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Qualitative Study of Foster Caregivers' Views on Adherence to Pediatric Appointments

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Abstract

The current study is a qualitative investigation of how foster caregivers, primarily Latinos, view adherence to pediatric appointments with the purpose of identifying how the child welfare system, pediatric clinics, and pediatric health providers serving foster children might promote appointment attendance. Participants in the study had a return appointment at an outpatient pediatric clinic that only served children in the child welfare system. Twenty-eight caregivers (13 related and 15 unrelated) participated in telephone interviews after the date of their scheduled pediatric appointment (32% missed their return appointment). Semistructured interview guides included general questions about what promotes attending the pediatric appointment, what makes it difficult to attend the pediatric appointment, and how pediatric care affects the foster child. Analysis of qualitative data using content analysis identified three themes: (a) multiple methods to attend appointments, which included caregivers' organizational and problem-solving skills; (b) positive health care experiences, which consisted of caregivers' personal relationships with providers and staff members and clinic organization; and (c) necessity of pediatric care, which included recognition of the need for health care, especially timely immunizations. All caregivers also reported that appointments reminders would be helpful. Unrelated caregivers more often said that appointment attendance was facilitated by clinic organization compared to related caregivers. Nonadherent caregivers mentioned their need to solve problems to attend appointments or reschedule appointments more than attenders. In summary, caregivers said they valued regular pediatric health care to treat their child's chronic conditions and prevent illnesses, but they acknowledged that their home lives were hectic and attending scheduled appointments was sometimes difficult. Foster caregivers in this study identified the ideal pediatric clinic environment

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that encourages adherence to health care appointments. This environment is an organized clinic with easy access including parking, engaged pediatric health providers, ability to reschedule appointments when necessary, and an individualized and consistent appointment reminder system.

Keywords

return appointment adherence; foster care; pediatric health care; foster caregivers

Children in foster care have higher rates of chronic illness and greater healthcare needs than the general population (e.g., Ringeisen, Casanueva, Urato, & Cross, 2008; Stein et al., 2013). Therefore, the child welfare system has an important responsibility to promote access to and use of health care services (Szilagyi et al., 2015). In Los Angeles, almost all children supervised by the Department of Children and Family Services (DCFS) receive an initial medical evaluation at a clinic that is part of the Medical HUB System (DCFS, 2014). Some foster caregivers elect to continue accessing pediatric medical care at a Medical HUB System clinic or pediatric providers sometimes request a follow-up appointment for a medical problem. This presents an opportunity to tailor the provision of health care services to the needs of this specific population. In a recent study, almost 40% of children receiving medical care from a Medical HUB System clinic did not attend their follow-up appointment (Schneiderman, Smith, Arnold-Clark, Fuentes, & Kennedy, 2016). The only predictor of missing an appointment identified in this study was the length of time between the initial and return appointments; longer time between appointments was related to a greater chance of missing the return appointment. The current study is a qualitative investigation of how foster caregivers, primarily Latinos, view adherence to pediatric appointments, with the goal of identifying how the child welfare system, pediatric clinics and pediatric health providers serving foster children might promote appointment attendance.

We selected foster caregivers as the population of interest in this study because caregivers are vital gatekeepers through which children access health care services (Schneiderman, Smith, & Palinkas, 2012; Schneiderman & Villagrana, 2010). Although child welfare system workers and Medical HUB System clinic providers offer health care services to children, caregivers are ultimately responsible for ensuring that children attend appointments. We included a specific focus on how related (or kinship) versus unrelated caregivers viewed pediatric appointment attendance, because previous research has indicated that children living with related foster caregivers may be less likely to receive pediatric health services than children placed with unrelated caregivers (Timmer, Sedlar, & Urquiza, 2004). Changes in U.S. public policy have increased the number of children living with related foster caregivers (Geen, 2004). These related foster caregivers have to navigate potentially complex and burdensome health care regimens that often require frequent pediatric medical appointments, with fewer resources than unrelated foster caregivers (Sakai, Lin, & Flores, 2011; Stein et al., 2014). The present study provided an opportunity to explore how related foster caregivers might view medical adherence differently from unrelated caregivers.

