

# Challenges Faced by Latino Caregivers in Transportation of Children with Medical Complexity

Savithri Nageswaran, Aura I. Rosado, Mark S. Beveridge Jr

**BACKGROUND** Transportation challenges affect access to health care. Our objective was to describe transportation challenges faced by Latino children with medical complexity and identify strategies that could address these challenges.

**METHODS** This is a qualitative study. Seventy Latino children with medical complexity who were enrolled in a complex care program of a tertiary care children's hospital were followed for a median duration of 18 months. Qualitative data were care coordination notes for each child obtained from care coordinators' encounter logs and reported experiences. Using thematic content analysis and an iterative process, we identified recurrent themes related to transportation challenges.

**RESULTS** Caregivers of Latino children with medical complexity face many challenges transporting their children to medical appointments. These include lack of vehicle, inability to drive, lack of driver's license due to immigration status, and lack of resources to maintain a vehicle. As a result, Latino children with medical complexity often need non-emergency medical transportation, but caregivers find these systems difficult to use, in part because of language difficulties. Thus, they rely on care coordinators to access non-emergency medical transportation. Transportation problems can lead to missed medical appointments for the child and lost work for the caregiver. We identified interrelated factors that contributed to transportation issues for Latino children with medical complexity and potential strategies to address them.

**LIMITATIONS** The extent of transportation challenges cannot be discerned because this is a qualitative study.

**CONCLUSIONS** Transportation is difficult for Latino children with medical complexity, who rely on non-emergency medical transportation to access medical services. Care coordinators play a major role in addressing transportation problems for Latino children with medical complexity and their caregivers.

Latino children in the United States have poor access to health care [1-5], in part because they lack transportation to attend medical appointments [6, 7]. Children without personal transportation have a higher chance of missing appointments and delaying medical care [8]. For Latino caregivers, lack of transportation is a major reason for delayed medical care for their children [1]. Transportation problems lead to poor health care outcomes for adult patients [9-11], and these are particularly pronounced for Latinos [12, 13].

Medicaid provides non-emergency medical transportation (NEMT) to help its clients access medical appointments. States are federally mandated to provide NEMT services to Medicaid beneficiaries [14]. However, states vary in the services provided and how NEMT is administered. In North Carolina, the county Department of Social Services (DSS) acts as an agent for the state to administer NEMT; DSS contracts with private transportation agencies to provide transportation services [15]. NEMT is used predominantly by individuals with chronic illnesses [14]. NEMT users, compared to those who do not use NEMT, are more likely to attend clinic appointments for their chronic conditions [16]. NEMT use has been shown to improve access to health services for children with asthma and adults with diabetes [17]. However, NEMT is underutilized. Studies of adults using NEMT show that frailty and need for wheelchair

access limits clients' use of NEMT [9], and timeliness of service is a cause of dissatisfaction with the program [18].

Although children have transportation problems [8, 19, 20], there is limited research about use of NEMT among children. In particular, children with special health care needs face transportation problems [21-24]. Children with medical complexity (CMC), a sub-group of children with special health care needs, have many different medical conditions, need care from multiple specialists, are hospitalized frequently, and have more emergency room visits than children without medical complexity [25]. Hence, it is reasonable to postulate that Latino CMC may face especially daunting transportation issues to access medical care; however, research is limited on this topic. We conducted a qualitative research study about the care coordination needs of Latino CMC. In this study, themes related to transportation challenges emerged that we sought to explore further. The objectives of the present study are to characterize trans-

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Address correspondence to Savithri Nageswaran, Wake Forest School of Medicine, 1 Medical Center Blvd, Winston-Salem, NC 27157 (snageswa@wakehealth.edu).

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portation challenges faced by Latino CMC and their use of NEMT, and identify factors and potential strategies to address these challenges.

