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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.

Keywords

access to pediatric health care; kinship foster caregivers; unrelated foster caregivers; foster children

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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 increasingly relying on kinship caregivers (Allen, DeVoght, & 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 Figure 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. Including both unrelated and kinship caregivers offers important information that previously has not been addressed in the literature.

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 responsibilities for their child's health care (e.g., only legal guardians can consent to medical procedures) (Task Force, 2005). The sample of 25 caregivers came from 34 caregivers who volunteered for the study. Of the 34 volunteers, 20% were not eligible as determined by the Los Angeles Department of Children and Family Services (DCFS) screening; e.g., the foster child was not in the home for at least 6 months, there was no open case, or the foster caregiver was a guardian (see Table 1). Two-thirds of the 34 caregivers who volunteered were recruited by DCFS and one-third of the volunteers were recruited at foster caregiver meetings. Two participants who volunteered

and qualified decided not to participate; one declined due to the time commitment and the second declined due to illness. Caregivers were recruited with the goal of representing different geographic regions of the county, different languages (English and Spanish), and different types of caregivers (unrelated and kinship).

The study was approved by the University of Southern California Health Sciences institutional review board, DCFS, and the county juvenile court. Caregivers were contacted by telephone to set up an in-home interview. When the interviewers arrived at the home, participants were provided an information sheet about the study and verbally consented to participate. The first author or the bilingual graduate research assistant conducted the interviews. Interviews were conducted in the participant's choice of language, either English or Spanish. If the caregiver had more than one foster child in the home, interviewers spoke to the caregiver about the child most recently placed in their home who had been there at least 6 months. If more than one foster child was in the home and the children were placed at the same time, the interviewer randomly selected one of the children as the subject of the interview. Interviews lasted approximately 1 hour. Interviews were audio-recorded and transcribed for analysis. Spanish interviews were transcribed first in Spanish and, then translated to English. We reviewed 4 randomly selected transcriptions (2 in English and 2 in Spanish) to check for accuracy. All caregivers received a \$35 gift certificate for participation.

2.2. Interview Guide

A semi-structured interview guide was formulated to capture the caregivers' help-seeking and access to and use of health services. Both interviewers tested the interview guide on a caregiver prior to the start of the study. The interview guide was translated into Spanish and also tested with a Spanish-speaking caregiver to ensure the translation and content was appropriate. The guide gathered initial demographic information on the caregiver and foster child. The first section of interview questions were related to predisposing factors associated with access to health care, such as assistance by individuals or organizations and the caregiver's ability to transport the child to health appointments. The second section of the interview guide included need factors such as caregivers' perceptions of the child's health, how the child's health affects daily living, and causes of health problems. The third section included questions on the caregivers' perceptions and knowledge of pediatric health care. In this section, the questions included information on obtaining appropriate medical care for the foster child and understanding doctor's explanations of the child's health problems and treatment plan. The final section included questions on how helpful DCFS was in assisting caregivers with obtaining pediatric health services and what else DCFS could do to help caregivers obtain pediatric health services.

2.3. Analysis

Analysis of the data was conducted with Atlas.ti computer software. Thematic analysis used a template approach (Patton, 2002) based on the conceptual model. Hierarchical coding was used to illustrate the relationship of broad themes (e.g., risk and protective factors, need factors, and perceptions and knowledge), which encompass successively narrower, more specific themes (e.g., social support and caregiver stress) (School of Human & Health Sciences, 2007). The initial thematic coding followed the template but new themes emerged during analysis that were not included in the model. Therefore, subsequent new coding themes were developed when the two reviewers met after coding 4 initial interviews. The agreement between the two coders was 76%. The themes and subthemes were constantly compared across cases to identify evidence of the concepts. Themes identified for all participants had at least 80% endorsement by both unrelated and kinship caregivers. We considered subthemes with a 20% or greater difference in endorsement between unrelated

and kinship caregivers to be different by caregiver type. The relationship among themes was examined using a format that placed them within the larger social welfare and health care context. Interpretation also used concepts of family dynamics as we compared the data across caregiver types.

3. Results

3.1. Participant Demographics

Participants included 13 kinship caregivers and 12 unrelated caregivers who resided in 19 zip code areas throughout Los Angeles County. Extensive demographic information is presented for kinship caregivers, unrelated caregivers, and foster children in Table 2. Most caregivers spoke English, were female, and had an average age of 50. Kinship caregivers identified more often as Hispanic or Black compared with unrelated caregivers. Child demographics were similar regardless of caregiver relationship type, except youth living with kinship caregivers had lived with their caregivers longer.

