Social Science & Medicine 61 (2005) 1560–1566

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

Discrepancy in the preferences of place of death between terminally ill cancer patients and their primary family caregivers in Taiwan

Siew Tzuh Tang[a,*], Tsang-Wu Liu[b], Mei-Shu Lai[c], Ruth McCorkle[d]

[a] *National Yang-Ming University, School of Nursing, # 155, Sec. 2, Li-Nong Street, Taipei, Taiwan, R.O.C*
[b] *Taiwan Cooperative Oncology Group, 3F, 109, Min-Chuan East Road, Sec.6, Taipei 114, Taiwan, R.O.C.*
[c] *Division of Preventive Medicine, The Institute of Public Health, College of Public Health, National Taiwan University, Rm. 211, No. 19, Hsuchow Rd, Taipei, Taiwan, R.O.C*
[d] *Center for Excellence in Chronic Illness Care, School of Nursing, Yale University, P.O. Box 9740, New Haven, CT, 06536-0740*

Abstract

There is a worldwide common preference for dying at home. However, death at home does not come without significant challenges and potential consequences for families. Given the interactive nature of decisions regarding the place of death, the family's perspective is important and needs to be investigated. The purposes of this study were to compare (1) Taiwanese terminally ill cancer patients' and their family caregivers' preferences for the patient's place of death; and (2) important factors that are considered in choosing the preferred place of death from both points of view.

A total of 617 dyads of terminally ill cancer patients and their family caregivers were surveyed. The majority of both terminally ill cancer patients and their family caregivers preferred to die at home (61.0% and 56.9%, respectively). A higher proportion of the family caregivers indicated a preference for hospital death for the patients. There was a moderate association between the two respondents in the preferences of place of death.

Results underscore discrepancies between patients and their families in the importance given to cultural concerns, quality of health care, worries of being a burden to others, lack of availability of families, relationships with health care providers, and being surrounded by the home environment.

Effective interventions need to be developed which can lighten the caregiving burden and help families retain dying patients at home, avoid unnecessary re-hospitalizations and unfavorable hospital deaths, and improve accordance with the patient's wishes.

Keywords: End-of-life care; Terminally ill cancer patients; Place of death; Taiwan

Introduction

The basic tenets of end-of-life care have been suggested as philosophically rooted in recognition of the inherent dignity of individuals (Latimer, 1991; Pullman, 1996) and one of the main goals of end-of-life care is to help patients die with dignity (Chochinov,

---

*Corresponding author. Tel.: +886 2 2826 7033; fax: +886 2 2820 3080.
E-mail addresses: sttang@ym.edu.tw (S.T. Tang), walter@nhri.org.tw (T.-W. Liu), mslai@episer.cph.ntu.edu.tw (M.-S. Lai), ruth.mccorkle@yale.edu (R. McCorkle).

0277-9536/$ - see front matter © 2005 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2005.02.006

2002; Pullman, 1996). To maintain dignity, terminally ill cancer patients must have a sense of control or autonomy over their dying circumstances and must be able to make their own end-of-life care decisions (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Duda, 1982). One specific task that patients must make is to decide where they prefer to spend their final days of life and to die (Patrick, Engelberg, & Curtis, 2001). The setting affects the philosophy of care as well as the type and intensity of services that can be delivered to the dying; therefore, setting has a tangible, direct, and immediate impact on the quality of life that a patient experiences at the end of life or even the quality of death itself (Mezey, Dubler, Mitty, & Brody, 2002). Patrick et al. (2001) specifically defined one of the domains of quality of dying and death as dying at the place of one's choice.

Reviews from empirical studies (Higginson & Sen-Gupta, 2000; Tang & McCorkle, 2001) show that the great majority (approximately two-thirds) of cancer patients, when asked about their preferred place of death, wish to spend their final days of life and die at home. Home is a place where people may feel safety and a sense of belonging (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). When dying at home, terminally ill cancer patients also may have a greater chance to control their environment, more autonomy and privacy, and a sense of normality (Tang, 2003). Particularly, for Chinese people, dying at home has a special cultural meaning (Tang, 2000). When death occurs at home, the spirit of the dead can reunite with the forebears, thus, "the fallen leaves can return to their roots". When one dies at home, the spirit of the dead has a place to rest and the dead will not be a '*koo'un' ia' kui* '(spirit wanderer), a solitary soul with no one to depend on. Furthermore, a death at home is believed to be crucial to the well-being of the living descendants. Chinese believe that the dead family member will intercede with a supernatural power on behalf of the descendants for special blessings. In addition, the Chinese recognize that death is the utmost adversity in human life. The deceased is the victim of the family's disaster. When he dies, he takes the misfortune of earthly life and leaves good fortune to the family. However, if an individual has died outside the home, the person lacks the domain through which to shelter or bless his descendants.

Despite the worldwide unanimous strong preference for dying at home, the reality is that, when the time comes, few cancer patients achieve their preferences in regard to the place of death (Grande, Addington-Hall, & Todd, 1998; Hunt, Fazekas, Luke, & Roder, 2001; Gatrell et al., 2003), as research has shown for many decades. Mor and Hiris (1983) recognized the determinants of place of death as a function of a complex interplay of personal and cultural values, support network characteristics, physical and medical factors, and various health care systems forces. From over 50 studies investigating the determinants of place of death for terminally ill cancer patients, few definite conclusions can be made (Higginson & Sen-Gupta, 2000; Tang & McCorkle, 2001). The availability of health care resources (i.e., acute care hospital beds, hospice care, and physician supplies) has been documented as the most powerful determinant of place of death (Gallo, Baker, & Bradley, 2001; Mor & Hiris, 1983; Pritchard et al., 1998; Virning, McBean, King, & Dholakia, 2002) followed by the preference for dying at home (Cantwell et al., 2000; Hinton, 1994a; Karlsen & Addington-Hall, 1998; McWhinney, Bass, & Orr, 1995). Other frequently observed factors are the availability, ability, and attitudes of family caregivers (Cantwell et al., 2000; Clifford, Jolley, & Giles, 1991; Fukui, Fukui, & Kawagoe, 2004; Mor & Hiris, 1983; Visser et al., 2004). Specifically, Cantwell et al. (2000) reported that the main predictor of home death for terminally ill cancer patients under palliative home care was the agreement between the patient and the family caregiver. If there is a desire for a home death by both, the likelihood of dying at home is 8.38 times higher than when there is lack of agreement.

One of society's great assets is the many family members who provide care to ill or dying relatives. This nurturing and caring role of the family is even more prominent in Taiwan, based on the filial duty which is strongly emphasized in Asian cultures. Chinese (including Taiwanese) follow the doctrine that children should take care of parents when they are aged, sick, or even dying in return of parents' efforts in bringing them up. However, death at home does not come without significant challenges and potential consequences for families. While many caregivers value their caregiving role, the achievement of the patient's preference of dying at home involves their own emotional and physical sacrifice as well as profound economic difficulties for an undetermined length of time (Christakis & Iwashyna, 2003; Donelan et al., 2002; Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Schulz et al., 2001). Given the interactive nature of decisions regarding the place of death, the family's perspective is an important force that needs to be further investigated. Patients and family members may or may not be in rhythm as they deal with the anticipated death or in their preferences of the place of death. The purposes of this study were to: (1) compare Taiwanese terminally ill cancer patients' and their primary family caregivers' preferences for the patient's place of death; and (2) explore and compare the factors that are considered as important in choosing the preferred place of death from both points of view. Currently, Chinese (including Taiwanese) represent nearly a quarter of the world's population, and encountering them becomes common in clinicians' everyday practice. Findings from this study may have