## Methods

This study was conducted in Brenner Children's Hospital (BCH), a tertiary care children's hospital within the Wake Forest Baptist Health system located in Winston-Salem, North Carolina, which serves a 19-county region. Approximately 4,500 children are hospitalized at BCH annually. Children included in the study were enrolled in the Pediatric Enhanced Care Program (PECP), a complex care/palliative care program started at BCH in 2008. PECP consists of an interdisciplinary team of physicians, nurses, a social worker, and a patient navigator. The social worker and patient navigator—henceforth referred to as coordinators—are bilingual. Children are eligible for PECP if they have a chronic condition that has lasted/is expected to last  $\geq 12$  months, need care from  $\geq 5$  specialists/services, or use  $\geq 2$  types of technology (eg, gastrostomy tube, tracheostomy tube). A total of 1,112 children have been enrolled in PECP since the start of the program. Demographic information of PECP enrollees is as follows: race/ethnicity (N = 960): 55% white, 21% black, 18% Hispanic, 1% Asian, and 5% other; health insurance (N = 1,066): 76% Medicaid, 8% both Medicaid and private, 15% private, and 1% uninsured; and annual household income (N = 102): 53%  $< \$20,000$ , 26%  $\$20,000$ – $\$40,000$ , and 21%  $> \$40,000$ .

The Wake Forest Institutional Review Board approved the study protocol. Children were included in this study if: they were enrolled in PECP between December 6, 2011, and December 31, 2014; their caregiver's primary spoken language was Spanish, as indicated at program enrollment; and they received services from 1 of the 2 bilingual coordinators of PECP. The coordinators' efforts were funded by 3 different grant project sources and hence were limited by those projects' inclusion criteria. As a result, the social worker served only CMC in a 9-county region around BCH, and the patient navigator served only CMC who had Medicaid. During the study period, 533 children were enrolled in PECP. Of these, 70 children (13 %) met the inclusion criteria and were included in the study cohort. We use the term "Latino CMC" to refer to this population.

### Quantitative Data

Child characteristics (demographic and diagnosis) were obtained from information in a clinical database [26] that was gathered by the coordinators at each child's enrollment in PECP. These data were exported into Excel. Diagnoses were categorized into 6 groups. US Census data were used to determine counties' population density [27]. Counties were categorized as rural, suburban, or urban based on the population density of  $\leq 250$ , 251–750, and  $> 750$  people per square mile, respectively [28]. Follow-up period was the number of days between the date of enrollment and

February 28, 2015, or date of death for children who died. Summary statistics were calculated in Excel.

### Qualitative Data

Both coordinators provided longitudinal care for children. Coordinators checked on children and caregivers in person when children were hospitalized and at clinic visits, or by phone when they were at home; these contacts occurred periodically, but not at a set frequency. Coordinators contacted other health care providers to coordinate the care of CMC. In addition, caregivers contacted coordinators by phone when they needed help. As interactions with caregivers and other health care providers occurred, coordinators entered the date of the encounter with a brief description about each encounter in an electronic database (referred to as the "encounter log"). Within the encounter log, each child had a separate section with a list of all encounters, including dates and descriptions for that child.

Textual data in the encounter log that contained care coordination tasks for each child from the time of enrollment until February 2015 or child's date of death were abstracted. One of the authors reviewed the data from the encounter log for each child with the coordinator involved in the child's care in a series of in-person interviews. During this review, existing information in the encounter logs for each child was clarified and additional information about the care coordination needs of the child was solicited. This review with care coordinators enabled us to enrich the data from the encounter logs with information obtained directly from coordinators based on their recall. Thus, care coordination needs of the child that might not have been captured in the encounter logs were identified.

Qualitative data were entered into ATLAS.ti software (Version 7.2, Berlin), a tool designed specifically for qualitative data management. Each child's encounter log, augmented by the text from coordinator review, was entered as a separate document into ATLAS.ti. Data obtained from the encounter logs and from the coordinators were delineated within each document.

Two authors reviewed the qualitative data independently. A codebook was developed based on this review and was revised as coding progressed. One author coded the data using the ATLAS.ti software, which was then reviewed by another author. Then, the authors compared and discussed each coded segment of the documents line by line until agreement on the coding scheme was reached. The final coding scheme was applied to all documents.

