

# Communication Challenges Faced by Spanish-Speaking Caregivers of Children with Medical Complexity

Savithri Nageswaran (✉ [snageswa@wakehealth.edu](mailto:snageswa@wakehealth.edu))

Wake Forest School of Medicine: Wake Forest University School of Medicine

Margaret Ellis

Levine Children's Hospital

Mark Stockton Beveridge

UT Southwestern: The University of Texas Southwestern Medical Center

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## Research article

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# Abstract

**Background:** Children with medical complexity (CMC) are at increased risk of fragmented care. Communication between caregivers and healthcare providers is important in the delivery of high-quality healthcare for children with medical complexity (CMC). Latino CMC face greater challenges in access to healthcare services. Hispanic children face greater challenges in access to healthcare services. Our objective was to describe the communication challenges faced by Spanish-speaking parents/caregivers of CMC.

**Methods:** This was a retrospective cohort study of 70 CMC enrolled in a complex care program of a tertiary care children's hospital in western North Carolina. We reviewed the care coordination tasks from encounter logs maintained by the program's two bilingual care coordinators for a median observation period of 45 months. Data were then validated by the care coordinators. Data containing care coordination tasks were entered into ATLAS.ti and coded. Qualitative data analysis was performed. Using thematic content analysis and an iterative process, we identified recurrent themes related to communication challenges of Spanish-speaking caregivers.

**Results:** Median age of children was 5 years; 51% were girls; 97% had Medicaid; and 3% were uninsured. Seven children died during the observation period. Three major themes were identified: 1) Spanish-speaking caregivers faced many communication challenges primarily because of language barrier. 2) Multiple factors at caregiver-, provider-, and system-levels, in addition to language barrier, contributed to communication challenges. 3) Communication challenges had serious consequences for CMC. These consequences were lessened by bilingual care coordinators.

**Conclusion:** Spanish-speaking caregivers of CMC face unique communication challenges resulting in negative impact on the healthcare of these children. Bilingual care coordinators can help improve communication between Spanish-speaking caregivers of CMC and their healthcare providers. Interventions to address communication challenges of Spanish-speaking caregivers are warranted.

## Background

Children with medical complexity (CMC), a subgroup of children with special healthcare needs (CSHCN), have congenital or acquired health conditions that involve multiple organ systems.<sup>1,2</sup> CMC are medically fragile, depend on technology for survival, and need many healthcare services.<sup>1</sup> Due to advances in medical care and technology, CMC are living longer.<sup>3</sup> While CMC constitute < 1% of all children, they account for 33% of healthcare expenditures for children.<sup>4</sup> CMC face many challenges with access to healthcare and are at increased risk of unmet healthcare needs.<sup>2</sup>

Parents of CMC report that the healthcare system is fragmented and difficult to navigate.<sup>5,6</sup> Research about disparities within the CMC population in navigating the healthcare system is limited. However, within the CSHCN population (of which CMC is a subgroup), difficulty using services, obtaining referrals

to specialty care, and dissatisfaction with care are more prevalent in Hispanic children compared to non-Hispanic children.<sup>7,8</sup> These disparities largely disappear when parental language is taken into account.<sup>7</sup> Parental limited English proficiency (LEP) is associated with poor healthcare quality measures for CSHCN, such as access to a medical home, and receipt of family-centered care.<sup>9,10</sup>

Spanish-speaking parents/caregivers (SSP) are less satisfied than English-speaking parents with healthcare provider communication about their children.<sup>11,12</sup> Children whose parents have LEP are more likely to experience delays in diagnosis, serious adverse events and longer hospitalizations, and are less likely to be assessed for pain or receive pain medication.<sup>13-16</sup> Because CMC have high healthcare utilization, the consequences of parental LEP are likely to be greater for these children compared to other children. However, research about the unique challenges faced by SSP of CMC is limited. The objective of this paper is to describe: (1) the communication challenges faced by SSP; and (2) the consequences of communication challenges on the healthcare received by CMC. For purposes of this manuscript, we define communication as any verbal or written interaction between parents/caregivers (henceforth referred to as caregivers) and healthcare providers about healthcare or services for CMC.

## Methods

This paper is part of a larger study about care coordination needs of CMC whose caregivers' primary language is Spanish. The methodology is described previously.<sup>17</sup> This study was conducted at Brenner Children's Hospital (BCH), a tertiary care children's hospital within the Wake Forest Health Sciences (WFHS) system located in Winston-Salem, North Carolina. Children included in the study were enrolled in the Pediatric Enhanced Care Program (PECP), a complex/palliative care program at BCH. 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 lasted/ expected to last  $\geq 12$  months, need care from  $\geq 5$  specialists/ services, or use  $\geq 2$  types of technology (e.g. gastrostomy tube, tracheostomy tube, etc.).

