a concept; and 4) to analyze data and develop one's own concepts and theory. Similarly, according to Sandelowski (1993), theory functions to justify a methodological approach for a particular target phenomenon as opposed to serving as the theoretical basis for the phenomenon itself. Theory also functions to "provide a comparative context or an organizational framework for both the interpretation and re-presentation of data" (Sandelowski, 1993, p. 216).

Thus, depending on the way theory is being used, theory may enter into the research process at different points. Firstly, theory may be the initial drive and underlying rationale for the inquiry process itself. Secondly, theory may be the final product of the study. Finally, theory may be brought into a study for organizational or interpretive purposes during analysis (Sandelowski, 1993). For Sandelowski (1993), there is theoretical fit when the data does not have to be forced to conform to the theory. The data should speak to the theory, rather than the theory dictating the data; this ensures the inductive nature of qualitative analysis.

### Postcolonial Theory: A Lens for Inquiry

As seen, theory has many functions in qualitative research. To examine the preferences for place of death among Chinese Canadian immigrants, a postcolonial theoretical lens may be useful in directing the inquiry and providing rationale for the method. Firstly, the tenets of postcolonial theory will be discussed, and then subsequently, an examination of its relevance to examining preference for place of death among Chinese Canadian immigrants will be presented.

#### *Postcolonial Theory*

There is no singular definition of postcolonial theory. The theory has been described as “both remarkably focused and distinctly unruly” (Prasad, 2005, p. 266). Postcolonialism is a critical theory that examines the everyday experiences of marginalization and oppression based in political, structural, and historical developments of power originating from colonial rule (Prasad, 2005; Reimer Kirkham, & Anderson, 2002). Specifically, postcolonial theory critically examines the West’s relationship to the *Other*, either in former colonies, such as India, or within its own geographical boundaries, such as Canada or the UK (Ashcroft, Griffiths, & Tiffin, 1998; Prasad, 2005). The underlying perception of postcolonial theory is that colonialism is “one of the most significant and omniscient social processes to have taken place over the last five centuries” (Prasad, 2005, p. 267). Although postcolonial theorists do not follow a consistent, rigid methodology, the unifying goal is to resist colonial domination, and engage in changing power relationships between the West and *Other* and how the power imbalances that results may be based in Western hegemonic discourses (Prasad, 2005). Postcolonial theorists work to expose how Western domination creates power differentials and constrains choice amongst those that are marginalized.

#### *Postcolonial Theory: Inquiry, Methods, and Analysis*

Historically, hospices have been associated with Christian values of providing care to the dying sick and poor. In Europe, the first hospices were operating as early as the 4<sup>th</sup> century (CHPCA, 2005). More recently, the first modern palliative care hospice was founded in South London by Dame Cicely Saunders in 1967 (Clark, Have, & Janssens, 2000). In Canada, palliative care programs developed out of an understanding of the modern hospice, and were predicated on similar Christian values. As well, within the last few decades, there has been a resurgence of support for death in the home (Smith & Nickel, 1999). Increasingly, receiving palliative end-of-life care in the home has been advocated, and has prevailed as how quality palliative end-of-life care should be delivered. A process of inquiry may develop when considering two important issues here. Firstly, the historical development of hospice and palliative care is based in a discourse that presents Christian beliefs (Western religion) as normative, thus, holding greater moral value in our society. Secondly, there now exists a discourse that advocates dying at home as representing the “good death”. Under a postcolonial lens, the notion that most Canadians prefer to die at home is problematized because such a generalized statement does not take into account the variable beliefs of different ethnic groups and individuals. It may be argued that this statement is based on Western assumptions around death, and does not reflect the needs of Chinese Canadians.

In adopting a postcolonial stance, the research question that develops from this worldview should reflect the central tenets of the theory. Through a postcolonial lens, the theory proposes a framework to understanding the social world and provides the researcher with critical points to address in research. Because the theory is looking at how political, structural, and historical remnants of colonialism continue to influence the everyday lives of marginalized groups, the question on preference of place of death may examine one or more of these facets.

Thus, for the proposed thesis work, the questions will be 1) how are preferences for place of death depicted among Chinese Canadian immigrants diagnosed with a terminal illness and their family caregivers? and 2) how do Chinese Canadian immigrants and their family caregivers negotiate and navigate care with health care providers to organize palliative end-of-life care in the home? These questions may begin to elucidate the structural barriers and facilitators to care.

As discussed, an ethnographic study will be conducted. Ethnographies aim to describe and interpret meanings of cultural groups or social systems through observation of behaviour, customs, and ways of life (Creswell, 1998). In addition, a critical theoretical lens, such as postcolonial theory, will help the research adopt a reflective approach to evaluating the value-laden meanings in everyday life, specifically how processes of marginalization can affect how terminally ill Chinese patients decide to die at home. Postcolonial theory works well with conducting ethnography because both seek to expose and describe the complexities of meanings in everyday life. In its critique of current health care structures, postcolonialism problematizes the assumptions around the meaning of health to expose and explore the historical effects of colonialism on health in the present day (Mohammed, 2006). What postcolonial theory allows the researcher to do is understand how possibly the choice for place of death of Chinese Canadian immigrants may be constrained because of the dominating view that death at home is preferred by most terminally ill patients. Chinese families may feel obligated to provide end-of-life care at home because of their trust in the Western medical system, even if it does not match their own personal beliefs.