Qualitative data were analyzed using thematic content methods [29]. The content of each code was summarized by one author, and reviewed and validated by the other. By reviewing codes through an iterative process, recurrent themes and subthemes were derived by their prevalence and salience in the data. Both authors discussed themes until agreement was reached. Analysis for this manuscript was limited to themes and subthemes about transportation.

## Results

Characteristics of CMC are presented in Table 1. The median observation period was 535 days (18 months). Major themes related to transportation are presented below, along with illustrative quotes from coordinator notes/reviews. Numbers represent a child's unique identification number.

### *Latino Caregivers of CMC Faced Many Challenges with Personal Transportation*

Many families faced difficulty with transportation. Some families did not possess a car. In many cases, only one parent (typically the father) was available for transporting the child, either because the family owned only one car and/or only one parent knew how to drive. Since the parent who drove was also the one who worked, appointments were often scheduled around the parent's work schedule. Long work hours made it difficult for the parent who drove to bring the child to appointments. Some families used friends or other family members for transportation. In these cases, caregivers coordinated their children's medical appointments based on that person's availability. One coordinator provided this insight about child 46: "Mom doesn't drive. If there is an appointment, she has to work around her sister-in-law's kids' schedule so that she can drive her to the appointments."

Some caregivers who drove children for medical appointments lacked valid driver's licenses; several had experiences of being stopped by police and given traffic tickets. One parent was pulled over by the same police officer 3 times for driving with an expired license plate. These penalties contributed to caregivers' financial burdens.

Other problems with transportation included lack of modifications in the vehicle to transport CMC and money for gas. Several children lacked specialized car seats needed

for transportation. Specialized car seats are not paid for by insurance, but by alternative programs such as Medicaid's Home- and Community-Based Services (HCBS) [30]. Even if children were eligible to receive vehicle modification services (eg, vehicle ramp) through HCBS, they could not receive these services because their parents/family members did not have driver's licenses. Vehicle malfunctions were also a challenge; in one case, a child had breathing difficulties due to lack of air-conditioning in the car. Since personal transportation was limited and highly unpredictable for Latino CMC, many relied heavily on NEMT.

### *Latino Caregivers of CMC had Difficulties Using NEMT Services*

Latino caregivers had difficulties navigating the multiple procedures involved in accessing NEMT. At the time of Medicaid enrollment, paperwork describing NEMT benefits was sent to the child, but often families could not read or understand it. Consequently, many families were unaware of the NEMT benefits available to their children. Coordinators asked families about their transportation needs and educated them about the NEMT benefits. In some cases, caregivers asked the coordinator to explain the letter about NEMT benefits. Once a transportation need was identified, the caregiver or the coordinator contacted the county's Department of Social Services (DSS) to request services. Caregivers were required to complete a screening survey to determine eligibility administered by the DSS. Although non-English-speaking caregivers could request an interpreter to complete this survey, some did not know how to request an interpreter and instead hung up. Hence, they were unable to complete the survey and could not access NEMT. Interpreter services in the DSS were highly variable, as illustrated by this quote from the coordinator log for child 21: "I called transportation again and they state it will be a new application. I stated that mom has tried to reach transportation and left several messages but no answer. I asked to set up with interpreter to contact mom for appointment and transportation needs."

The transportation screening survey had to be completed annually; some CMC lost NEMT services for failure to complete the survey. Children whose residence was on a bus route received vouchers for travel by bus instead of NEMT. This was problematic for many reasons. Families had difficulty picking up these vouchers from DSS in person, and were often not familiar with bus schedules. Additionally, carrying CMC and their equipment to the bus stop was difficult. A Medicaid Transportation Exception Verification Form (Form 4058), completed by the child's physician, was needed for NEMT outside the county. This requirement made NEMT less accessible for CMC receiving health care services outside of their county.