An increasing number of Latino children are entering foster care in the United States (Children's Bureau, 2015). In Los Angeles, where the present study took place, 60.2% of

children in foster care are Latino (DCFS, 2016). Although Latino children tend not to be overrepresented in child welfare compared to other minority groups (Hines, Lemon, Wyatt, & Merdinger, 2004; Summers, Wood, & Russell, 2012), there is some evidence that particular counties and states have disproportionate numbers of Latinos in child welfare (Dettlaff, 2014). The child welfare system prefers to place children with kinship caregivers or culturally similar unrelated caregivers, thus Latino children most often have Latino caregivers (Bass, Shields, & Behrman, 2004). This growing demographic requires additional attention from researchers and providers to deliver appropriate and effective health care, particularly because Latino children have poorer health and more barriers to accessing to health care than children of other ethnicities (Flores, 2010).

Qualitative methods are well suited to investigating how vulnerable populations interact with health care systems, largely because they allow individuals from underserved or disempowered groups to describe the phenomena they have experienced in naturalistic language that is meaningful to them (Green & Thorogood, 2013; Sullivan-Bolyai, Bova, & Harper, 2005). Furthermore, using qualitative interviews with health care consumers prior to developing adherence interventions provides a foundation for health promotion efforts that meet specific expressed needs (Campbell et al., 2007; Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). Because this was a qualitative study, we did not use a theoretical framework, as our goal was to generate explanation, but we were informed by the health belief model (Rosenstock, 1974), which describes how individuals' perceptions of medical conditions and health behaviors influence the actions they take. We interviewed foster caregivers using general prompts about barriers, supports, and benefits of appointment attendance. However, instead of structuring interviews to map closely onto the health belief model or any other existing theory of medical adherence, interviewers used open-ended questions and reflections to allow foster caregivers to express their subjective views on pediatric appointment attendance. The aim of this study was to investigate the specific experience of Los Angeles foster caregivers accessing pediatric medical care at a clinic focused on the child welfare system. Results of this investigation are expected to inform strategies that child welfare systems and pediatric health providers could implement to improve appointment adherence in the future.

Materials and Methods

Recruitment and Sample

The initial recruitment of participants for a quantitative study of return appointment adherence occurred at the Community Assessment and Treatment Clinic (CATC), which is part of the Medical HUB System in Los Angeles, California. Caregivers were recruited by physicians and nurse practitioners if the caregivers wanted or were requested to attend a return appointment at CATC. All health care providers were bilingual. The physicians and nurse practitioners obtained consent from the caregivers at their initial appointment and the caregivers completed a questionnaire with their demographic information, including telephone number. The consent form included a statement that caregivers might be telephoned by the researchers. The research protocol was approved by the affiliated university and health center's institutional review board. When a caregiver made a return

appointment, a written reminder card was given to them by the clinic personnel making the appointment. Only 14% of caregivers received a telephone reminder prior to their scheduled appointment because of lack of staff availability.

After the date of the scheduled or rescheduled return appointment, we recruited caregivers for this qualitative study, including both caregivers who returned for their pediatric appointments and those who did not return. Because almost all participants (89%) in the initial study were foster caregivers and access to and use of health services differ between foster caregivers and birth parents, we decided to recruit only foster caregiver participants. Possible participants were 77 foster caregivers. Of the 40 caregivers we initially reached by phone, 70% decided to participate in the interview. All caregivers received a \$10 gift card, even if they decided not to participate. The caregivers who decided not to participate often stated that they did not have the time. The final sample was 28 caregivers. We concluded that we had sufficient data to reach saturation with 28 interviews.

Interview Procedure

The telephone interviews lasted approximately 20 minutes and were recorded by the interviewer. The interviews occurred between January 2014 and August 2014. The interviewers repeated what they recorded to the caregivers on the phone to assure accuracy. The interviewers conducted the interviews in Spanish or English, depending on the caregivers' preference. The two interviewees were doctoral social work or clinical psychology students trained by the primary investigator.

