

The caregiver as gatekeeper for accessing health care for children in foster care: A qualitative study of kinship and unrelated caregivers

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ABSTRACT

The objective of this qualitative study was to examine issues that unrelated and kinship foster caregivers in Los Angeles, CA, have in seeking help and accessing and using health care for children in foster care. There were four themes identified for all caregivers: (1) "Doing Our Best" (caregivers advocated persistently and creatively for health care); (2) "Support from Others Helped" (caregivers relied on caseworkers, organizations, and their social network); (3) "Child has Complicated, Serious, Chronic Health Problems" (caregivers had difficulty securing specialty services and with Medicaid insurance to meet health care needs); and (4) "Caregiver Competence in Meeting Health Needs" (caregivers noted their ability to attend health appointments and understand instructions). An additional theme of "Differences between Unrelated and Kinship Foster Caregivers" highlighted more difficulties among kinship caregivers in finding and using primary health care services and more financial stress, whereas unrelated caregivers were less satisfied with child welfare caseworker help. Despite wide-ranging stressors and serious frustrations with the child welfare and health care systems, caregivers emerged as powerful drivers of health care for foster children. National adoption of a medical home model would ameliorate some of the access barriers identified by foster caregivers in this study.

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1. Introduction

Children in foster care have a higher prevalence of chronic and acute health conditions than their peers which makes access to health care services essential for this population (Hansen, Mawjee, Barton, Metcalf, & Joye, 2004; Jaudes, Bilaver, Goerge, Masterson, & Catania, 2004; Ringeisen, Casanueva, Urato, & Cross, 2008; Steele & Buchi, 2008). Although the Child Welfare League of America and the American Academy of Pediatrics have developed standards for the mental and physical health care of foster children living in out-of-home care, these standards primarily address communication between the *health care provider* and *child welfare caseworker* and do not address in detail how to incorporate the *caregiver* into health care delivery (Child Welfare League of America, 2007; Task Force on Health Care for Children in Foster Care, 2005). The caregiver is a vital link in meeting the health care needs of foster children, as caregivers are responsible for finding health care providers, transporting foster children to appointments, communicating needs to the health care provider, and following instructions for home care (Schneiderman & Villagrana, 2010). This qualitative study sheds light on a poorly understood but important group in the provision of health care to foster children by investigating the views of unrelated and kinship caregivers on

seeking help to meet their child's health care needs, accessing pediatric and mental health care, and using health care.

1.1. Use of health services

Children in foster care utilize pediatric health services frequently, especially for chronic illnesses (Sphere Institute, 2003). Despite the high rate of service use, evidence indicates that foster children as a group do not receive services at a level commensurate with their needs. For example, using a national sample, Leslie et al. (2003) found that health assessments of children in foster care are not consistent. Using the 1999 National Survey of America's Families, researchers found that 16% of children in out-of-home placement were not covered by health insurance at some point in the past year, and 20% to 40% received no preventive health or dental care (Kortenkamp & Macomber, 2002). Another study found that foster children receive fewer outpatient services than their Medicaid-eligible peers, and that as foster children age and have multiple placements, their reliance on emergency room visits increases (Rubin, Alessandrini, Feudtner, Localio, & Hadley, 2004). Emergency room use is often related to lack of early treatment of health problems or lack of preventive health care. For children in foster care, placement often affects the type of health services received. Studies that focused on kinship care found that children under the care of family members are less likely to receive mental and pediatric health services than children placed with unrelated caregivers (James, Landsverk, Slymen, & Leslie, 2004; Timmer, Sedlar, & Urquiza, 2004). Child welfare systems are

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increasingly relying on kinship caregivers (Allen, DeVooght, & Geen, 2008), and in a national sample, kinship foster caregivers had lower socioeconomic status and were less likely to receive child welfare support services compared to unrelated caregivers (Sakai, Lin, & Flores, 2011).

1.2. Caregiver role

There is growing recognition of the role of foster caregivers in assuring adequate health care for foster children. Pasztor, Hollinger, Inkelas, and Halfon (2006) conducted one of the first studies to explore the role of foster caregivers and pediatric health care. This qualitative study of unrelated foster caregivers found that caregivers most often noted the lack of continuity of care, as well as transportation and childcare difficulties. Caregivers did note, however, that they were better able to access services when they had preexisting relationships with a pediatrician who provided health care to the caregivers' biological children. In a quantitative study using standard pediatric access barriers, Schneiderman, McDaniel, Xie, and Arnold Clark (2010) found that child welfare caregivers rated "difficulty understanding doctor's explanation," "wait too long to see a doctor," and "clinic hours inconvenient" as the most difficult access barriers; yet, unrelated caregivers rated inconvenience factors less important than kinship foster caregivers or birth parents receiving services from child welfare. It is not clear from this study how foster caregivers' ratings of standard access barriers are affected by financial compensation from child welfare and case management services. Qualitatively, Schneiderman, Traube, and McDaniel (2011) found that placement changes and limited access to health records exacerbated the need of foster caregivers for child welfare case management; the authors noted that more thorough analysis was needed to assess how child welfare caregivers' help-seeking affects access to and use of health services.