Since caregivers were not automatically notified once the child was deemed eligible for NEMT, they had to call DSS repeatedly to determine the status of their child's applica-

**TABLE 1.**  
Characteristics of Children with Medical Complexity  
(N = 70)

| Characteristics                          | N (%)          |
|--|----------------|
| Male                                     | 34 (49)        |
| Female                                   | 36 (51)        |
| Age, years (median, range)               | 5 (6 mo–18)    |
| Rural                                    | 9 (13)         |
| Suburban                                 | 5 (7)          |
| Urban                                    | 56 (80)        |
| Forsyth county                           | 49 (70)        |
| Other counties                           | 21 (30)        |
| Uninsured                                | 2 (3)          |
| Medicaid                                 | 68 (97)        |
| Chromosomal abnormality                  | 15 (21)        |
| Other genetic conditions                 | 23 (33)        |
| Neuromuscular disorders                  | 8 (12)         |
| Prematurity                              | 5 (7)          |
| Anoxic brain injury                      | 11 (16)        |
| Other                                    | 8 (11)         |
| Observation period, days (median, range) | 535 (24–1,158) |
| Died during the study period             | 7 (10)         |

tion. Once eligibility was determined, the child's file was sent to the private transportation firm providing NEMT for DSS. Miscommunication during this transfer of information was common and resulted in delays in setting up NEMT. This is illustrated by a quote from the coordinator log notes for child 26: "Medicaid transportation said to call [transportation agency] to set up transportation. [Transportation agency] said patient was not in the system and to contact Medicaid transportation [DSS] so that they can fax over information to set patient up."

Once the NEMT process was set up, caregivers called the transportation agency and requested NEMT for medical appointments. Caregivers had to provide the appointment date and time, and the name, address, and phone number of the physician when requesting NEMT for medical appointments. Requests had to be made 3–5 days, but not more than 1 week, before appointments. Out-of-county transportation required a 2-week notice. This requirement was problematic when urgent appointments were needed or when personal transportation fell through. Services offered by transportation agencies were highly variable, and interpreters were not readily available. Hold time when requesting NEMT was long, sometimes lasting hours. Such prolonged wait times were difficult for caregivers with limited phone service.

NEMT rules permitted only one caregiver to travel with the child. If a home health nurse had to travel with the child, prior approval had to be obtained. Since siblings could not travel along in the NEMT vehicle, caregivers had to find child care for siblings. Car seats were required for children, and if caregivers did not have car seats or accommodations (eg, wheelchair) were not specified in advance, transportation was cancelled. Caregivers were often not familiar with these rules and hence had to forgo NEMT.

The transportation agency called the family with appointment reminders and the NEMT driver's phone number, but this information was provided in English and most NEMT drivers did not speak Spanish. Once the medical appointment was completed, the caregiver had to obtain the signature of the physician and contact the NEMT driver for pickup. There were many problems in transportation agencies picking up children at home or at the medical appointment. Caregivers had to notify the transportation agency about cancelled medical appointments. If a family did not keep 3 scheduled transportation appointments, NEMT services were cancelled. A 'no-show' was considered if the family did not answer the door for a pickup or call in advance to cancel transportation if an appointment was changed, either by the family or provider.

### **Care Coordinators Mitigated Transportation Challenges of Latino CMC**

A frequently noted consequence of transportation problems for the child was missing clinic appointments. In one case, a child missed so many medical appointments that the family was reported for child neglect. The coordinator

intervened, streamlined clinic appointments, and helped the family navigate NEMT. Also, NEMT sometimes did not pick up the child at the right time, causing late arrival at the appointment. This problem is illustrated by the following note from the coordinator log for child 47: "Mom mentioned transportation picked up late and was on her way to make her appointments. Mom in clinic but they [clinic] will not see patient because they [patient] arrived late." Delays in children being picked up after the appointments, sometimes for several hours, were also prevalent.

NEMT was limited to medical visits. Transportation to early intervention programs and other services was not covered by NEMT, thereby limiting CMC access to these services. Another problem with lack of predictable personal transportation was inability to pick up medications or difficulties in accessing supportive services (eg, parent support groups). The difficulty utilizing NEMT resulted in missed work for caregivers and added to caregiver burden. In some cases, because of the difficulty in navigating the NEMT system, caregivers without valid driver's licenses drove their children to appointments and risked legal consequences.

Arranging transportation was a frequent reason for caregivers to call coordinators. Coordinators interacted with NEMT agencies and transportation companies to problem-solve. They advocated with agency representatives for the child's transportation needs and served as a liaison between caregivers and transportation providers. They also educated caregivers about the NEMT process. Coordinators spent considerable amounts of time helping caregivers navigate the NEMT system.

