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Post-acute care for children with special health care needs

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ABSTRACT

Background: Almost all studies of post-acute care (PAC) focus on older persons, frequently those suffering from chronic health problems. Some research is available on PAC for the pediatric population in general. However, very few studies focus on PAC services for children with special health care needs (SHCN).

Objective: To investigate factors affecting the provision of PAC to children with SHCN.

Methods: Pooled cross-sectional data from Texas Department of State Health Services hospital discharge database from 2011-2014 were analyzed. Publicly available algorithms identified chronic conditions, complex chronic conditions, and the principal problem leading to hospitalization. Analysis involved estimating two logistic regressions, with clustered robust standard errors, concerning the likelihood of receiving PAC and where that PAC was delivered. Models included patient characteristics and conditions, as well as hospital characteristics and location.

Results: Only 5.8 percent of discharges for children with SHCN resulted in the provision of PAC. Two-thirds of PAC was provided in a health care facility (HCF). Severity of illness and the number of complex chronic conditions, though not the number of chronic problems, made PAC more likely. Patient demographics had no effect on PAC decisions. Hospital type and location also affected PAC decision-making.

Conclusions: PAC was provided to relatively few children with SHCN, which raises questions concerning the potential underutilization of PAC for children with SHCN. Also, the provision of most PAC in a HCF (66%) seems at odds with professional judgment and family preferences indicating that health care for children with SHCN is best provided in the home.

Background

Post-acute care for older persons has been the focus of considerable research. In part this emphasis stems from the prevalence of PAC for older adults. In 2008, estimates indicate that 38.7 percent of Medicare recipients received post-acute care.[1] In addition, PAC expenditures have proved to be the fastest growing major health care spending category.[2] Spending on Medicare PAC had risen to $635 billion by 2011.[1]

In contrast, Jay Berry and his colleagues' recent work focused on an area of post-acute care that they correctly indicate has historically received little attention – hospital discharges for those under 21 years of age.[3] Their research involved a sample of over two million 2012 discharges from hospitals in 44-states. Their effort provided an important and much needed foundation for additional analyses of pediatric hospital discharges and of the use of post-discharge services among children and youth. In that sample, just over six percent of discharges resulted in the provision of post-acute services. Of that 6.1 percent who received PAC, just 17.6 percent received those services in a health care facility (HCF), while the remainder (82.4%) received home health care (HHC) services.

The multivariate analyses in that study indicated how individual characteristics (race, age), the number of chronic diseases, diagnoses of complex chronic conditions, source of payment (Medicaid), the type of hospital (children's), as well as state and

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region of the nation significantly affected the use of different post-discharge services.[3]

This research complements that earlier effort. However, it approaches the analyses of PAC for children or youth differently. This research focused on post-discharge dispositions for an especially vulnerable pediatric population, children with special health care needs (SHCN). As the 20011/12 National Survey of Children with Special Health Care Needs estimated, 14.6 million children or youth under 18 years of age in the US faced health challenges requiring special health care services. This is almost one of every five (19.8%) persons under 18.[4]

This population presents special challenges to all elements of healthcare.[5–7] They need access to a relatively wide variety of health care services and absorb a disproportionate share of health care expenditures.[8–12] In 2009, for example, children in Texas's Early and Periodic Screening Diagnostic and Treatment (EPSDT) program, which is populated by children with chronic conditions, averaged Medicaid expenditures over 18 times ($33,628 vs. $1,834) that of the average Medicaid expenditure for a child or youth in Texas.[13]

As important as such information is, these prevalence and expenditure figures fail to include an important element in the lives of children with SHCN. Families bear much of the responsibility for care of children with SHCN and provide the equivalent of billions of dollars of family care to these children.[14] The burden of that care can at times be overwhelming, and the potential adverse effects of that responsibility on family members and family life can be devastating.[15] While family care, frequently called informal care, is an important aspect of post-discharge services, the research presented here will focus more narrowly on the distribution of post-discharge services provided by health care professionals (formal care).

