Panorama

Patient-Provider Communication in Pediatric Rheumatology: A Narrative Review and Presentation of Pilot Data

Rebecca Trachtman MD, MS, Assistant Professor, Julie Samuels BA, Research Coordinator, Emma Wojtal MSN, CPNP, Nurse Practitioner, Department of Pediatrics, Icahn School of Medicine at Mount Sinai, New York, New York, USA; Brian M. Feldman MD, MSc, FRCPC, Professor, Department of Paediatrics, The Hospital for Sick Children/University of Toronto, Toronto, Canada. Address correspondence to Dr. R. Trachtman, 1 Gustave Levy Place, NY, NY 10029, USA. Email: Rebecca.trachtman@mssm.edu. The authors declare no conflicts of interest relevant to this article. This study was approved by the Icahn School of Medicine at Mount Sinai Institutional Review Board.

The importance of communication in medical care has been recognized for decades. Communication skills have been considered a core competency by the Accreditation Council for Graduate Medical Education since 1999, illustrating its critical role in medicine and healthcare delivery in the United States. Although it is widely accepted that quality patient communication can improve patient satisfaction and disease outcomes, evidence about how to communicate effectively is lacking. Further, there is no true consensus on what defines good communication in medicine.

Communication in pediatric medicine is particularly complicated, as healthcare providers must navigate communication with both children and their parents or caregivers. Prior research in neonatal intensive care has demonstrated that despite its importance, little is known about communication in this context. In addition, research in pediatric oncology has investigated the core purpose of communication in the field and has shown that improved communication has been associated with increased hope, decreased regret, and improved psychosocial outcomes. Conversely, several studies have illustrated that across fields, children feel that they do not participate in their health care as much as desired, a reality that can be linked to provider communication styles and strategies. Therefore, further research is needed to assess and improve communication, to improve health outcomes in children.

In pediatric rheumatology practice, the importance of understanding and improving communication is evident. This population is varied, and includes many children with complex chronic disease processes, necessitating clear and effective communication. However, there is a paucity of data regarding communication. Though a small number of studies have begun to investigate communication quality in pediatrics, there is not a universally agreed upon, validated, comprehensive measure of communication quality that has been evaluated and used in the pediatric rheumatology population.

For that reason, we present here a narrative review, as well as pilot data about communication in our pediatric rheumatology practice. This review is not intended as a comprehensive systematic review; rather, it is intended as a brief exploration and presentation of pilot data using the Communication Assessment Tool (CAT), which we hope will highlight directions for future study.

We sought to identify all studies that examine communication quality, as well as measures of communication quality, to understand the current state of research in this area and support future work. We focused on patient- and parent-reported measures, rather than measures using direct observation of communication. We did this to identify measures that would be practically applicable in the context of clinical trials of communication interventions.

To identify available studies and measures, we reviewed the current literature in PubMed. We expanded our identification methods to find measures specific to pediatric rheumatology contexts. We searched the literature using the terms listed in the Figure. We also reviewed references from relevant articles identified through this search. It is important to note that this was not a systematic review; however, we present our findings to identify a gap that requires further investigation.

Between October 27 and December 22, 2022, a consecutive sample of children and adolescents were recruited from the pediatric rheumatology clinic at a single academic center during a standard of care visit. Inclusion criteria included any English-speaking patient with a follow-up appointment.

Data collected at the study visit included the following: demographic data, medical history, physical examination, Patient Reported Outcomes Measurement Information System Pediatric Global Health Measure 7 (PROMIS PGH7), Connor Davidson Resilience Scale 2 (CD-RISC 2), and CAT (Figure). Importantly, the CAT is a 14-question instrument for measuring patient perceptions of physicians’ communication skills. Designed for a Grade 4 reading level, the CAT has been shown to be both a reliable and valid instrument for assessing physician performance. PROMIS PGH7 results are reported as t-scores ranging from 1 to 100, with 50 being the US population mean and a standard deviation (SD) of 10. Higher scores represent better self-reported global health. CD-RISC 2 scores range from 0 to 8, with higher scores indicating higher resilience. CAT scores range from 0 to 5, representing the average of all 14 responses, with higher scores indicating higher-quality communication.
All questionnaires were completed by children aged ≥ 9 years, and by a parent for children aged 1 to 8 years; this was prespecified to standardize data collection based on expectations of children at those ages. All surveys were administered and managed using Research Electronic Data Capture tools hosted at the Icahn School of Medicine at Mount Sinai.

