



Risk factors for family time burdens providing and arranging health care for children with special health care needs: Lessons from nonproportional odds models



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ARTICLE INFO

Article history:

Received 29 May 2014

Revised 17 February 2015

Accepted 3 April 2015

Available online 11 April 2015

Keywords:

Children

Chronic illness

Insurance

Family time burden

Nonproportional odds

Ordered logistic models

ABSTRACT

We identify need, enabling, and predisposing factors for high family time burdens associated with the health care of chronically-ill children, using data from the U.S. 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), a population-based survey of 40,242 children with special health care needs (CSHCN). We estimate generalized ordered logistic multivariable regressions of time spent (1) providing health care for the child at home, (2) arranging/coordinating health care, and (3) combined time. Factors associated with higher time burdens included child's functional limitations, severe or unstable health conditions, public health insurance, lack of a medical home, low family income, low adult education, and non-white race. Nonproportional odds models revealed associations between risk factors and time burden that were obscured by binary and standard ordered logistic models. Clinicians and policymakers can use this information to design interventions to alleviate this important family stressor.

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1. Introduction

Successful medical care depends not only on professional services but also on the investment of time by patients and their families, an investment that has largely been taken for granted. Recently researchers have begun to document the magnitude of the burden on patients and informal caregivers (Reinhard et al., 2014). Time demands are particularly heavy for the elderly, those with diabetes, and those with poor health and multiple chronic conditions. Self-management of chronic conditions, crucial to good health, can be particularly time consuming (Jonas et al., 2011; Yen et al., 2013). For example, diabetic adults must spend 2 hours a day to meet recommendations of the American Diabetes Association for self care (Safford et al., 2005).

Children with special health care needs (CSHCN)¹ have chronic physical, developmental, behavioral, or emotional conditions that require medical care beyond that required by children generally (McPherson et al., 1998). In addition to often heavy

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¹ CAHMI: Child and Adolescent Health Measurement Initiative; CDC: U.S. Centers for Disease Control and Prevention; CSHCN: Children with special health care needs; MCHB: Maternal and Child Health Bureau; NS-CSHCN: National Survey of Children with Special Health Care Needs; SHCN: Special health care needs; SLAITS: U.S. State and Local Areas Integrated Telephone Survey.

financial burdens on families (Davis, 2011; DeRigne, 2012; Newacheck and Kim, 2005; Stabile and Allin, 2012), raising CSHCN imposes substantial time costs beyond the time involved in raising healthy children. Many families provide health care for the child at home (e.g., administering medication or maintaining medical equipment), sometimes spending 20 hours/week or more on these “shadow healthcare system” tasks (Leiter et al., 2004; Schuster et al., 2011). Arranging and coordinating health care is also time consuming because many CSHCN require numerous visits to primary care doctors, specialists, and emergency rooms, and an array of specialized and ancillary services (Bramlett et al., 2009; DuPaul et al., 2013; Kuo et al., 2011b; Schuster et al., 2011). Services such as speech, physical, or occupational therapy typically require separate providers who do not routinely communicate with each other (Schuster et al., 2011). Scheduling appointments, making sure providers share information, and following up on the child’s needs requires not only time but a high degree of organization. Families are often not prepared for the complexity of these tasks and have many other demands on their time, such as the care of other children, or paid employment.

The burden of caring for chronically ill children is associated with negative outcomes for parents and other family members, including diminished parental mental and physical health (Kuhlthau et al., 2010; Witt et al., 2009), increased chances of parents having to quit or cut back employment to care for their child (DeRigne and Porterfield, 2010; Okumura et al., 2009; Witt et al., 2009), and increased risk of marital disruption (Mauldon, 1992; Reichman et al., 2008). When navigating the healthcare system or providing home treatment regimens becomes too burdensome, some of the child’s medical needs can go unmet.

In 2010, more than 60% of families of CSHCN devoted at least 1 hour/week to arranging, coordinating, and providing health care for the child, and one-sixth spent 11 hours/week or more (U.S. Department of Health and Human Services, Maternal and Child Health Bureau, 2013). However, these burdens differ according to characteristics of CSHCN and their families. The Andersen model posits three broad categories of characteristics—need, enabling, and predisposing—that affect healthcare utilization (Andersen and Newman, 1973). Those same factors are likely to be associated with the time family members spend arranging or providing health care at home for the child because time spent on those tasks compensates for care not provided in the formal healthcare sector. Need factors such as chronic health conditions or functional limitations increase the time burden on families because they require more health care and more types of services. Enabling factors like adequate health insurance or patient-centered medical homes that make it easier to access healthcare can reduce family time burdens because the child receives more of the needed care in the formal healthcare system. Socioeconomic factors such as lower income may predispose family members to provide more healthcare at home.

Consistent with the Andersen model, studies have shown that time spent by family members arranging or providing health care at home for CSHCN is greater for need factors such as autism, Down Syndrome, or diabetes (Katz et al., 2012; Kogan et al., 2008; McGrath et al., 2011; Phelps et al., 2012), or when the child’s health conditions are more severe or complex (Bramlett et al., 2009; DuPaul et al., 2013; Kuo et al., 2011b; McCann et al., 2012; Okumura et al., 2009). Absence of factors that enable use of the formal healthcare system, such as health insurance or medical homes (Kogan et al., 2008; McManus et al., 2011; Miller et al., 2015; Turchi et al., 2009), are also associated with higher time burdens. Factors that predispose families to lower rates of healthcare utilization, such as being poor or a member of a racial/ethnic minority, are also associated with greater time burdens (DuPaul et al., 2013; McManus et al., 2011; U.S. Department of Health and Human Services, Maternal and Child Health Bureau, 2013).

Although these studies have contributed much to our understanding of the demands on families’ time, they analyzed either arranging/coordinating (Turchi et al., 2009), or providing care (Bramlett et al., 2009; Phelps et al., 2012), not both; used composite measures of family burden that included financial impact or job loss in addition to time (DuPaul et al., 2013; McManus et al., 2011); or studied only certain health conditions (McManus et al., 2011; Phelps et al., 2012). Moreover, they used dichotomized measures of time burden as the dependent variable for their multivariable analyses, leaving open the question of whether the size of the associations between risk factors and time burdens is uniform across levels of time burden. Other studies have analyzed time spent providing or obtaining health care for the general child population for which these tasks take less time than for chronically ill children. For example, using data from the American Time Use Survey, England and Srivastava (2013) found that parents spent well under an hour/week (about two *minutes/day*) on these tasks.

We use data from the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) to build on earlier studies by (1) examining three measures of time burden – providing health care for the child at home, arranging/coordinating health care, and the two combined; (2) testing for nonproportional odds across multichotomous ordered time categories rather than dichotomizing time; (3) analyzing the most recent round of the NS-CSHCN; and (4) investigating a large number of need, enabling, and predisposing factors.

Our results give a more complete picture of how the time families spend providing and arranging health care for their CSHCN varies by the characteristics of children and families. We find that, particularly for providing health care at home, some factors do not have uniform effects on time burden but are disproportionately associated with higher, or lower, time burdens.

2. Material and methods

The 2009–2010 NS-CSHCN is a national, population-based survey of 40,242 CSHCN conducted as part of the U.S. State and Local Areas Integrated Telephone Survey (SLAITS; (Bramlett et al., 2014). The response rate was 43.7% for the landline sample, 15.2% for the cellphone sample, and 25.5% overall (Bramlett et al., 2014). To be included, a household had to have at least

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