Original Article

Clusters of Multiple Complex Chronic Conditions: A Latent Class Analysis of Children at End of Life

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Abstract

Context. Children at end of life often experience multiple complex chronic conditions with more than 50% of children reportedly having two or more conditions. These complex chronic conditions are unlikely to occur in an entirely uniform manner in children at end of life. Previous work has not fully accounted for patterns of multiple conditions when evaluating care among these children.

Objectives. The objective of the study was to understand the clusters of complex chronic conditions present among children in the last year of life.

Methods. Participants were 1423 pediatric decedents from the 2007 to 2008 California Medicaid data. A latent class analysis was used to identify clusters of children with multiple complex chronic conditions (neurological, cardiovascular, respiratory, renal, gastrointestinal, hematologic, metabolic, congenital, cancer). Multinomial logistic regression analysis was used to examine the relationship between demographic characteristics and class membership.

Results. Four latent classes were yielded: medically fragile (31%); neurological (32%); cancer (25%); and cardiovascular (12%). Three classes were characterized by a 100% likelihood of having a complex chronic condition coupled with a low or moderate likelihood of having the other eight conditions. The four classes exhibited unique demographic profiles.

Conclusion. This analysis presented a novel way of understanding patterns of multiple complex chronic conditions among children that may inform tailored and targeted end-of-life care for different clusters.   J Pain Symptom Manage 2016;51:868—874. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Introduction

Children at end of life often experience multiple complex chronic conditions. From cancer to birth defects, complex chronic conditions are defined as conditions that are reasonably expected to last at least 12 months and to involve either several different organ systems or one organ system severely.[1] Multiple complex chronic conditions are common with more than 50% of children with chronic conditions reporting two or more conditions.[2] These complex chronic conditions are unlikely to occur in an entirely uniform manner in children at end of life.[3] For example, a child with cerebral palsy may have gastrointestinal conditions with feeding difficulties and recurrent aspiration pneumonia. As a result of these unpredictable patterns of multiple complex chronic conditions, children with complex chronic conditions generally have costly, high utilization of healthcare services, including the emergency room.[4–8]

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Previous work has not fully accounted for patterns of multiple conditions when evaluating care among these children. Instead, two strategies have been used. First, Feudtner et al.[1,9,10] have used death certificate diagnoses to assign a primary diagnosis to children with complex chronic conditions. Although this technique allows an understanding of the most clinically important condition that led to the child's death, many administrative data sources are not readily linked to death certificate data, limiting the availability of this information. In addition, this technique still assigns a single diagnosis to each child, even though some conditions may occur together. An alternative strategy has been to evaluate care within categories of complex chronic conditions using diagnostic data from inpatient and outpatient administrative records, a technique that means that a child with five chronic conditions may be counted five times in each analysis.[2,10,11] Therefore, current strategies have not effectively accounted for multiple complex chronic conditions among children.

Latent class analysis is a useful method for identifying patterns within a heterogeneous population.[12,13] Instead of creating every possible cluster, latent class analysis reduces the data into the most parsimonious set of clusters or classes. Latent class analysis has been used widely in healthcare research to identify patterns of community-based service use,[14] foster care provision,[15–18] and comorbidities.[19–21]

Identification of such groupings of co-occurring conditions among children with complex chronic conditions would be highly beneficial to future studies of the underlying mechanisms of these chronic conditions and in addressing the end-of-life care needs of these children. This information may guide the design of interventions specific to multiple complex chronic conditions, which are tailored to the health needs of children at end of life. Such tailored interventions may ultimately improve the quality of end-of-life care for children and their families. For researchers, the use of latent class analysis presents a unique methodological technique to account for patterns of comorbid conditions that might be used with administrative data sources.

Therefore, using latent class analysis, we sought to understand the patterns of conditions present among children in the last year of life, using clustering of conditions as a way to identify children with similar care needs and utilization patterns. Specifically, we aimed to clarify 1) the number of classes that could parsimoniously describe patterns of complex chronic conditions, 2) the configurations of complex chronic conditions represented in each class, with the expected prevalence of each class, and 3) the demographic correlates of class membership. Although we hypothesized that some children may have one primary condition that accounts for most of their healthcare needs, even if other conditions are also present, we did not formulate hypotheses regarding the particular number of classes or the configuration of each class.

Conceptual Model

Figure 1 depicts the conceptual relationships among the complex chronic conditions, the latent classes, and the covariate predictors for the latent class model estimated in these analyses. Our group of demographic characteristics included gender, race/ethnicity, and age, which may predispose children to certain complex chronic conditions. For example, infants may be more likely to suffer from congenital anomalies compared with older children, whereas sickle cell disease occurs among African-American children. We also included additional private insurance coverage because families with added health insurance coverage may have more resources to diagnose complex chronic conditions. Finally, we included Medicaid eligibility because disability
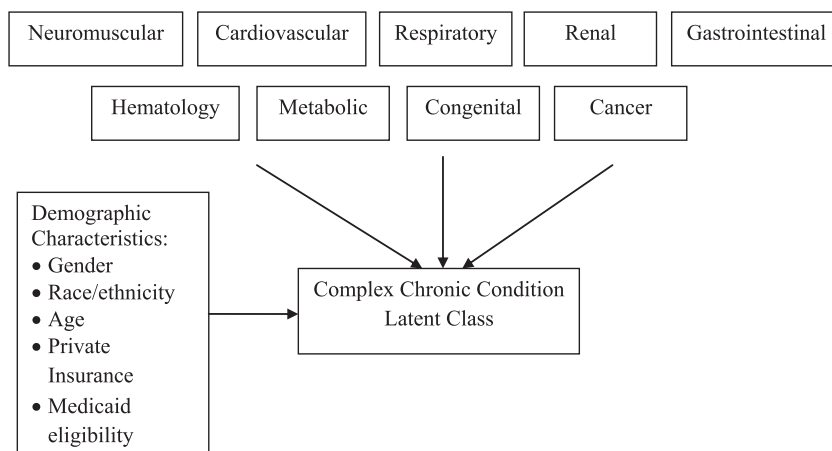

Fig. 1. Conceptual model of complex chronic condition latent class.