The interviews used a semistructured approach. The three general questions were: What helps you attend the pediatric medical appointment for your foster child? What makes it difficult to attend the pediatric medical appointment for your foster child? What does your child get from attending pediatric medical appointments? Interviewers were not aware of whether the caregiver attended the pediatric return appointment or not. After each interviewer completed five interviews, the research team convened to see if the questions and prompts were adequate to elicit the information needed to answer the research questions. Prompts were added to the script as needed.

Analysis

In preparation for analysis, two of the authors read through the interviews and employed content analysis to identify possible themes in the interview transcriptions (Krippendorff, 2013). The researchers discussed with one another their feelings about health care use for this population to make sure that their experiences and interests did not bias the coding procedure. The data were organized using ATLAS.ti software, and two of the authors coded the data separately. After each researcher coded five transcripts, the authors met and revised and added codes based on their discussion. The reliability of the coders after the initial coding was 77.5%. The authors reviewed each discrepancy and the differences were resolved using consensus discussion, adding complexity to the analysis. Themes were identified if at least 50% of the interviews included the code. Interviews were separated by caregiver type (unrelated vs. related) and by adherence (attended appointment vs. missed

appointment) to identify differences in themes. Differences in themes were identified if there was at least a 20% difference in codes by group.

Results

Participant Demographics

Participants were 13 related and 15 unrelated foster caregivers who resided in Los Angeles County. Demographic information for related and unrelated caregivers is presented in Table 1. Most caregivers were female and an average of 44 years old. An equal number of caregivers spoke English and Spanish. All related caregivers identified as Latino, compared to unrelated caregivers who were predominantly Latino but also had some diversity in reported race and ethnicity.

Summary of Findings

Of the study population, 67.9% attended their return appointment and 32.1% missed the return appointment. Universally, caregivers stated that an appointment reminder would be helpful for them. The caregivers suggested possible appointment reminder methods including via telephone (78.6%), text message (67.9%), email (21.4%), or postal mail (10.7%). Some caregivers proposed multiple methods. Three primary themes emerged in this study. The first theme, multiple methods to attend appointments, involved using caregivers' organizational and problem-solving skills in an effort to help them attend medical appointments. The second theme, positive health care experiences, consisted of acknowledging caregivers' personal relationships with providers and staff members and clinic organization as important in improving adherence. The last theme, necessity of pediatric care, involved recognizing the need for health care, especially timely immunizations.

Theme 1: Multiple Methods to Attend Appointments

Foster caregivers reported multiple strengths that helped them attend appointments. Caregivers expressed the importance of being organized both to remember appointments and to make it easier to attend appointments. One of the main organizational methods participants used to remember appointments was writing appointments on their calendars right away and posting any reminder cards on their refrigerators. One caregiver said, "I have two babies with special needs so I keep a calendar for the whole family on the fridge, and I usually write that appointment down as soon as I get it." According to caregivers, keeping an accurate schedule and planning appointments around other important activities helped them attend appointments. Securing transportation in advance was often cited, with multiple caregivers saying that having a car was the primary mechanism that helped them attend appointments. Planning for the appointment was another organizational tool that helped caregivers attend the appointment. In an effort to make the appointment and any wait times more manageable, foster caregivers recommended things like bringing snacks, toys, and games to occupy children during the wait.

In addition, caregivers brought up ways that they employed problem-solving skills when they could not attend a scheduled appointment. The most common response was to

reschedule any appointment that was missed. Some caregivers, however, commented that rescheduling can take time and therefore it is better to attend the original appointment. One participant stated that if they missed a scheduled appointment, “the rescheduling, it would probably be for another month or so, so that’s why it’s important that we attend each one because it usually takes a while to reschedule.” Other problem-solving methods included making appointment adherence easier, like scheduling the first appointment in the morning to save time in the waiting room or bringing a laptop and working during long wait times. “I can be in France right now, I can be on a boat. I can be anywhere there’s an Internet connection because I have one of those little things you stick in the side of the computer. So it doesn’t matter if I’m sitting in a doctor’s office or not.”

