Original Article

Preferences for Life-Sustaining Treatments and Associations With Accurate Prognostic Awareness and Depressive Symptoms in Terminally Ill Cancer Patients' Last Year of Life

Siew Tzuh Tang, DNSc, Fur-Hsing Wen, PhD, Chia-Hsun Hsieh, MD, Wen-Chi Chou, MD, Wen-Cheng Chang, MD, Jen-Shi Chen, MD, and Ming-Chu Chiang, MS

School of Nursing (S.T.T.), Chang Gung University, Taoyuan; Department of International Business (F.-H.W.), Soochow University, Taipei; Division of Hematology-Oncology (C.-H.H., W.-C.Cho., W.-C.Cha., J.-S.C.), Chang Gung Memorial Hospital, Taoyuan; Chang Gung University College of Medicine (W.-C.Cha., J.-S.C.), Taoyuan; and Department of Nursing (M.-C.C.), Chang Gung Memorial Hospital, Kaohsiung, Taiwan

Abstract

Context. The stability of life-sustaining treatment (LST) preferences at end of life (EOL) has been established. However, few studies have assessed preferences more than two times. Furthermore, associations of LST preferences with modifiable variables of accurate prognostic awareness, physician-patient EOL care discussions, and depressive symptoms have been investigated in cross-sectional studies only.

Objectives. To explore longitudinal changes in LST preferences and their associations with accurate prognostic awareness, physician-patient EOL care discussions, and depressive symptoms in terminally ill cancer patients' last year.

Methods. LST preferences (cardiopulmonary resuscitation, intensive care unit [ICU] care, intubation, and mechanical ventilation) were measured approximately every two weeks. Changes in LST preferences and their associations with independent variables were examined by hierarchical generalized linear modeling with logistic regression.

Results. Participants ($n = 249$) predominantly rejected cardiopulmonary resuscitation, ICU care, intubation, and mechanical ventilation at EOL without significant changes as death approached. Patients with inaccurate prognostic awareness were significantly more likely than those with accurate understanding to prefer ICU care, intubation, and mechanical ventilation than to reject these LSTs. Patients with more severe depressive symptoms were less likely to prefer ICU care and to be undecided about wanting ICU care and mechanical ventilation than to reject such LSTs. LST preferences were not associated with physician-patient EOL care discussions, which were rare in our sample.

Conclusion. LST preferences are stable in cancer patients' last year. Facilitating accurate prognostic awareness and providing adequate psychological support may counteract the increasing trend for aggressive EOL care and minimize emotional distress during EOL care decisions. J Pain Symptom Manage 2016;51:41–51 © *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, stability, terminally ill cancer patients

Introduction

Patients with advanced cancer would benefit from personalized end-of-life (EOL) care[1] if their preferred and actual care were congruent,[2] but reaching this goal is hampered by the clinical practice of discussing prognosis and EOL care preferences late in the illness trajectory, if at all. Thus, the current paradigm of caring for these patients should be changed to earlier

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

Accepted for publication: September 3, 2015.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2015.08.006

assessments of their fluctuating preferences[3] for life-sustaining treatments (LSTs) and tailoring care to their preferences throughout the dying process.[1,2] Such a shift would not only benefit patients and families by avoiding potentially futile LSTs[4] but might also counteract the current trend of increasingly aggressive and costly EOL care[5,6] in the U.S.,[7] Canada,[8] and Taiwan,[9] threatening national economies and the long-term sustainability of health-care systems.[10,11]

EOL care preferences were shown to be stable for most seriously ill patients,[12] yet preferences changed over time for a substantial minority. Furthermore, patients' EOL care preferences were shown in cross-sectional studies to be influenced by modifiable variables of prognostic awareness,[13–17] physician-patient EOL care discussions,[4,18,19] and emotional distress.[16,20–23] Cancer patients who recognize their terminal status prefer symptom-directed EOL care over life-extending therapy[13–15] and not receiving LSTs at EOL,[13,15] whereas community-dwelling elderly without accurate prognostic awareness but with overly optimistic expectations about LST effectiveness to prolong life or maintain function at EOL preferred treatments such as cardiopulmonary resuscitation (CPR)[16] and mechanical ventilation.[17] Cancer patients who discuss EOL care preferences with their physicians tend to strive for quality rather than quantity of life,[18] value comfort-oriented over life-extending EOL care,[4,19] but oppose dying in an intensive care unit (ICU)[4,19] and receiving CPR, intubation, and mechanical ventilation at EOL.[19] Regarding the effects of emotional distress on EOL care preferences, research has focused on depressive symptoms, with mixed results. Depressive symptoms have been associated with preferring to forgo CPR,[16,20] no impact on preferences for CPR, mechanical ventilation or other LSTs,[21,22] or preferring more LSTs.[23]

However, evidence for the stability of LST preferences from a review of 24 studies[12] is limited by preferences principally being measured in hypothetical scenarios that may not accurately predict treatment decisions during actual illness,[24,25] by small samples ($n = 13$ studies; 54.2% had <200 subjects), by seldom involving cancer patients ($n = 3$, 12.5% of studies)[26–28] for whom EOL care is extremely pertinent,[1] by measuring preferences only two times ($n = 16$, 66.7% of studies), and by highly variable times between initial and final assessments (range = 2 weeks to 7 years). Furthermore, no reviewed study was from an Asian country, despite cancer patients' cultural background influencing their LST preferences.[29] Asians constitute 60% of the world's current population,[30] highlighting the importance of investigating this issue for patients living in Asia. One Korean study[31] recently explored changes in cancer patients' LST preferences twice, about 2 months apart, after their physician disclosed their terminal status to them. Therefore, further study is warranted on whether the conclusion that EOL preferences are stable for the majority of seriously ill patients[12] applies to terminally ill cancer patients, particularly those living in Asia.

Moreover, the roles of modifiable variables such as prognostic awareness, physician-patient EOL care discussions, and depressive symptoms in LST preferences were only evaluated cross-sectionally. Thus, the roles of these variables would be clarified by prospective, longitudinal investigations on their associations with LST preferences as death approaches. Besides being modifiable, these variables are important because they are amenable to effective clinical care,[32,33] unlike unchangeable factors influencing LST preferences such as gender, age, or educational attainment, and the inevitable deterioration of health condition at EOL. Therefore, the purposes of this prospective study were to examine longitudinal changes in LST preferences and their associations with accurate prognostic awareness, physician-patient EOL care discussions, and depressive symptoms in a large sample of terminally ill Taiwanese cancer patients' last year of life.

Methods

Design and Sample

This longitudinal study extends our earlier study (conducted in 2009–2012) on psychosocial-spiritual factors predicting quality of life in Taiwanese cancer patients over their dying process[34] by following patients through December 2013. Methodological details have been published.[34] In brief, terminally ill adult cancer patients were referred by their oncologists to data collectors who were experienced oncology nurses. Oncologists determined patients' terminal status when their disease continued to progress and was unresponsive to current curative treatments. Patients who agreed to participate were interviewed in person while hospitalized and approximately every 2 weeks thereafter (during outpatient visits or rehospitalization) until they declined to participate or died. Patients who did not return to hospital were interviewed by telephone. The research ethics committee of the study site approved the study. All participants provided written informed consent.

Outcome Variables

LST preferences were evaluated using an adapted interview protocol (Appendix)[4,35] familiar to our