We first analyzed each item of the CAT separately using mean and SD, as well as median and IQR. We then analyzed the score for the entire CAT. PROMIS PGH7 raw scores were converted to \( t \) scores using standard software. A change of 0.5 (at least one-half SD) from the general population mean is considered clinically meaningful. Correlations between the CAT and all other measures, as well as patient-specific factors, were assessed using Spearman correlation coefficients. We report the correlation coefficient, or \( r \) value, which represents the magnitude of correlation, as well as the \( P \) value, which represents statistical significance. \( P \) value is set to < 0.05 for all analyses.

We queried PubMed, which yielded 307 unique results, only 2 of which were relevant to communication quality in the pediatric rheumatology context. In total, we found 9 validated communication instruments; however, only 2 instruments met our search criteria, relied on patient or caregiver report, and were developed to measure quality of communication and/or satisfaction with communication with pediatric patients or their caregivers: these were the CAT and the Pediatric Quality of Life Inventory (PedsQL). The CAT is described above, and the PedsQL is a measure of parental satisfaction with health care provided to patients with acute and chronic health conditions. The results of the literature review are detailed in the Figure.

The CAT was completed by 41 of 56 families approached, 31 of which were children and 10 of which were parents of younger children. The children were predominantly girls (68%) with a median age of 15 (IQR 9-17) years. Twenty-nine percent were White, 52% were Hispanic, and 66% had Medicaid insurance. The median PROMIS PGH 7 score was 48.4 (IQR 40.3-53.3) and the median CD-RISC 2 score was 6 (IQR 4-6), both of which are consistent with population means for overall well-being and resilience.

The mean for all CAT items ranged from 4.78 to 4.85, aside from the item, “The doctor talked in terms I could understand,” which had an average score of 4.59. The entire CAT had a mean score of 4.78 (SD 0.38) and a median score of 5 (IQR 4.79-5). Correlations between the CAT and all other instruments, as well as patient-specific factors, were performed (Table). The only statistically significant correlation was between CAT and sex, with females scoring higher on the CAT.

Although prior studies have investigated communication in medicine, ours is the first that we know of to assess communication in pediatric rheumatology, both through retrospective literature review and collection of pilot data using the CAT. The limited literature that exists suggests that there is substantial room for improvement in communication quality, particularly in terms of accessibility of information to patients and ensuring that children feel both safe and engaged in healthcare conversations. Further, studies have shown that improved communication leads to improved patient adherence and satisfaction. Finally, our literature review uncovered the CAT as a potentially useful tool to measure patient perception of communication quality.
We found that in general, communication in our pediatric rheumatology practice is perceived as high quality by patients, as evidenced by the high CAT mean score. However, the percentage of scores of 5 was lower than in the original paper, and the item regarding using understandable terms had a lower average score. This highlights that there remain areas for improvement in communication in the pediatric rheumatology setting. In addition, although there were few statistically significant correlations between the CAT and other measures or patient-specific factors, the CAT did have a statistically significant correlation with sex, with females perceiving communication quality to be higher. Interestingly, the majority of our providers are female, so further exploration is required to determine the cause of lower scores in males, and whether this may be a result of different communication styles or intrinsic biases.

A strength of our study is that this is the first study that we know of to evaluate communication in a pediatric rheumatology context. We have completed both a narrative review and collected pilot data using the CAT, in order to show the current state of communication in our field and highlight future areas for study.

Limitations of this study include a relatively small sample size at a single center. It is important for future studies of communication to assess larger, multicenter populations through prospective data collection. Further, additional research is needed to assess the drivers of high and low communication quality in pediatric rheumatology and improve communication quality in this population.

REFERENCES