3.2. Summary of Findings: Themes

There were four primary themes for all caregivers in the study. The first theme was “Doing Our Best”—caregivers reported that they had to advocate and be persistent and creative in finding the best possible health care for their foster child. The second theme was “Support from Others Helped”—caregivers relied on caseworkers, organizations, and others from their social network (family, friends, and other foster caregivers) to meet their foster child's health care needs. The third theme was “Child has Complicated, Serious, Chronic Health Problems”—caregivers had difficulty securing needed specialty services (e.g., eye doctors, dentists, mental health providers) and difficulty with Medicaid insurance when attempting to meet their child's chronic health needs. The final theme for all caregivers was “Caregiver Competence in Meeting Health Needs”—caregivers stated that they were able to attend health appointments and understand health care providers’ instructions. There was an additional theme of “Differences between Unrelated and Kinship Foster caregivers.” Kinship caregivers noted more difficulty in finding and using primary pediatric health care (54% compared to 33% of unrelated caregivers) and more financial stress (62% compared to 42% of unrelated caregivers). Furthermore, unrelated caregivers reported more dissatisfaction with child welfare assistance from caseworkers (75% compared to 38% of kinship caregivers).

3.3. Theme 1: Doing Our Best

Caregivers felt they had a very vital role in obtaining health care services for their foster children. Caregivers wanted to do their best in terms of finding health care and providing a home environment that would decrease the possibility of exacerbating the child's health conditions. Many caregivers talked about advocating with the court, DCFS, and the county health care system to find the best health care for their children. Caregivers expressed their frustration in not receiving needed services to whomever they felt would be most helpful. One caregiver stated: “But it's not wonderful, because at least we have a voice, and yes, it's a nuisance to go down to the court but at least somebody [the judge] hears us. At least somebody who is to for the most part unbiased, to hear our concerns to hear our complaints and say to DCFS, you need to do this for this child.” This persistent advocacy was apparent, as one caregiver stated: “I don't let anything stand in my way. ... Call a higher-up somewhere. Call somebody else. Go to a different doctor. Go through the DCFS and Regional Center [a case management organization for developmentally delayed children] and ask for a doctor.”

Many caregivers were creative in their advocacy skills. Caregivers noted that they would try anything to get what their foster child needed. A kinship caregiver brought her foster child to the emergency department and waited 8 to 9 hours to be seen. The caregiver was frustrated with the long process and said: "And I kept saying, 'But he's diabetic.' And they would say, 'Well, we can't do anything until the doctor sees him.' We had finally got moved to a room. And then finally I said, 'I really don't care what the doctor's doing, but I'm about to give him insulin. And I need you to come in here and check his blood sugar. And I'm gonna give him insulin.' And sure enough, his blood sugar had dropped because it was such a long time."

Caregivers noted that asking once was never enough; one had to ask again and again to obtain a referral or the correct type of care. This often required daily phone calls and sometimes more assertive behavior, such as raising his or her voice. Many caregivers talked about the need to advocate for appropriate mental health services and doctors who provided quality pediatric care. One caregiver was creative and proactive in ensuring that her foster child had what he needed: "I had to get a little smart, so what I did was, I started [asking for the prescriptions] ahead of time so that ... we would always have an extra month."

3.4. Theme 2: Support from Others Helped

Caregivers noted that they relied on assistance from organizations, family, friends, and other foster caregivers to help with the care of their foster children, provide advice, and offer support. The organizations most often identified by caregivers were the Regional Center (a case management program for individuals with developmental disabilities), California Children's Services (a state program providing diagnostic and treatment services for children with chronic diseases), and wrap-around services providing mental health care. Some caregivers noted that DCFS caseworkers were helpful in providing referrals for services, obtaining doctor appointments, and offering advice on obtaining and using Medicaid. For example, a caregiver stated: "We had paperwork showing that his Medi-Cal [the term used for Medicaid in California] was active and that everything was OK, so she [the DCFS caseworker] does an awesome job. Shows up when she needs to be, or shows up when she's scheduled to show up. ... Yeah, and she is only an email away. That's probably the best part."

