Original Article

Determinants of Patient-Family Caregiver Congruence on Preferred Place of Death in Taiwan

Siew Tzuh Tang, DNSc, Cheryl Chia-Hui Chen, DNSc, Woung-Ru Tang, PhD, and Tsang-Wu Liu, MD

School of Nursing (S.T.T., W.-R.T.), College of Medicine, Chang Gung University, Tao-Yuan; Nursing Department (S.T.T.), Chung Gung Memorial Hospital, Kaohsiung; School of Nursing (C.C.-H.C.), College of Medicine, National Taiwan University, Taipei; National Institute of Cancer Research (T.-W.L.); and Department of Research Planning and Development (T.-W.L.), National Health Research Institutes, Taipei, Taiwan, Republic of China

Abstract

Context. Patient-family caregiver congruence on preferred place of death not only increases the likelihood of dying at home but also contributes significantly to terminally ill cancer patients' quality of life.

Objectives. To examine the determinants of patient-family caregiver congruence on the preferred place of death in Taiwan.

Methods. Patient-family caregiver dyads ($n = 1{,}108$) were surveyed on preferences and needs for end-of-life (EOL) care. Determinants of congruence on preferences were identified by multivariate logistic regression.

Results. Patient-caregiver dyads achieved 78.1% agreement on the preferred place of death. The kappa coefficient of congruence was 0.55 (95% confidence interval [CI] = 0.50, 0.60). The extent of patient-family caregiver congruence on preferred place of death increased with the patient's higher functional dependence (adjusted odds ratio [AOR] and 95% CI = 1.04 [1.02, 1.05]), higher patient-rated importance for dying at preferred place of death (AOR [95% CI] = 1.60 [1.43, 1.79]), and having a spousal caregiver (AOR [95% CI] = 1.62 [1.14, 2.31]). Other determinants of patient-family caregiver congruence included patient age (AOR [95% CI] = 1.01 [1.00, 1.03]), patient-family concordance on preferred EOL care options (AOR = 1.68−1.73), patient knowledge of prognosis (AOR [95% CI] = 0.68 [0.48, 0.97]), and impact of caregiving on the family caregiver's life (AOR [95% CI] = 0.98 [0.96, 0.99]).

Conclusion. Increasing patient-family congruence on preferred place of death not only requires knowledge of the patient's prognosis and advance planning by

---

This work was funded by the Bureau of Health Promotion, Department of Health, Taiwan, R.O.C., with partial support from the National Health Research Institute (NHRI-EX99-9906PI). The authors declare no conflicts of interest.

Address correspondence to: Siew Tzuh Tang, DNSc, School of Nursing, Chang Gung University, 259 Wen-Hwa 1st Road, Kwei-Shan, Tao-Yuan, Taiwan, 333, R.O.C. E-mail: sttang@mail.cgu.edu.tw

Accepted for publication: January 19, 2010.

0885-3924/$–see front matter
doi:10.1016/j.jpainsymman.2009.12.018

both parties but also depends on family caregivers endorsing patient preferences for EOL care options and ensuring that supporting patients dying at home does not create an intolerable burden for family caregivers. J Pain Symptom Manage 2010;40:235–245.

Key Words

Place of death, end-of-life care, terminally ill cancer patients, family caregivers, preferences for end-of-life care

Introduction

Terminally ill cancer patients worldwide have a strong preference for dying at home.[1–6] Correspondingly, promoting dying at home has increasingly been regarded as a "gold standard" of end-of-life (EOL) care.[7–9] However, few cancer patients realize their preferences about the place of death.[2,7,9–11] Such a discrepancy between preferred and actual place of death for terminally ill cancer patients highlights the dilemma inherent in making and achieving patient preferences regarding place of death.

The decision about preferred place of death is mediated by a range of complex interpersonal, social, and pragmatic considerations.[12–14] One of the most consistently reported and influential determinants of home death is social support.[10] Realizing patients' preference for dying at home has been shown to be influenced by family caregivers' clear recognition and endorsement of patients' preferences.[10,15–17]

Patient-family caregiver congruence on the preferred place of death not only increases the likelihood of dying at a place the patient prefers (either home or hospice)[15,17] but also contributes significantly to terminally ill cancer patients' quality of life.[18] Nonetheless, empirical evidence indicates that patients do not always agree with their family caregivers regarding preferences for place of death.[5,6,19] Moreover, no currently available studies have investigated factors that influence patient-family caregiver congruence on the preferred place of death. Therefore, the present study was undertaken to examine the extent of patient-family caregiver congruence on the preferred place of death and factors influencing congruence among a cohort of terminally ill cancer patients and their family caregivers in Taiwan.

Methods

Study Design and Sample

A cross-sectional design was used to survey terminally ill cancer patients and their family caregivers from February 2003 through November 2004 about preferences and needs for EOL care. The patients were not under hospice care and were being treated at 24 hospitals throughout Taiwan, which provided care for most of the cancer patients (54.9%) who died during 2000–2006 in Taiwan.[20] After the human subject research review committees of the 24 hospitals approved the study, subjects were recruited by convenience sampling. Patients were eligible for the study if they 1) had a malignancy judged by their primary physician to be at a terminal stage, continuing to progress, and unresponsive to curative cancer treatments; 2) were cognitively competent; 3) could communicate coherently with data collectors; and 4) had a designated family caregiver who agreed to participate in the survey.

Primary physicians at each study site were given a detailed explanation of the study and were asked to identify patients without judging their emotional readiness to talk about their preferences for EOL care. After verifying the eligibility of patients, data collectors invited them to participate in this study without seeking their family's permission. This strategy avoided excluding patients because of conflict of opinion between them and the family caregiver about the patient's participation.

Each patient-participant identified one primary family caregiver as the person most involved in the patient's care without receiving financial reimbursement for the care provided. Identified family caregivers were recruited if they were 18 years or older, agreed to participate, and could communicate with data collectors. Patient-caregiver dyads were