The WFHS Institutional Review Board approved the study protocol. Children were included in this study if: (1) they were enrolled in PECP between December 6, 2011 and December 31, 2014, (2) their caregiver's primary spoken language was Spanish as indicated at program enrollment, and (3) they received services from one of the 2 bilingual coordinators of PECP. During the study period, 533 children were enrolled in PECP. Of these, 70 (13%) children met the inclusion criteria and were included in the study cohort.

### Quantitative Data

Child characteristics were obtained from information in a clinical REDCap database<sup>18</sup> that was gathered by the coordinators at each child's enrollment in PECP. Diagnoses were categorized into 6 groups. U.S. Census data were used to determine counties' population density.<sup>19</sup> Counties were categorized into rural, suburban, and urban based on the population density of  $\leq 250$ , 251-750, and  $>750$  people per square

mile respectively.<sup>20</sup> Follow-up period was the number of days between the date of enrollment and February 28 2015, or the date of death for children who died. Summary statistics were calculated in Excel.

## **Qualitative Data**

Both coordinators provided longitudinal care for children through regular interactions with their caregivers. These interactions occurred in-person when children were hospitalized or at clinic visits, or by phone when they were at home. These contacts occurred periodically, but not at a set frequency. Coordinators contacted other healthcare providers to coordinate the care of children. Caregivers contacted coordinators by phone when they needed help. As interactions with caregivers and other healthcare providers occurred, coordinators entered the date of the encounter with a brief description about each encounter in an electronic database (referred to the “encounter log”) for each 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 extracted. One of the authors (MSB) 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, a tool designed specifically for qualitative data management.<sup>21</sup> 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 (SN and MSB) reviewed the qualitative data independently. A codebook was developed based on this review and revised as coding progressed. One author (MSB) coded the data using the ATLAS.ti software, which was then reviewed by another author (SN). 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.<sup>22</sup> The content of each code was summarized by one author (MSB or SN), 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 communication.

## **Results**

Seventy CMC were observed for a median period of 535 days (range: 24 to 1,158 days). Seven children (10%) died during the observation period. Demographic characteristics of CMC were - sex: 34 boys (49%) and 36 girls (51%); median age 5 years (range: 6 months to 18 years); insurance: 68 (97%) had Medicaid and 2 (3%) were uninsured; residence: 56 (80%) urban, 9 (13%) rural and 5 (7%) suburban. Health conditions were: chromosomal abnormality 15 (21%); other genetic conditions 23 (33%); neuromuscular disorders 8 (12%); prematurity 5 (7%); anoxic brain injury 11 (16%); others 8 (11%). Major themes identified that are related to communication are presented below. Illustrative quotes from care coordinator interviews/ notes of care coordinators are in italics. Numbers represent a child's unique identification number.

### **Theme 1: Spanish-speaking caregivers of CMC faced many communication challenges, primarily because of language barrier.**

Most caregivers faced challenges in communication with healthcare providers. Language barrier was an important contributor of challenges to in-person, telephone, and written communications.

In the hospital and clinic settings, in-person or telephone interpreters were used by healthcare providers; but this did not occur consistently. Interpreters were not readily available in community agencies (e.g. pharmacy, home health nursing agency, equipment company etc.). Without interpreters, caregivers communicated by resorting to gestures, or soliciting the help of English-speaking family members.

*Patient's parents don't speak much English, so at first they communicated with their providers mostly through hand gestures.* [Coordinator quote about C08]

Phone calls to and from healthcare providers or agency representatives were frequent sources of miscommunication for families. Phone messages were most often left for families in English. Caregivers did not understand the messages and were not able to call back for clarification. Interpreters were used infrequently for phone interactions and, as such, caregivers were often confused about the content of the phone calls. Caregivers also experienced difficulty when making phone calls to providers because those who were answering the phone were English speakers. Additionally, they had difficulty navigating the phone instructions and prompts in English. Caregivers did not feel empowered to request an interpreter if one was not offered. In some cases, even if caregivers requested interpreter help for phone communication, this service was not provided.

*Language played a role in the pharmacy issue; mother cannot get interpreters to call her back to refill a prescription* [Coordinator quote about C06]

*Mother receives a call from Equipment Company in English, confused about the meaning* [Encounter log for C17]

Language barrier was also a significant problem in written communications. Medication instructions were sometimes provided in English. Caregivers received appointment reminders or other documents in English and were not always able to decipher them. Other times, results of tests and procedures were sent

to families in English. Caregivers could not comprehend letters and paperwork about benefits including Social Security, Medicaid forms or expiration letters, application for camps, and Medicaid waiver program applications.