Many foster caregivers had family members, primarily children or grandchildren, who provided help with babysitting and physical care (e.g., lifting and bathing) of the foster child. Several caregivers had friends or brothers or sisters who would help out when the foster caregiver had appointments or needed a break. Foster caregivers felt especially safe leaving their foster child with a trusted relative because they would "treat my [foster] child like family." Foster caregivers noted that both other foster caregivers and classes required by DCFS provided assistance in finding health care. A caregiver said: "I still go to the foster care classes they have right there at the college. ... You pick up, you know, information and helpful hints." Kinship caregivers noted that they have foster care groups designed for relatives that offered support and information. Veteran foster caregivers had telephone networks of other foster caregivers and felt these networks provided more support and advice than DCFS caseworkers could provide.

3.5. Theme 3: Child has Complicated, Serious, Chronic Health Problems

Eighty-four percent of the caregivers noted that their foster child had at least one chronic health condition. The chronic health conditions included: (1) medical problems such as cardiac conditions, asthma, and diabetes; (2) behavioral/psychological problems such as attention deficit hyperactivity disorder and aggressive behavior; and (3) developmental disabilities such as cerebral palsy, autism, and auditory processing disorder. Many children

had more than one chronic health problem, which made caring for the child difficult and time-consuming as well as finding adequate health care problematic. Although these health problems were serious, caregivers did not identify that family life was disrupted by the foster child's health problems.

Some caregivers needed to go to more than one medical center to obtain specialty medical services. The most frequently used specialty service for the caregivers in this study was speech and language therapy. Many caregivers noted that they were connected to wrap-around services for psychological counseling. Caregivers were thankful for Medicaid funding for health care for their foster child, but many caregivers identified serious problems with finding appropriate health care providers who accepted Medicaid insurance. One caregiver stated: "Because there's a lot of doctors that won't accept Medi-Cal. You've got to find a doctor that accepts Medi-Cal—one. And then you've got to find a good doctor at the same time and it's hard to do. Right, both the things. It's hard to get both in the same man or woman." Dental care was problematic for caregivers, especially finding dentists who accepted Medicaid. Many caregivers were frustrated with the delay in receiving Medicaid authorization for needed dental services such as filling cavities and braces. One caregiver said:

"I really, really had trouble, because we went to like maybe, almost 5 or 6 dentists ... because when you called the services, the numbers that they give us, and they [DCFS] will prescribe us to a dentist that would do the work ... but then when you get there we find out that they didn't update their list ... because each and every dentist would tell us, 'No, we don't do that anymore ... we can't do it anymore because of cutbacks.' ... And it was like, Oh, boy! ... and they have you driving to other cities ... sometimes I had to drive to other cities and even they wouldn't do it. ... So I said, 'Well forget it. I'm gonna have to pay for this,' because I didn't want him to have, you know ... cuz it [the child's tooth] start ... really started to get dark. ... I started to panic ... until someone informed me about USC [University of Southern California Ostrow School of Dentistry clinics]. ... Thank god for that. And then it was real close to my home too ... it was, Oh! ... [The wait] was almost a year and a half. Uh-huh, that's how long it took, really."

3.6. Theme 4: Caregiver Competence in Meeting Health Needs

Caregivers emphasized that they were capable of meeting the health care needs of the children under their care. Although the caregivers noted it was difficult to attend all the appointments that were scheduled (e.g., pediatric, mental health), they stated that they attended them. Caregivers made sure that they understood doctors' instructions and if they did not, they asked the doctors to repeat what needed to be done, when to bring back the child, and what to monitor. The caregivers wanted as much detail as possible in order to do what needed to be done. A caregiver even asked the doctor to "draw pictures" so she could better understand what the doctor was talking about. A few caregivers mentioned using a computer to look up medications when they were unclear about the instructions. Caregivers made notes at home about their child's health care. One caregiver stated: "I can write down what they are allergic to ... cause they [doctors] can give them something that can make their heart race [and it] is not good for them. So you always have to be on top of knowing what they can take and what they can't take." Spanish-speaking caregivers noted that they looked for Spanish-speaking doctors but would seek out translators whenever they could not understand a concept.

3.7. Theme 5: Differences between Unrelated and Kinship Caregivers

Kinship caregivers noted that they had more problems in finding primary care. In general, kinship caregivers did not have a network of previously screened primary care providers

when the child was placed in their home. Unrelated caregivers often noted that they knew a cadre of primary care providers from previous foster children, from other foster children in their home, and from their own children. Even when kinship caregivers found adequate health care, some felt unsure of their ability to care for young children. Another kinship caregiver said she was confused with doctor's instructions about obtaining medication: "When she [the foster child] was released from the hospital, they said if she has any pain, give her baby Tylenol. And I said 'OK, are we going to get a prescription for that?' ... They said get it at the pharmacy. I think I gave her the half a teaspoon that [the pharmacist recommended] ... twice and then after that she seemed fine. But that was not nice."