1.3. Conceptual framework

This qualitative study of foster caregivers is guided by a conceptual framework adapted from the Gateway Provider Model (Stiffman, Pescosolido, & Cabassa, 2004) (see Fig. 1). Concepts from the original model (which was developed to explain mental health service use by

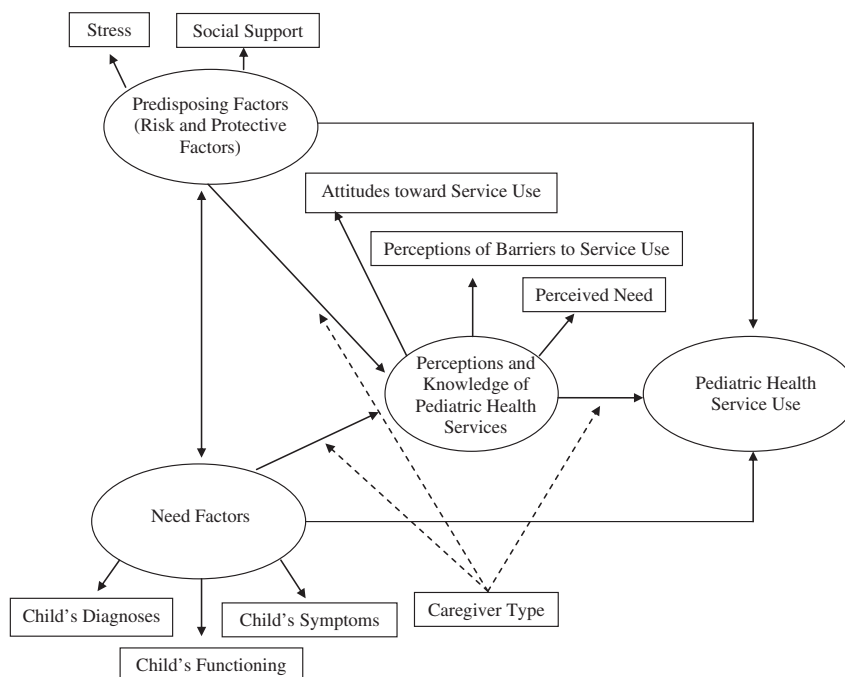
youth) were adapted and modified for use with caregivers of children in foster care. For these children, the caregiver is the most important gatekeeper to meeting health care needs. Specifically, the model proposes that caregivers' perceptions and knowledge of pediatric health services affect the relationship between need and predisposing factors and the subsequent use of pediatric health services use by caregivers for children under their care. The model also proposes that the type of caregiver moderates the effects of perceptions and knowledge of pediatric health services and the risk, protective, and need factors. This model is not specific for families in foster care and therefore does not include the relationship between the child welfare system and foster caregivers in providing health care. Thus, qualitative methods were utilized to explore how foster caregivers are affected by the child welfare system's authority over both their role and healthcare decision-making for children in foster care. This study adds important information that previously has not been addressed in the literature by including the views of both unrelated and kinship caregivers.

The objective of this study was to examine in-depth the issues that unrelated and kinship foster caregivers in Los Angeles, CA, have in seeking help and accessing and using health care for children in foster care. The specific research questions were: (1) what personal/family factors influence caregivers' decision-making regarding care for their child's physical and mental health problems?; (2) what impact does caring for a child with health problems have on caregivers and their families?; and (3) what suggestions do caregivers have to improve their access to and use of health care?

2. Research design and methods

2.1. Participants and setting

A purposive sample of 25 caregivers of children in foster care in Los Angeles County was recruited for participation. In order to ensure that caregivers had sufficient experience obtaining health services, caregivers were only eligible for the study if they cared for the child in their home for at least 6 months. Legal guardians of children in foster care were also excluded because they have different



Model adapted from the Gateway Provider Model (Stiffman, Pescosolido, & Cabassa, 2004).

Fig. 1. Conceptual model. Model adapted from the Gateway Provider Model (Stiffman et al., 2004).

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