*Mother receives letter in English from Social Security, tries calling to get an interpreter, but cannot do so successfully [Encounter log for C01]*

**Theme 2: Multiple factors at caregiver-, provider-, and system-levels, in addition to language barrier, contributed to communication challenges.**

Practical factors contributed to communication challenges. Many caregivers used go-phones or pay-by-the-minute numbers; therefore, their phone numbers changed frequently. Oftentimes, a single phone was shared between multiple family members. In some cases, the phone number listed in the Electronic Medical Record (EMR) was not accurate. This resulted in healthcare providers and agency representatives not being able to contact caregivers reliably. In addition, some phones did not have voicemail option available. Sometimes families did not return voice messages left on their phones.

*Patient's father works at a distance from family, has the only cell phone, makes the family difficult to contact [Encounter log for C03]*

*Equipment companies have a difficult time getting in touch with mom because of lack of reliable phone number [Coordinator quote about C11]*

Other caregiver-level factors that affected communication were caregivers' poor health literacy, lack of trust of healthcare providers, and inability to navigate the healthcare system. Families with poor health literacy were confused by instructions and did not follow them as a result. This resulted in children not receiving medications according to instructions on the prescription.

*Mother often misses appointments because she is not literate, cannot read the reminders [Encounter log for C20]*

*Family is very shy, and won't ask questions of doctors directly; they ask questions only through the coordinator [Coordinator quote C24]*

Some caregivers did not understand the prescription refill system; they thought that they had to have another prescription instead of going directly to the pharmacy for refills. As a result, refills were delayed or missed. For controlled substances when identification was required by pharmacy, caregivers felt as though they were being discriminated against and did not understand that the system required identification for obtaining a controlled substance. Caregivers did not understand healthcare rules and regulations such as prior-authorization requirement for medications or procedures.

*Mother thought she was being discriminated against because she was made to show passport to get medication [Coordinator quote about C17]*

Several provider-level factors that contributed to communication problems were also identified. Pharmacies did not use interpreters either for their phone calls or when labeling their medications after purchase. When families attempted to call the pharmacies for refills they were unable to communicate and therefore the refills were delayed. Surgeries and procedures were not explained resulting in misunderstanding about or delay in procedures.

*Mom calling because she never received a call about test results* [Encounter log for C61]

*Pharmacy gives 30-day supply instead of 90-day supply, pharmacy's mistake; once new prescription written mother was not notified* [Encounter log for C02]

### **Theme 3: Communication challenges had serious consequences for CMC. These consequences were lessened by bilingual care coordinators.**

The consequences of communication issues varied but affected both CMC and their caregivers. A common problem identified was missed appointments. When appointment reminders were sent or voice messages left in English, children missed these appointments. When there were appointment conflicts, caregivers were unable to call providers' offices to reschedule these appointments.

*Patient missed appointment because they never received a call from [specialty] clinic* [Encounter log for C01]

*Mom missed appointment because she did not know the time* [Encounter log C04]

Medication issues were another common consequence of miscommunication or misunderstanding. CMC experienced delayed or missed refills because of caregivers' lack of understanding of the system or inability of the caregiver to communicate with the pharmacy. Incorrect administration of medication, and failure to administer medication were also seen.

*Patient has gone for months without supplies because mother didn't know who to call* [Coordinator description about C17]

*Patient took medication incorrectly because family spoke with a non-Spanish speaking nurse, causing a misunderstanding about how it is taken and when* [Coordinator description about C19]

Communication challenges resulted in missed or delayed services for some children. Children did not receive health and support services they were qualified for, such as Early Intervention Services or special camps for CMC. One child had a surgical procedure delayed for months due to a miscommunication between the surgical team and the caregiver. Due to misconceptions about helpfulness of the procedure, one family missed multiple appointments delaying a diagnosis of seizure and appropriate seizure control for their daughter. Caregivers' inability to complete paperwork needed to obtain services resulted in missed or delayed services for children.

*Mom was not responding to letters written in English asking her for supplies she needed, and consequently she stopped receiving supplies [Encounter log for C06]*

Caregivers were unable to advocate for services for their children secondary to the language barrier. Caregivers experienced stress as a result of communication challenges surrounding the care of their children. Communication problems contributed to lack of caregiver trust of providers that resulted in less adherence to medical instructions.

*Mom concerned about patient, but cannot contact PCP because of language barrier, since she cannot negotiate Spanish line [Encounter log for C29]*

*Family was buying formula that should have been paid for because they could not negotiate the process. [Encounter log for C38]*

Bilingual care coordinators identified caregivers' communication challenges and served as intermediaries in communication between caregivers and healthcare providers. They also helped caregivers navigate the healthcare system. Involvement of care coordinators mitigated the consequences of communication problems for families.