Kinship caregivers had more financial stress than unrelated caregivers. Unrelated caregivers noted that it was difficult to receive financial assistance from DCFS, but they would wait for the authorizations. Kinship caregivers were more worried about out-of-pocket expenses for their foster child and did not want to wait for DCFS to pay for needed items (e.g., glasses and good psychiatric support). One kinship caregiver said: "Like when I got that one, my oldest one, I got her shortly after she was born and DCFS brought her to me with nothing. She had a car seat, two short bottles of formula, an undershirt, and a Pamper [diaper]. No clothes. They gave me the Medi-Cal card ... and [said] you need to take her immediately to the pediatrician. ... No financial help, no help as far as direction." Kinship caregivers voiced concern about how their lack of finances affected their ability to care for their foster child. One kinship caregiver said:

"But we just take it a day at a time, and they just told me what to do, both, well whoever is around them [foster children] has to learn CPR and the cardiologist suggested that I get a defibrillator at home. ... I am in the process of seeing how I can get one. That would really help to see if someone could help financially to get that. I got to see if I can borrow money. It would really help to have one at home. ... If I would have to pay any out of pocket, that kind of scares me. Like right now I am faced with that problem to get that defibrillator, but I'm like, Oh my gosh, what am I going to do? You know the funds are really low, I cannot wait so long so you know, I need to get one."

Additionally, unrelated foster caregivers stated that they were more dissatisfied with child welfare assistance from caseworkers than kinship caregivers. When kinship caregivers voiced dissatisfaction about how long it took to get things done, they attributed it to caseworkers being overworked. Unrelated caregivers were more vocal about difficulties they had in obtaining help with accessing health services. They complained about the lack of timeliness among caseworkers in responding to caregiver requests, the fact that caseworkers were often switched, and that too little information was given to them about the child's previous health problems and treatments. Unrelated caregivers noted there was inconsistency in the quality of caseworkers, and they felt lucky if they had a caseworker who was "good." A few unrelated caregivers stated that when the caseworker used email, they were better at responding to the caregivers' requests, but some caseworkers did not use email. An unrelated caregiver said: "It was like a run-around. When I got the kids, I got one social worker and she dropped the ball. ... So then they got transferred to another social worker and then they had a person who was investigating the case and then... they switched [from one office to another office], so then I had a new person who had just got demoted from another position, so he kept saying, 'I don't know anything. I don't know anything.'" A particularly vocal unrelated caregiver said: "DCFS is no help, at all. And they are so young coming out to be caseworkers, it's ironic and it's like, 'I don't want to be bothered with them.' And it's sad. It is so sad. You are losing foster parents because of this. They are losing foster parents by the truck loads."

4. Discussion

In this study, unrelated and kinship foster caregivers saw themselves as key players in accessing and using health services for children in foster care. Although caregivers were faced with significant burdens of caring for chronically ill children with multiple demands, most stated they were able to meet those demands. In fact, caregivers said they were responsible for advocating for quality pediatric and mental health care for their foster children within systems (both health care and child welfare) that were sometimes disorganized, noncommunicative, and difficult to navigate. Caregivers in this study were not particularly bothered by barriers to obtaining health care (e.g., transportation to appointments or inconvenient time or location of appointments), which is different than previous studies (Pasztor et al., 2006; Schneiderman et al., 2010). For the participants in this study, it is possible that social supports and help from family, friends, and organizations mitigated some of the inconveniences of finding and using health services. The interviews also illustrated differences in how kinship and unrelated caregivers were able to access and use health services.

Much of the caregivers' advocacy was directed toward obtaining specialty medical services, a process caregivers found very arduous. Child welfare caregivers are not alone in this problem; nationally, long wait times are common for pediatric specialists and many subspecialists are not available in rural areas (American Academy of Pediatrics, 2010). The older age of the foster children in this study may also influenced need for specialty medical services, as Ringeisen et al. (2008) found that older children in foster care nationally have a higher level of special health care needs than younger children. Because foster children are wards of the state, foster caregivers were also somewhat limited in their health care advocacy. In this study, caregiver advocacy was primarily about finding appropriate health care services and remaining informed about medical conditions and treatments, unlike parental pediatric health care advocacy, which may also include making medical care decisions and limiting the actions of medical professionals (Holm, Patterson, & Gurney, 2003).

