Original Article

A Decade of Changes in Family Caregivers' Preferences for Life-Sustaining Treatments for Terminally Ill Cancer Patients at End of Life in the Context of a Family-Oriented Society

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Abstract

Context. Temporal changes in different family caregiver cohorts' preferences for life-sustaining treatments (LSTs) at end of life (EOL) have not been examined nor have the concept of whether caregivers' LST preferences represent a homogeneous or heterogeneous construct. Furthermore, LST preferences are frequently assessed from multiple treatments, making clinical applications difficult/infeasible.

Objectives. To identify parsimonious patterns and changes in the pattern of LST preferences for two independent cohorts of family caregivers for terminally ill Taiwanese cancer patients.

Methods. Preferences for cardiopulmonary resuscitation, intensive care unit care, cardiac massage, intubation with mechanical ventilation, intravenous nutritional support, tube feeding, and dialysis were assessed among 1617 and 2056 family caregivers in 2003–2004 and 2011–2012, respectively. Patterns and changes in LST preferences were examined by multigroup latent class analysis.

Results. Five distinct classes were identified: uniformly preferring, uniformly rejecting, uniformly uncertain, and favoring nutritional support but rejecting or uncertain about other treatments. Class probability significantly decreased from 29.3% to 23.7% for the uniformly rejecting class, remained largely unchanged for the uniformly preferring (16.9%–18.6%), and favoring nutritional support but rejecting (37.1%–37.5%) or uncertain about other treatments (8.0%–10.4%) classes, but significantly increased from 7.0% to 11.5% for the uniformly uncertain class over time.

Conclusion. Family caregivers' LST preferences for terminally ill cancer patients are a heterogeneous construct and shifted from uniformly rejecting all LSTs toward greater uncertainty. Surrogate EOL-care decision making may be facilitated by earlier and thorough assessments of caregivers' LST preferences and tailoring interventions to the unique needs of caregivers in each class identified in this study. J Pain Symptom Manage 2016;51:907–915 © *2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Preferences, life-sustaining treatments, end-of-life care, family caregivers, oncology, cancer

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Introduction

Personalized end-of-life (EOL) care aims to respect patient autonomy by tailoring treatment decisions for dying patients to their own preferences.[1,2] However, a substantial majority of patients at EOL cannot make treatment decisions for themselves because of physical deterioration or mental incapacity,[3–8] and a minority of seriously/terminally ill patients have advance directives[6,9] to guide their medical care at EOL, especially patients in most Asian countries where advance directives are still uncommon.[10] In Taiwan, physicians often do not disclose prognosis to terminally ill cancer patients as requested by their families[11] who play a significant role in EOL-care decision making. Indeed, families have the right to refuse life-sustaining treatments (LSTs) for a dying relative under Taiwan's Natural Death Act.[12] Without an advance directive, current clinical/legal practice strives to promote incapacitated patients' values and EOL-care goals by relying on family members to make treatment decisions,[9] reflecting that individuals facing death prefer having family members make treatment decisions for them.[13,14]

However, surrogate decision making for seriously/terminally ill patients has been shown to be a challenging and emotionally tumultuous task.[3] Accurately understanding patients' preferences for EOL care can buffer the psychological burden of surrogate decision making[3,15] but surrogates frequently do not accurately know their loved one's treatment preferences.[16] Without accurately understanding patients' EOL-care preferences, family members and other surrogates often project their own preferences to shape the EOL care actually received by terminally ill patients.[17–20] Understanding family surrogates' preferences for LSTs and addressing any unrealistic expectations for their efficacy in restoring their loved one's life and function[21] may counteract the trends toward increasingly aggressive and costly EOL cancer care over recent decades in the U.S.,[22] Canada,[23] and Taiwan.[24] Understanding family members' LST preferences is especially important for terminally ill cancer patients in Taiwan, a Confucian society where the cultural value of filial piety and the relative power of family are strongly exercised in EOL-care decision making.[25] Taiwanese families have the authority[12] to make medical decisions on behalf of their members even for physically capable or consciously competent patients.[26] This policy intentionally avoids emotionally harming dying patients by forcing them to confront their poor prognosis and forthcoming death.

Worldwide, family caregivers' LST preferences for seriously/terminally ill patients have been studied in the U.S.,[27] Canada,[5] the U.K.,[28] Greece,[29] Israel,[7,30] Korea,[31–34] Singapore,[35] and Taiwan.[36,37] However, no studies were found on changes in LST preferences of family cohorts recruited at different times, despite an emphasis on avoiding LSTs that are nonbeneficial and discordant with patient preferences/wishes[1] and the substantial global hospice movement over the past decade,[38] including in Taiwan. Since 2004, Taiwan's government has launched multiple nationwide projects to facilitate dissemination of hospice philosophy and palliative care services. Thus, the number of hospice programs increased substantially from 2004 to 2012: 49 to 77 for hospice home care, 27 to 50 for inpatient-hospice units, and 8 to 69 for hospital-based palliative care teams.[39]

Furthermore, previous studies on family members' LST preferences frequently assessed multiple treatments (1–30[16] and ≥three treatments[30,31,33,35–37]), focusing on cardiopulmonary resuscitation (CPR), mechanical ventilation, artificial nutrition, and intensive care unit (ICU) care. These multiple options hinder clinical application of research findings, especially in busy clinical practices. Furthermore, these findings do not resolve whether family caregivers' multifaceted LST preferences represent a homogeneous phenomenon dichotomized into two groups (preferring/not preferring all treatments examined) or more than two preference groups as indicated by one study,[5] complicating interpretation of research findings.

One way to minimize the burden on families and clinicians is to parsimoniously identify LST-preference patterns/states ("latent states") rather than focusing on individual treatments. Parsimonious classification of family LST preferences can facilitate earlier, more timely, and thorough assessments of these preferences and increase the feasibility of implementing clinical interventions tailored to the needs of caregivers in distinct classes. Therefore, the purpose of this study was to identify parsimonious patterns and changes in patterns of LST preferences for two independent cohorts of family caregivers for terminally ill Taiwanese cancer patients recruited a decade apart. We hypothesized that family caregivers' LST preferences at EOL are a heterogeneous construct, and these preferences change over time in response to social and political changes.

Methods

Changes over time in LST-preference patterns of terminally ill cancer patients' family caregivers were analyzed in data from two nationwide studies (one not published) conducted a decade apart in Taiwan.[36] Both studies used the same methods for subject recruitment, instruments, and data collection, with the second study following up the first.

Study Design and Sample

Family caregivers of adult cancer patients were recruited by convenience from 24 and 23 of 37 major