*Care coordinator assisted mom in reading 2 letters, one from Social Security and the other from Medicaid transportation [Encounter Log for C26]*

*Mother calls to verify time and place of appointment [Encounter log for C13]*

## **Discussion**

We found that SSP of CMC faced challenges with in-person, telephone and written communications due to language barrier. Many previous reports have shown the importance of language barrier as a factor in children of SSP not receiving good communication and needed healthcare services.<sup>10, 14, 15, 23, 24</sup> Some of the healthcare communication challenges are mitigated by the use of medical interpreters.<sup>16, 24, 25</sup> However, in our study, caregivers had difficulty accessing interpreters in community settings, such as pharmacies. In a survey of pharmacists, only 55% were satisfied with their communication with patients with LEP; a large majority did not have access to interpreters.<sup>26</sup> Interpreters are more likely to be available in hospitals or hospital-based clinics; even in these settings, visits for Spanish-speaking families were frequently conducted in English.<sup>11, 24</sup> Machine translation is increasingly available and has the potential to address the challenges of language barrier in healthcare communications.<sup>26</sup>

In addition to language barrier, our study showed that other factors at the caregiver-, provider- and system-level, contributed to the communication challenges experienced by SSP of CMC. Poor health literacy may be an additional barrier faced by Hispanic families. Hispanic families were less likely to understand their children's diagnosis, medications, treatment, and follow-up instructions than proficient English speakers.<sup>27, 28</sup> Even among those comfortable speaking English, only 50% of Hispanic caregivers

administered medication correctly after reading the drug instruction sheet.<sup>28</sup> Cultural differences between Hispanic families of children with serious illnesses compared to their counterparts also contribute to healthcare communication challenges.<sup>29,30</sup> System-level factors – providers sending forms, letters, and instructions, and leaving phone messages in English – made it difficult for SSP to access services for their CMC. This is because the healthcare system is designed for English-speaking patients. For example, during the recent coronavirus pandemic, when telehealth services were expanded, we observed that the process to access telehealth in our institution was available only in English; this made it difficult for CMC of SSP to receive telehealth services. Healthcare institutions and programs should consider the needs of SSP when structuring systems and processes.

Poor communication had consequences for CMC including missed clinic appointments, delay in getting needed services, and medication non-adherence. Our findings are consistent with prior research that showed delays in diagnosis and treatment of children whose parents had LEP.<sup>13-16</sup> Bilingual care coordinators played a key role in mitigating the consequences of parental communication challenges for CMC. Prior studies have reported the difficulties faced by SSP in navigating the health system for their children.<sup>29,31</sup> Hispanic mothers with LEP reported care coordination as a strategy to improve the quality of primary care, and valued ongoing relationships with providers.<sup>32</sup> In a randomized controlled trial, Flores et al showed that bilingual care coordinators with specialized training facilitated SSP to obtain health insurance for their children.<sup>33</sup> National organizations have recommended that CMC have access to an interdisciplinary care team that can address the unique needs of CMC and their families.<sup>34</sup> Inclusion of coordinators, in teams caring for CMC, with expertise in helping SSP could be a strategy to address the unique needs of these children.

Our study has certain limitations. Because of the qualitative nature of this study, we were unable to quantify the extent of the communication problems faced by SSP and their impact on CMC. Since this study is regional in scope, the experiences of SSP may not be representative of all caregivers of CMC in the U.S. Although the data from encounter logs was augmented with data from interviews, qualitative data may not have captured all care coordination activities. We did not obtain information directly from caregivers. Caregiver perspectives on communication will be valuable to identify communication challenges as well as potential solutions.

## **Conclusion**

SSP of CMC face many communication challenges that negatively affect access to and quality of health services for these children. The role of care coordinators in addressing these challenges is worth further evaluation.

## **Abbreviations**

CMC: Children with Medical Complexity

SSP: Spanish-speaking Parents/Caregivers

LEP: Limited English Proficiency

WFUHS: Wake Forest University Health Sciences

BCH: Brenner Children's Hospital

CSHCN: Children with Special Healthcare Needs

PECP: Pediatric Enhanced Care Program

## Declarations

**Ethics approval:** The Wake Forest Health Sciences Institutional Review Board approved the study protocol. This manuscript reports aggregate data and does not report private information from any one individual.

**Availability of Data:** The qualitative dataset generated and/or analyzed during the current study are not publicly available because of the potential for compromising privacy of individuals, but summarized data are available from the corresponding author on reasonable request.

**Conflict of Interest:** None

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### **Authors' Contributions:**

SN conceptualized and designed the study, analyzed the data, and interpreted the results, drafted the manuscript, approved the submitted version, and agreed to be personally accountable for the authors' contributions and the accuracy or integrity of any part of the work.

MBE interpreted the results, conducted literature review, revised the manuscript, approved the submitted version, and agreed to be personally accountable for the authors' contributions and the accuracy or integrity of any part of the work.

MSB collected data, analyzed data, interpreted the results, revised the manuscript, approved the submitted version, and agreed to be personally accountable for the authors' contributions and the accuracy or integrity of any part of the work.

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