*Dad attempted several times to contact transportation. He used the correct number. I called transportation and was on hold for 18 minutes before I was able to speak with a representative. I was able to set up transportation for this appointment and they will pick up patient; call took 22 min*

[Notes from coordinator log for child 47].

Coordinators also assisted caregivers with other factors that contributed to transportation problems, such as provision of gas money or arranging for a car seat.

### **Inter-Related Factors Contributed to Transportation Problems of Latino CMC**

As shown in Figure 1, multiple interrelated factors contributed to transportation problems. Although families tried to use NEMT services by themselves, many caregivers had difficulty navigating the complex NEMT process. Language barriers were a major contributing factor in difficulty accessing and using NEMT services. Paperwork was sent and phone systems were set up in English. Since interpreters were not consistently available, caregivers could not communicate with providers.

Other difficulties were caregivers' lack of literacy, health literacy, or understanding of rules and systems. Lack of a functioning telephone was another major problem. Many

caregivers had temporary phones (ie, “pay-by-the-minute” phone plans) and could not stay on hold for a long time. Furthermore, lack of legal status and related fears of deportation contributed to families’ reluctance to complete paperwork and answer phone calls. Another contributing factor to transportation challenges was lack of social support, especially regarding babysitting. One coordinator provided the following quote about child 43: “Family was unwilling to leave their many kids with babysitters because they didn’t trust them, but they couldn’t bring them to appointments because Medicaid transportation wouldn’t allow them to.”

Complexity of the child’s health condition also contributed to transportation problems. CMC sometimes needed urgent appointments for acute illnesses, and could not use NEMT in such situations. Additionally, CMC needed multiple appointments, exacerbating all the issues noted above.