Caregivers sought help from family, friends, and organizations to obtain quality health care that meets the comprehensive physical and mental health needs of their foster child. Caregivers needed to use their network of supports because they were frustrated with the lack of available quality providers that accept Medicaid. This frustration may be justified; researchers have found that many children with Medicaid receive pediatric health services with poor continuity of care and preventive services for their chronic health conditions (Christakis, Feudtner, Pihoker, & Connell, 2001; Lieu et al., 2002). Similar to Pasztor et al.'s (2006) study, unrelated caregivers had a network of health care providers already identified. Kinship providers used other foster parents, especially kinship foster care groups, to find health care. Both unrelated and kinship caregivers also noted that their family and friends offered instrumental and psychological support to them as foster caregivers, the inverse of findings in another study that found that unrelated foster caregivers had a stronger support system than kinship caregivers (Villagrana, 2010). Kinship caregivers in this study had no reluctance asking for organizational or financial help for their foster child, whereas other researchers (Ehrle & Geen, 2002) found that even when kinship caregivers were aware of their eligibility for public assistance, they were reluctant to apply due to stigma. It may be that kinship caregivers feel that asking for help for children is acceptable, but asking for help for themselves is not acceptable. Thus, the foster caregivers in this study were seeking help, using their resources as best they could, and finding support in their social networks.

All caregivers sought help from DCFS caseworkers. Unrelated caregivers were especially vocal about what they needed from child welfare caseworkers, and described difficulties

with some caseworkers. In a national survey, when caregivers had fewer than two child welfare workers and more recent contact with timely responsive services, caregivers reported a higher quality of relationship with their child welfare caseworker (Chapman, Gibbons, Barth, McCrae, & the NSCAW Research Group, 2003). Many unrelated caregivers did not view caseworker services as timely or responsive. Although kinship caregivers in this study acknowledged that they did not always receive sufficient help from caseworkers, they remained thankful for the help they did receive. Kinship caregivers' expectations for child welfare assistance were lower compared with unrelated caregivers; this perception may be due to the fact that unrelated caregivers generally receive augmented services with a higher level of service congruence than kinship caregivers (Geen & Malm, 2003). Unfortunately, kinship foster parents are frequently left to navigate the system with less assistance because caseworkers assume that their familiarity with the child and the child's history will translate into a lesser need for assistance (Geen, 2003a, 2003b; Shlonsky & Berrick, 2001). Child welfare systems do not systematically collect client feedback about services, although such feedback might improve child welfare services by helping to provide family-centered casework and empowering the people it serves (Baker, 2007).

Similar to other studies, kinship caregivers noted more stress related to financial problems than unrelated caregivers (Sakai et al., 2011; Timmer et al., 2004). Child welfare caseworkers and pediatric clinicians need to be aware of the stresses often present for kinship caregivers, and that kinship caregivers may be in crisis mode before they ask for help (Geen, 2004). Child welfare caseworkers should not wait until kinship caregivers ask for help, but offer help with accessing and using health services as soon as the child is placed in foster care (Harden, 2004). Additionally, health care providers should not assume that kinship foster caregivers know how to care for their foster child, and should give detailed instructions, allow for questions, and provide linkages to needed services (Grinwis, Smith, & Dannison, 2004).

The theme of caregiver competence suggests that caseworkers in the child welfare system and pediatric clinicians should have confidence that caregivers are motivated and capable of exerting much effort and performing complex tasks necessary to assure adequate health care for children on their caseloads. On the other hand, several themes (e.g., financial stress, dissatisfaction, need for perseverance and advocacy) suggest that caseworkers and pediatric clinicians could help caregivers seek, access, and use health care services for foster children more efficiently and less stressfully. Recognizing stressors in caregivers' lives could help the child welfare system provide clients with better referrals for case management, health insurance, and stress management. Acknowledging the dissatisfaction some caregivers feel with the child welfare system could prompt DCFS to train caseworkers to do things caregivers find helpful (e.g., using email) or to leverage department resources to improve particular health care-related resources (e.g., constantly update lists of primary and specialty care providers who currently accept Medicaid). Providing caregivers with the tools to cope with stressors and reliable information about health care opportunities could reinforce their strong motivation and persistence, allowing them to use these personal strengths to care for their children in several domains, rather than creating an environment in which they spend significant time and mental energy on health care alone.

