

Original Article

Determinants of Hospital Death for Taiwanese Pediatric Cancer Decedents, 2001–2010

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Abstract

Context. Factors influencing pediatric cancer patients' place of death may have evolved with advances in medical and hospice care since earlier studies were done.

Objectives. To comprehensively analyze factors associated with hospital death in an unbiased population of pediatric cancer patients in Taiwan.

Methods. This was a retrospective cohort study using administrative data for 1603 Taiwanese pediatric cancer patients who died in 2001–2010. Place of death was hypothesized to be associated with 1) patient sociodemographics and disease characteristics, 2) primary physician's specialty, 3) characteristics and health care resources at both the hospital and regional levels, and 4) historical trends.

Results. Most Taiwanese pediatric cancer patients (87.4%) died in an acute care hospital. The probability of dying in hospital increased slightly over time, reaching significance only in 2009 (adjusted odds ratio [AOR], 95% CI: 2.84 [1.32–6.11]). Children were more likely to die in an acute care hospital if they resided in the most urbanized area, were diagnosed with leukemia or lymphoma (2.32 [1.39–3.87]), and received care from a pediatrician (1.58 [1.01–2.47]) in a nonprofit proprietary hospital (1.50 [1.01–2.24]) or large hospital, reaching significance for the third quartile (2.57 [1.28–5.18]) of acute care hospital beds.

Conclusion. Taiwanese pediatric cancer patients predominantly died in an acute care hospital with a slightly increasing trend of shifting place of death from home to hospital. Propensity for hospital death was determined by residential urbanization level, diagnosis, primary physician's specialty, and the primary hospital's characteristics and health care resources. Clinical interventions and health policies should ensure that resources are allocated to allow pediatric cancer patients to die in the place they and their parents prefer to achieve a good death and promote their parents' bereavement adjustment. *J Pain Symptom Manage* 2015;■:■–■. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Child, cancer death, place of death, pediatric end-of-life care, hospital death

Introduction

Where terminally ill children die is important for both cost-containment and humanitarian concerns about end-of-life (EOL) care. For children, dying in a preferred place reduces current and future separation anxieties, enhances quality of life, and facilitates

parent bereavement closure.^{1,2} However, children with cancer around the world, except in Germany,³ Australia,⁴ and New Zealand,⁵ continue to die predominantly in acute care settings^{2,6–9} rather than at home or in hospice, in contrast to their own or parents' preference.^{4,10–12} To better organize EOL care

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and ultimately to develop policies that facilitate dying in a preferred place, the logical first step is to identify factors predisposing pediatric cancer patients to die in an acute care hospital.

Where adult cancer patients die is influenced by complex and multifaceted factors,¹³ including personal attitudes, patient demographic and disease characteristics, availability of informal and social support, health care resources, and macrosocial factors, that is, historical trends.¹³ However, determinants of place of death for pediatric cancer patients have never been comprehensively clarified and examined, with most studies reporting that hospital death was more likely for patients with leukemia or lymphoma than solid tumors.^{2,8,9,14–16} Furthermore, except for epidemiologic studies conducted in England^{8,14} and Sweden,² previous studies on factors influencing terminally ill pediatric cancer patients' place of death were primarily based on data from a single institution.^{6,9,15,16} For the previous population-based studies,^{2,14} the data are almost 20 years old. Thus, factors influencing pediatric cancer patients' place of death may have evolved with advances in medical and hospice care. To fill these gaps in knowledge, this population-based study was undertaken to comprehensively investigate factors associated with death in an acute care hospital among a cohort of 1603 Taiwanese pediatric cancer patients who died in 2001–2010.

Methods

Data Source and Sample

A retrospective cohort design was used by linking individual patient-level data with encrypted personal identification numbers from digitized administration data of the National Register of Deaths Database (NRDD), Cancer Registration System (CRS) database, National Health Insurance (NHI) claims database, and the Database of Medical Care Institutions Status (DMCIS). These databases are monitored for completeness and accuracy by Taiwan's government.

The CRS included 97.34% of incident cancer cases, with 97.00% completeness and 91.11% accuracy.¹⁷ The unique characteristics of the NHI in Taiwan include universal insurance coverage and the government as the sole insurer. Patients have free access to any health care system they choose. Health care systems are reimbursed for services provided. By 2010, the NHI covered 99.6% of Taiwan's population.¹⁸ The DMCIS provides information on hospital characteristics (ownership) and health care resources (acute care hospital and hospice beds) for each hospital and region.

Cancer continues to be the number one cause of nonaccidental death in Taiwanese children,

accounting for 6.9%–9.3% of deaths in 2005–2010.¹⁹ The NRDD identified 1735 cancer deaths for individuals aged 18 years or younger from 2001 to 2010. However, 132 cancer decedents were deleted from our analyses primarily because of lack of data on demographics and their primary hospital's characteristics. Therefore, the final sample comprised 1603 pediatric cancer decedents.

Measures and Data Encoding

Outcome Variables. Place of death, the outcome variable, was categorized into home and hospital. Place of death is coded by the NRDD as hospital, home, or other. However, we chose not to use these codes because dying children may be discharged “against medical advice” and often with artificial respiratory support to allow family members to keep the child alive to die at home.²⁰ Therefore, if the discharge date for the last admission was also the date of death, the child was recognized as dying in the hospital,²¹ which occurred in one-quarter (23.32%) of our study subjects. Death in an acute care hospital included dying on a general ward, in an intensive care unit (ICU), or in an inpatient hospice unit, which were not differentiated in either the NRDD or NHI data sets.

Independent Variables. Place of death was hypothesized to be associated with four groups of independent variables:¹³ patient sociodemographics and disease characteristics, primary physician's specialty, primary hospital characteristics and health care resources, and regional health care resources.

Differences in the outcome variable were examined across gender and four age categories (≤ 6 , 7–12, 13–15, 16–18 years) obtained from the NRDD. Urbanization of the community where a child with cancer and his/her family resided was stratified from 1 (most urbanized) to 5 (least urbanized).²² These five levels resulted from combining levels 5–8 (remote and rural areas) in the original classification to avoid too few patients at these levels.²² This urbanization classification system²² was based on population density and the proportions of the population with at least a college education, more than 65 years of age, or agricultural workers.

Disease characteristics included comorbidities, cancer diagnosis, metastatic status, and survival time. Comorbidities were identified from *International Classification of Diseases, Ninth Revision* (ICD-9) codes for primary and secondary diagnoses, excluding cancer-related codes, in NHI claims for inpatients and outpatients in months one to 12 before death. These ICD-9 codes were used to calculate the Deyo-Charlson Comorbidity Index²³ and categorized as 0, 1, or ≥ 2 comorbidities. Diagnosis and date of diagnosis were identified from the CRS. Metastatic status

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