Analysis in ethnography aims to 1) describe the social phenomenon, 2) analyze data for themes and patterns, 3) interpret and make sense of findings (Creswell, 1998). Ethnography also examines the meanings individuals generate in the social world, and how structural systems,

such as economic, political, and cultural influences affect people's everyday actions (Cook, 2005). By adopting a postcolonial lens, the analysis would specifically examine how the meanings in the everyday world are influenced by political and historical ramifications of colonization. For instance, the discourse around palliative end-of-life home care may be examined to elucidate how home has been constructed as the ideal place to die and how it has affected the meaning of dying at home. Analysis of these issues may help describe how dominant discourses may affect how Chinese Canadian immigrants exert choice when confronted with the matter of place and palliative end-of-life care.

### Fit between Examining Preference for Place of Death of Chinese Immigrants through a Postcolonial Lens

#### *Reconceptualizing Culture: Hybridity*

Hybridity is a commonly used concept in postcolonial theory (Ashcroft, Griffiths, & Tiffin, 1998). Hybridity is borrowed from the horticultural description of the cross-breeding of two plant species. Specifically, hybridity in postcolonial theory refers to the intermingling and blending of cultures (Ashcroft, Griffiths, & Tiffin, 1998; Prasad, 2005). There is also no single definition of hybridity, but the term has been taken up by many scholars because of its “progressive way of adopting an anti-purist stand on race and culture without necessarily relinquishing the importance of difference” (Prasad, 2005, p. 275). Hybridity, according to the writings of Homi Bhabha, is presented as “how newness enters the world” (1994, p. 227). For Bhabha (1994), culture and its representation of difference is in the use of “language, manners, words, rituals, customs, [and] time” (p. 125). Bhabha (1994) writes that migrants negotiate their identity “in-between” the old and the new spaces. The old space refers to where the migrant

came from and the new space is where he/she now occupies. This in-between space is what he calls the Third Space of Enunciation (Bhabha, 1994). This newness represents the hybrid of culture that emerges when the migrant's cultural beliefs intermingle with the beliefs of the society they are now trying to integrate with.

The Third Space “constitutes the discursive conditions of enunciation that ensure that the meaning and symbols of culture have no primordial unity or fixity” (Bhabha, 1994, p. 37). Therefore, cultural identity is fluid and dynamic, rather than static and fixed. He also emphasizes the fact that identity is never constructed in a vacuum but is subject to political and cultural influences (Papastergiadis, 1997). This understanding of hybridity is significant in conceptualizing culture as a dynamic and negotiated process for Chinese Canadian immigrants. The Chinese Canadian immigrant can be seen as occupying the “in-between” space that combines their old values, beliefs, and practices with the dominant Western beliefs of the new space. Hybridity is a useful concept in understanding how Chinese Canadian immigrants engage with the health care system to exert choice in place of death. The Chinese Canadian immigrants' negotiation of their cultural identity in this Third Space is mitigated by their “old” cultural beliefs with the political, structural, and historical context they now occupy.

Using postcolonial theory to examine preference for place of death of Chinese Canadian immigrants is appropriate because the theory allows for a critical examination of how choice is constructed and enacted amongst a marginalized group; and specifically, how it is negotiated and mitigated through cultural identity and the political, structural, and historical effects of colonization. Since postcolonial theory is a critical theory, it warrants using qualitative methods, specifically ethnography, because both seek to examine the influences of meaning on everyday life. Therefore, examining preference for place of death of Chinese Canadian immigrants

through a postcolonial theoretical lens using an ethnographic approach is congruent with each other because of the potential for revealing the continued influences of colonialism on everyday lives. By studying how Chinese Canadians' beliefs around palliation, death, and care for the dying intermingle (hybrid) with the dominant message for dying in the home in the current medical system, only then, can it be better understood how the health care system and providers can accommodate and facilitate genuine choice for place of death within this population.

### Conclusion

Conducting qualitative research requires careful planning and theoretical consideration. Theory is a tool that helps qualitative researchers understand what is happening in the social world. In trying to understand what the preferences for place of death amongst Chinese Canadian immigrants are, it becomes apparent that there are multiple factors at play. A qualitative research approach allows the researcher to take into account the varying factors and the interplay between them that influences preference for place of death. Additionally, postcolonial theory provides a framework for the researcher to make sense of the phenomena and to begin to build a process of inquiry. An ethnographic approach is an appropriate method to address the inquiry topic. Working with theory also makes the researcher identify and understand their beliefs about the social world and their own subjectivities; thus, theory positions the researcher and grounds their thinking. The process of constructing a qualitative research study may be difficult since fit between the topic, the theory, and the method is crucial to the overall goal(s) of the research. And in this case, it is to ensure that Chinese Canadian immigrants' palliative end-of-life care needs are understood and met in terms of their preference for place of death.

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