4.1. Policy Implications

The emphasis on a medical home and patient- and family-centered pediatric health care would ameliorate some of the access barriers identified by foster caregivers in this study (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; Strickland, Jones, Ghandour, Kogan, & Newacheck, 2011). A medical home comprises five elements: having a usual source of care; having a personal physician or nurse; receiving all needed referrals for specialty care; receiving help as needed in coordinating health and

health-related care; and receiving family-centered care. The patient- and family-centered approach recognizes that the perspectives and information provided by caregivers and children are essential components of high-quality clinical decision-making, and that patients and family are integral partners with the health care team. The American Academy of Pediatrics' Committee on Foster Care and the Child Welfare League of America endorsed the need for medical homes for children in foster care (CWLA, 2007; Task Force, 2005). Unfortunately, placement instability sometimes precludes the continuous care component in medical homes (Mekonnen, Noonan, & Rubin, 2009). Having a medical home is important for all children in foster care, but especially for foster children identified as "medically fragile" and for foster children who are placed in a "medical foster home." Foster caregivers in this study wanted to be active members in providing health care to their foster children and voiced their need for all the factors encompassed by the medical home and patient- and family-centered care policy statements.

4.2. Limitations

The purposive sampling, which aimed to include a diverse range of participants from different locations within the county and of different ethnic backgrounds, genders, ages, and relationships to children under their care, was a strength of the study. However, the results of this qualitative study have limited generalizability because the small sample of willing interview participants were not randomly selected and therefore is not necessarily representative of the larger population of foster caregivers in Los Angeles County. Furthermore, their experiences may differ substantially from the interactions caregivers have with health care systems in other regions. We also recruited participants for the study with a flyer which stated that we were interested in caregivers' views on accessing and using pediatric health care services. This may have recruited caregivers who had children with more health problems and/or caregivers who had more difficulties with finding and using health services. The results of this study are also limited by the model used by researchers to construct the semi-structured interview; caregivers responded to interviewers' questions that were intended to explore the Gateway Provider Model (Stiffman et al., 2004), which may have constrained the qualitative data to fit within predetermined themes. On the other hand, using a model to guide the interviews lent a theoretical structure to the qualitative design, giving researchers a tool to cover important aspects of health care access and use. Finally, qualitative research is generally limited by the inability to test statistical significance. A theme of difference between kinship and unrelated caregivers emerged in this study, but the research design did not allow for statistical testing of the significance of this difference.

5. Conclusion

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. They described going to great lengths to seek out primary and specialty care, accessing needed care through resourcefulness and perseverance, and feeling competent in using health care services once they found and accessed care. Caregivers perceived their role as a parent as an obligation to take responsibility for providing necessary health care to children in their homes. This caregiver perspective represents a significant strength and hope for facilitating healthy outcomes for foster children. Regardless of challenges, irritations, or barriers, caregivers feel they can find a way to help the children under their care receive adequate services. Studies about improving health care access and health outcomes for children in foster care should include the voices of caregivers as an integral part of the child welfare and health care team.

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Highlights

- Foster caregivers advocated persistently and creatively for pediatric health care
- Caregivers emerged as powerful drivers of health care for foster children
- Kinship caregivers had difficulties finding/using primary pediatric health services
- Foster caregivers relied on social networks/organizations for pediatric services
- Specialty pediatric care was difficult to find for foster caregivers

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Figure 1. Conceptual Model

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

Table 1

Recruitment of Participants

Subjects	<i>n</i>	%
Referred	34	100
Referred but found ineligible	7	20.6
Referred and eligible	27	79.4
Eligible but declined to participate	2	7.4
Eligible and participated	25	92.6

Table 2**Caregiver and Child Demographics**

	Kinship Caregivers (<i>n</i> = 13)	Unrelated Caregivers (<i>n</i> = 12)
Caregiver Demographics		
Ethnicity		
Black	38	33
Hispanic	54	33
White	8	25
Other	0	8
Language		
English	77	75
Spanish	23	25
Gender		
Male	15	17
Female	85	83
Age	50.92 (11.72)	53.33 (11.73)
Child Demographics		
Ethnicity		
Black	23	17
Hispanic	31	33
White	8	25
Other	38	25
Gender		
Male	54	50
Female	46	50
Age	10.23 (5.10)	11.79 (4.04)
Months with Caregiver	37.96 (46.21)	16.58 (9.12)

Note. Values represent % except for demographics of age and months with caregiver, which represent $M(SD)$.