Like many issues in health services research, elaborate theoretical frameworks have not driven investigations into the provision of formal PAC services.[16] Instead, previous research on PAC provides a basic conceptual model for guidance, identifying factors associated with PAC use in previous analyses of hospital discharge data. A graphical representation of the basic model used in this research appears in Fig. 1.

The elements of the model that focus on those variables associated with PAC are relatively standard in such analyses.[17–19] This effort, however, focuses on children with SHCN, which differs from other populations in which PAC has been investigated. Therefore, these analyses elaborate on the basic model found in earlier research by using more finely-grained information on the number of complex chronic conditions, condition severity, as well as categories of presenting conditions. The model, unlike others, also allows for the investigation for the effect of time on PAC decisions.

In addition, the dependent variables representing PAC decisions in this research differ from that in other analyses. Other efforts consider PAC best defined as a single dependent variable with separate categories for no services and for each setting where PAC is provided. This type of analysis results in separate estimates for receiving no services versus receiving services in a particular setting (e.g., likelihood of no services versus home care or the likelihood of no services versus PAC in an HCF). This strategy was used by earlier analyses of PAC for children and youth.[3]

However, the analyses here conceptualize PAC provision as a two-stage, rather than one-stage, decision process. These two decisions are: (1) whether any type of PAC will be provided, and (2) for those receiving PAC, where that PAC will be provided. This approach is like that used by Gage and her colleagues in their analyses of PAC for older persons and allows one to investigate directly any important differences between those children receiving PAC at home or those children receiving PAC in a health care facility.[20]

This formulation results in two questions concerning formal post-discharge services provided to this vulnerable population.

- What affects the likelihood that an acute care discharge involving a child or youth with SHCN will result in the provision of formal PAC?
- For those discharges where children or youth with SHCN receive formal post-discharge services, what differentiates between those discharges receiving HHC and those receiving services in a HCF?

Methods

Data

The Texas Department of State Health Services maintains public use data files of all hospital discharges. From those data, a pooled cross-sectional database of hospital discharges for those discharges involving patients under the age of 18 for three years (10/2011-3/2014) were extracted.[21] Of these 1,688,454 discharges for children or youth under the age of eighteen, 476,144 (28.2%) involved a child or youth with at least one chronic condition. After excluding those discharges for children without a chronic condition, those who died, or those who discharged against medical advice, a total of 472,825 discharges involving children or youth with a chronic condition remained. We identified these discharges as discharges involving children with SHCN. All aspects of this project were approved by the Institutional Review Board at Texas A&M University.

Measurement

Dependent variables

The dependent variables in this effort focused on the services identified in the discharge record. They focus on two very clear distinctions in post-discharge services for children with SHCN. As noted earlier, the dependent variable for the first multivariate model defined two categories: those discharges with no formal services and those discharges involving any type of formal services.

The second dependent variable focused only on those discharges that involved services. It differentiated between the sites where care was received after discharge, an important distinction for the patient, as well as informal and formal caregivers.[22] This dependent variable differentiated between those discharges involving children and youth discharged to home with HHC (i.e., home health or private duty nursing) and those who received care after discharge in a HCF of some type (i.e., rehabilitation facility, nursing facility, residential hospice, mental health facility, specialty hospital, or another acute care facility).[23]

Independent variables

Any discharge involving a child or youth with at least one diagnosis of a chronic condition was included in our study database as a discharge involving a child or youth with special health care needs.[24] The presence of a chronic condition was indicated if the principal diagnosis or any of the other diagnoses listed in the discharge record (up to 24) were included in the list of chronic conditions developed in the Healthcare Costs and Utilization Project.[25]

Complex chronic conditions were identified using Feudtner and his colleagues pediatric complex chronic condition system.[26] The standard demographic characteristics of age, sex, and race/ethnicity were provided in the Texas discharge data. The ages under

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