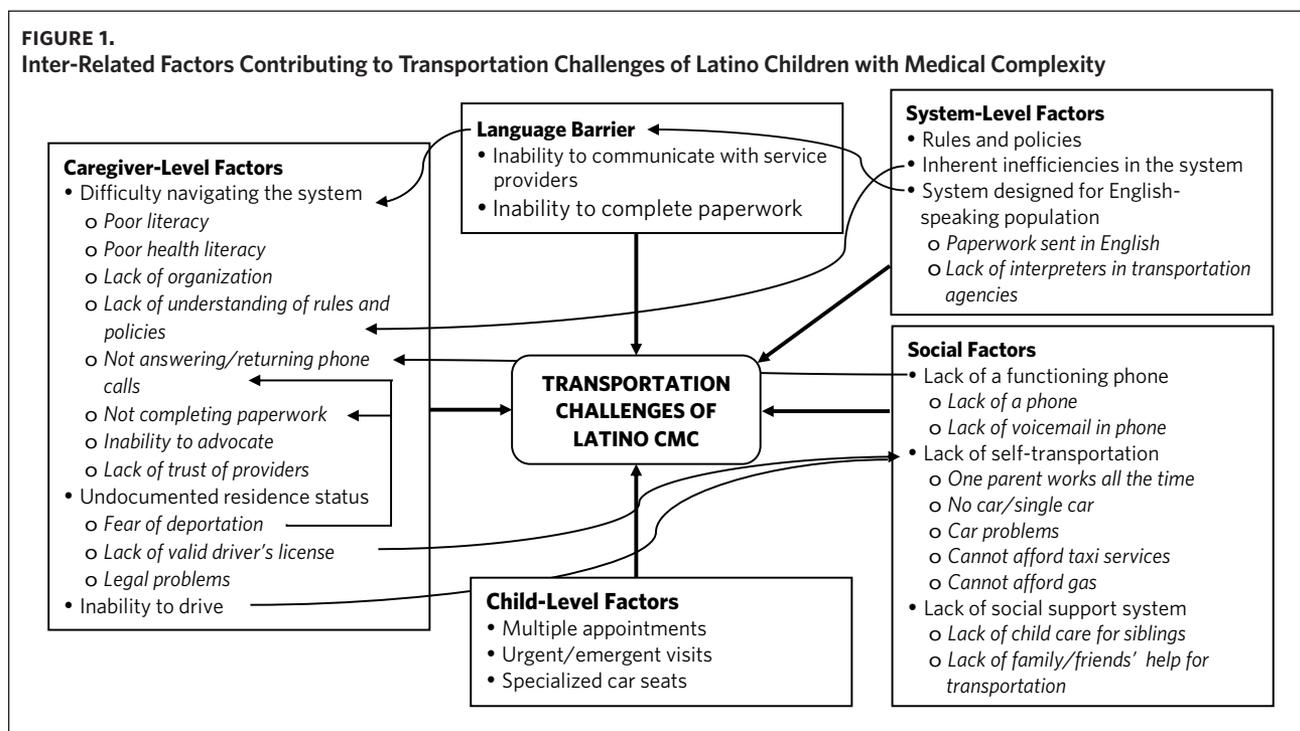
## Discussion

Our study shows that Latino caregivers of CMC in North Carolina have unpredictable personal transportation for bringing their children to medical appointments and have difficulty using NEMT. Consistent with prior research [8], we found lack of predictable transportation to be a factor in children missing clinic appointments. Missing appointments can have serious consequences on the outcomes of CMC, as these children may lose the opportunity to receive medical care that they need in a timely fashion. In addition to the negative impact on the child, transportation challenges caused caregiver burden. Our study is the first to highlight the many factors contributing to barriers in personal transportation for Latino CMC. Quantitative studies should explore the extent of these barriers.

We found NEMT to be important for Latino CMC to access medical care. Although NEMT is federally mandated for Medicaid beneficiaries, states are considering ways to cut or reduce this benefit [17]. Policies to cut NEMT services will likely further reduce Latino CMCs’ access to medical care. Although NEMT is underutilized [31], the reasons for this have attracted little research. Our study indicates that the inherent complexity in the NEMT process makes it especially difficult for Latino caregivers to navigate. Prospective studies are needed to fully understand the challenges as well as aspects that work well in the NEMT system for CMC.

A significant proportion of emergency medical services (EMS) calls are for non-emergency issues [32-34]. Half of the pediatric transport in an urban community was for non-emergency issues [35]. In another study, a majority of adult patients used EMS for reoccurring medical conditions [36]. Interestingly, use of EMS due to lack of transportation was not seen in our cohort. Coordinators’ resolution of transportation problems may have avoided use of EMS. It is possible that CMC not enrolled in a structured care coordination program such as ours may be at higher risk than those without medical complexity for using EMS for non-emergency transportation needs. Improving access to NEMT will likely reduce unnecessary use of EMS transportation.

Based on the multiple interrelated factors contributing to transportation problems for Latino CMC in this study (see Figure 1), we created a list of potential interventions targeted at multiple levels to address these challenges (see Table 2). Several of these potential interventions apply to alleviating transportation challenges of all CMC. One such intervention is to create systems in clinical settings to screen children for transportation problems. Another is



to prepare caregivers for NEMT rules, how to navigate the NEMT system, and children's rights in receiving NEMT benefits. Clinicians, especially primary care physicians, should also be educated about transportation problems, NEMT, and how to help families with the NEMT process.

While some of the factors contributing to transportation challenges and potential interventions to address them are applicable to all children, some are unique to Latino CMC. Language barriers contributed significantly to difficulties in accessing NEMT, as has been reported in accessing services for Latino children in general [1]. The NEMT system could be modified so that paperwork is in Spanish and interpreter services are more readily available. Such changes require engaging multiple community stakeholders, including health care providers (community and hospital-based), Latino community organizations, transportation agencies, and DSS, and creating community level processes to address this complex issue. The Affordable Care Act has called for demonstration programs to create accountable health communities, which create clinical-community linkages that can address health-related social needs such as transportation [37].

Finally, lack of driver's licenses is a major problem faced by Latino caregivers. Twelve states and the District of Columbia have enacted laws to provide alternative driver's licenses to unauthorized immigrants [38]. While multiple factors play into policies to provide alternative licenses [38], provision of such licenses to caregivers might alleviate problems in personal transportation faced by Latino CMC. Recent immigration policies [39] could enhance the fear of deportation among Latino caregivers and further restrict their ability to transport CMC to receive medical care.