Theme 2: Positive Health Care Experiences

Caregivers noted that positive health care experiences influenced how they felt about keeping return appointments. This theme included both caregivers’ personal relationships with providers and staff members and clinic organization as important in improving adherence. Caregivers described opportunities to ask a lot of questions and receive personalized attention as incentives to attend medical appointments. “It helps that the staff are amazing and I want to make their job easier.” One caregiver reported a willingness to drive a longer distance to a particular clinic because of the level of care received there. Having multicultural staff is also important, as one caregiver pointed out. “I like Dr. [name] and he speaks Spanish and is Hispanic like me. He speaks to my culture and everything.” Clinic organization and good service were crucial in improving adherence. In particular, a few caregivers said they liked receiving reminder calls about their child’s appointment from the clinic. One participant said, “They remind me that I have an appointment the next day, so I don’t forget ... because sometimes the appointment is a really long way off.” Fast waiting times, ease of parking, and location were all mentioned as other clinic characteristics that make it easy to attend return appointments. “Because they saw me very fast, it was very helpful.”

Theme 3: Necessity of Pediatric Care

Recognition of the need for health care was particularly strong in the interviews; 78.6% of caregivers reported that improving health was an important concern and a primary reason that attending medical appointments was essential. Despite foster children at times having severe physical health problems, caregivers were particularly concerned with immunization schedules. Caregivers said, “You want to keep them current with shots and check-ups” and “They need to get their vaccinations.” A smaller group was concerned with obtaining the proper medication or adjusting medication levels for their child, stating things like, “He will get meds if needed and peace of mind if no meds are needed.” Participants frequently reported viewing these return appointments as a preventive measure for ensuring child health. Respondents noted that if an appointment was missed, a medical condition might go undetected and worsen a child’s health. Caregivers said things like, “Something might not be detected right away” if an appointment was missed and “If there was something wrong it could be addressed right away.”

Comparisons between Caregivers

Despite general consensus regarding these three themes, related and unrelated caregivers and adherent and nonadherent caregivers differed in what they described as important for appointment adherence. Unrelated caregivers more often said that appointment attendance was facilitated by clinic organization compared to related caregivers. Unrelated caregivers were also more likely to state that attending appointments was necessary, not only for a child's health but also to avoid repercussions from child welfare workers. They cited reasons such as not wanting to lose their license and desiring to avoid reprimands or problems with the social worker. When speaking about not attending a follow-up appointment, unrelated participants said, "A whole bunch of social workers would be calling me" and "I don't want to lose my license." Nonadherent caregivers mentioned their need to solve problems to attend appointments more than attenders. Primarily, they talked about the necessity of rescheduling appointments if they had to miss an appointment. Although there were no questions or prompts about whether appointments were missed, three caregivers noted in their interview that they had never missed a pediatric appointment. These three caregivers were all in the nonadherent group. Caregivers who attended appointments were more likely to credit their relationships with clinic staff members and their own organizational skills as helpful compared to nonadherent caregivers.

Discussion

The foster caregivers in this study voiced that they were invested in bringing their children back for follow-up medical appointments, although they needed assistance to ensure it happened. Caregivers stated that they valued regular pediatric health care to treat their child's chronic conditions, prevent illnesses, and ensure their child had all needed immunizations, but they acknowledged that their home lives were hectic and always making their scheduled appointments was difficult. Remembering appointments was identified as problematic for them and they universally identified that a reminder system would benefit them greatly. Instituting an automated telephone or text message reminder system may be the most cost-effective and efficient way to provide the desired reminder to caregivers (Hofstetter, Vargas, Kennedy, Kitayama, & Stockwell, 2013).