## Limitations

Our study has several limitations. We augmented data

from encounter logs with data from coordinators; however, we may not have captured all care coordination activities. We described caregivers' experiences about transportation challenges indirectly from logs and coordinators' experiences and did not obtain data directly from caregivers. Studies that elicit caregiver perspectives on transportation will be valuable. Since this is a retrospective study, we were limited by the availability of existing data and recall of care coordinators. As such, care coordinators may not have captured all transportation challenges or documented caregivers' positive experiences with the NEMT system. Two children in this cohort were uninsured and ineligible for NEMT. Since lack of insurance is a major barrier to access to services, further research should focus on transportation challenges faced by uninsured CMC. Although our study is limited to one geographic region, the NEMT system and transportation problems for Latino CMC are likely to be similar across North Carolina. Since this is a qualitative study, the extent of personal transportation problems, use of NEMT, and problems with NEMT access cannot be quantified.

## Conclusion

Our study shows that Latino CMC in North Carolina face transportation challenges that negatively affect their health care access. NEMT helps mitigate transportation challenges, but its processes are difficult to navigate. Future research should build on the results of our study to address transportation challenges faced by this vulnerable population. **NCMJ**

**Savithri Nageswaran, MD, MPH** associate professor, Department of Pediatrics, Wake Forest School of Medicine, Winston-Salem, North Carolina.

**Aura I. Rosado, MSW** care coordinator, Pediatric Enhanced Care Program, Department of Pediatrics, Wake Forest School of Medicine, Winston-Salem, North Carolina.

**Mark S. Beveridge Jr, MD** pediatric resident (PGY2), Department of Pediatrics, Vanderbilt School of Medicine, Nashville, Tennessee.

**TABLE 2.**  
**Potential Interventions to Address Transportation Problems of Latino Children with Medical Complexity in North Carolina**

|                                       |   |
|---------------------------------------|---|
| Screen for transportation problems    | <ul style="list-style-type: none"> <li>• Create a checklist/incorporate an existing checklist to screen all families for transportation problems during clinical encounters.</li> </ul>   |
| Define care coordinators' roles       | <ul style="list-style-type: none"> <li>• Ask families about any paperwork that they received and need help understanding</li> <li>• Schedule appointments to accommodate transportation needs</li> <li>• Prepare families for accessing NEMT (below)</li> </ul>   |
| Prepare families for accessing NEMT   | <ul style="list-style-type: none"> <li>• Create Spanish language educational materials that describe rules, process, and ways to access NEMT</li> <li>• Augment health care providers' preparation of families about transportation</li> </ul>  |
| Engage clinicians                     | <ul style="list-style-type: none"> <li>• Educate clinicians about transportation problems, NEMT, and need for flexibility in appointments</li> <li>• Create a system to screen for transportation problems and facilitate paperwork completion</li> </ul>   |
| Engage NEMT providers                 | <ul style="list-style-type: none"> <li>• Clarify rules and policies, explaining problems with current system (eg, lack of interpreters, miscommunication, poor phone response)</li> <li>• Simplify the NEMT process</li> </ul>  |
| Engage waiver programs                | <ul style="list-style-type: none"> <li>• Improve wrap-around services related to transportation (eg, specialized car seat, vehicle ramp)</li> </ul>   |
| Engage Latino community organizations | <ul style="list-style-type: none"> <li>• Create support groups for families to enhance social networks</li> <li>• Foster peer-to-peer mentoring, educate families about navigating the system</li> <li>• Explore reasons for challenges faced by Latino caregivers (eg, unpredictable phone service)</li> </ul> |
| Advocate for policy changes           | <ul style="list-style-type: none"> <li>• Alternative drivers' licenses, if needed, for parents of CMC</li> <li>• Sustain Medicaid NEMT benefits for CMC</li> </ul>  |

Note. CMC, children with medical complexity; NEMT, nonemergency medical transportation.

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