Unrelated caregivers in particular noted the importance of clinic organization, potentially because they often have more foster children to care for compared to related caregivers (e.g., Chamberlain et al., 2006). Although the goal of child welfare is to provide a nonpunitive, supportive approach (Pecora et al., 2010), some of the unrelated caregivers expressed fear of reprisals from their child welfare case worker as a motivation for attending appointments. In a previous study of patients' perspectives on nonattendance at primary care appointments, most participants reported that they did not think punitive approaches to improving attendance would work very well (Martin, Perfect, & Mantle, 2005). Related caregivers did not identify any fear motivation and may have felt more secure in their role as foster care providers because of their familial relationship to their foster child.

Caregivers who did not bring their child back to the return appointment expressed more often that they needed to employ problem-solving skills than caregivers who attended their appointment. The nonadherent caregivers may have had more logistical problems in their

daily lives that made the need to reschedule appointments more likely. It is also possible that these caregivers brought their children to another pediatric facility rather than CATC because of difficulties getting to CATC. However, the fact that one third of caregivers who did not adhere to their appointment at CATC stated that they never miss a pediatric medical appointment is concerning. Foster caregivers are responsible to the state for providing needed care to foster children, including medical care (Putnick, 1998).

Caregivers who attended appointments appreciated engagement with clinic personnel more than nonadherent caregivers. Making foster caregivers feel important and welcome in the health care environment has been shown to improve adherence in other environments, such as mental health (Pecora, Jensen, Romanelli, Jackson, & Ortiz, 2009). Thus, an organized clinic environment with engaged medical personnel and a seamless, easy appointment system featuring the ability to change appointments may improve adherence. In busy pediatric practices, this type of clinic environment may not be easy to achieve, but it may help increase appointment adherence in this population of caregivers. Furthermore, it is important to make a clinic environment welcoming for ethnically diverse caregivers by offering linguistically and culturally appropriate services, ensuring that caregivers understand the purpose of follow-up appointments (Taveras & Flores, 2004).

There are limitations to consider. The primarily Latino and urban population of caregivers in this study limits transferability of the findings. The clinic where this research took place only serves children in the child welfare system and is connected to that system; thus, some problems that caregivers in general might have in terms of interfacing with both child welfare and health systems might have been missed. There may be differences in findings between caregivers who participated and those we telephoned but who declined to participate.

In summary, foster caregivers in this study identified the ideal pediatric clinic environment that encourages adherence to health care appointments. This environment is an organized clinic with easy access including parking, engaged pediatric health providers, ability to reschedule appointments and an individualized and consistent appointment reminder system. Further research is needed to evaluate if a reminder system developed based on the individual preferences of foster caregivers improves appointment adherence in this population. By identifying foster caregivers who have a particularly hectic home life and making sure that they get special attention from the clinic staff and feel engaged with their child's health care plan, it may be possible to improve their pediatric appointment adherence. Pediatric nurse practitioners provide much of the primary care for underserved child populations, including children in foster care (Coddington, Sands, Edwards, Kirkpatrick, & Chen, 2011; Hapak, 2014). Pediatric nurse practitioners can help foster caregivers by making sure that the clinic environment supports their needs and by engaging caregivers in their child's health care. Attending pediatric appointments is an important part of improving the health outcomes of children in foster care, although future research is also needed on adherence to home health care recommendations.

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Table 1

Participant Descriptive Statistics (N = 28)

	Kinship (n = 13) n (%)	Unrelated (n = 15) n (%)
Race and ethnicity		
Black	0 (0.00)	1 (6.67)
Hispanic	13 (100.00)	10 (66.67)
White	0 (0.00)	1 (6.67)
Other	0 (0.00)	2 (13.33)
Not listed	0 (0.00)	1 (6.67)
Language		
English	8 (61.54)	6 (40.00)
Spanish	5 (38.46)	9 (60.00)
Gender		
Male	1 (7.69)	2 (13.33)
Female	12 (92.31)	13 (86.67)
Age ^a	44.08 (12.05)	44.13 (12.80)

^aFigures reflect $M(SD)$.