

Feature

Epistemic Justice and the Structural Silencing of Linguistically Diverse Parents

Jennifer Needle-Suarez

ABSTRACT

Pediatric healthcare encounters are inherently communicative acts that depend on the exchange of knowledge, trust, and understanding between careproviders and parents. Yet, for families with non-English language preference (NELP), these interactions occur within systems that may privilege biomedical expertise as they systematically devalue parental knowledge. In this article I explore the concept of epistemic injustice and how it manifests structurally and interpersonally in pediatric care. Institutional workflows, time pressures, and underinvestment in interpreter services can amplify these injustices and transform language barriers into epistemic silencing. These dynamics not only can impede the process of informed consent and shared decision making, but can generate moral distress among clinicians and lasting mistrust among families.

THE CASE OF AMIRA

Amira is a nine-year-old girl with advanced congenital heart disease. (The case is hypothetical.) Amira's family recently immigrated from

Somalia to the United States and primarily speak Somali at home. Amira's parents speak a little conversational English and have limited familiarity with the US healthcare system. They hold deep religious and cultural beliefs about illness, healing, and family responsibility.

Amira presented to the emergency department in severe heart failure. On arrival, a professional Somali interpreter was not available onsite. A telephone interpreter was offered, but Amira's father felt uncomfortable with the impersonal format and declined. He insisted he could communicate "enough" in English. The medical team, pressed for time, agreed to proceed without an interpreter.

The cardiology team recommended urgent initiation of mechanical extracorporeal circulatory support (ECMO) as a bridge to either recovery or evaluation for transplant. The risks, benefits, and alternatives were complex, and the window for decision making was narrow. The parents nodded during the explanation, but did not ask questions. The team interpreted the parents' nodding and lack of questions as understanding and consent.

The parents left the conversation with an understanding that ECMO is a short-term treatment that would cure Amira's heart condition. They did not realize it was invasive, carried high

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risk, and was not a definitive cure. They did not fully understand the risks, and they were unprepared for the possibility of complications or death. Amira was placed on ECMO but developed a catastrophic brain hemorrhage 48 hours later. The parents were shocked, devastated, and distrustful. They accused the team of hiding information and not telling them the truth.

The medical team discussed withdrawal of ECMO. The family insisted that stopping was an unacceptable option, as it would cause her death. An in-person interpreter was present for the discussion and pulled the team aside afterward. She explained that the family did not understand that this was a possible complication of ECMO when they agreed to it. The situation escalated into conflict, which caused significant moral distress among the team and necessitated the involvement of the ethics service.

INTRODUCTION

Pediatric healthcare encounters are fundamentally communicative acts, in which careproviders and parents negotiate meaning, share knowledge, and make decisions under conditions of uncertainty. However, these interactions are shaped by profound power asymmetries, institutional constraints, and cultural norms that systematically privilege certain forms of knowledge and marginalize others. *Epistemic injustice*, defined by Fricker as “harm done to someone in their capacity as a knower,” can arise when patients’ and families’ lived experiences, narratives, or cultural frameworks are dismissed, undervalued, or excluded from clinical reasoning.¹ These injustices can undermine trust, exacerbate inequities, and contribute to moral distress among patients and families and their careproviders. Pediatric encounters are unique because children often cannot fully articulate their own symptoms, which makes parents and guardians the primary epistemic agents. When patients’ and families’ accounts are discounted, the consequences can be particularly severe.

This article expands on a conceptual framework of epistemic injustice in healthcare. I high-

light how systemic structures, provider-level behaviors, medical culture, and institutional workflows can interact to diminish the credibility of parents of hospitalized children, particularly those with non-English language preference (NELP). Finally, I examine the consequences of epistemic injustice for patients and clinicians and consider pathways toward more equitable and just healthcare encounters.

THEORETICAL FRAMEWORK: EPISTEMIC INJUSTICE IN MEDICINE

Fricker distinguished between two forms of epistemic injustice: *testimonial injustice*, which describes how a speaker’s credibility can be unfairly reduced, and *hermeneutical injustice*, which describes how gaps in collective interpretive resources, on both the individual and structural levels, leave a person unable to make sense of their own experience.¹ Both types of injustice occur regularly in healthcare. Medicine is particularly prone to epistemic injustice because professional training and hierarchies can privilege biomedical knowledge and devalue subjective accounts. An extra layer of risk of *epistemic silencing* exists in pediatrics because knowledge is filtered not only through providers and systems, but also through parents and guardians.

Testimonial injustice can arise when patients are disbelieved or discounted due to stereotypes. For example, parents of children with complex medical needs are often primary witnesses to their child’s daily symptoms and responses to treatment, but their concerns about symptoms or a treatment may be dismissed when they do not align with medical data. In these situations, parents are seen as communicators of their child’s illness experience and, at the same time, often treated as unreliable informants. This creates a significant vulnerability to testimonial injustice.

Hermeneutical injustice occurs when patients lack the conceptual tools to articulate their suffering in medically recognized terms, or when cultural meanings of illness are invisible within biomedical frameworks.² In Amira’s case, when the cardiology team recommended

ECMO, Amira's parents nodded politely but understood ECMO as a curative treatment, not as a risky, invasive bridge therapy. Their cultural background emphasized hope, faith, and deference to authority, but the system offered no space or resources to help them integrate those beliefs with medical decision making. In pediatrics, epistemic injustice can directly intersect with questions of justice, autonomy, and beneficence. Amira's parent's voices were structurally constrained, and thus their capacity to fulfill ethical obligations to advocate for their

reimbursement for the provision of language services.⁵ As a result, hospitals may view interpreter services as ancillary compliance costs rather than as essential to high-quality care, which makes services vulnerable to budget cuts and underutilization.⁶ This disconnect between legislative intent and clinical reality can produce conditions in which NELP families who navigate the care of children with complex medical needs are unable to communicate their lived experiences or participate fully in decision making. Parents' voices are central to con-

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child were compromised, which raises questions of fairness and distributive justice.

STRUCTURAL AND SYSTEM-LEVEL CONTRIBUTORS

Healthcare is organized through institutional structures, policies, and workflows that can perpetuate epistemic injustice. On an institutional level, hospitals and clinics are governed by protocols that emphasize efficiency, liability protection, and standardized documentation. While necessary for safety and accountability, these structures can limit opportunities for narrative-based care.

LANGUAGE ACCESS

Although Section 1557 of the Affordable Care Act mandates "meaningful access" to interpreter services, the regulation's limited enforcement mechanisms and lack of reimbursement pathways result in chronic underfunding and inconsistent implementation.^{3,4} A 2013 report by the National Health Law Program found that only 3 percent of hospitals received direct

textualizing illness and shaping values-based care. Inadequate language access does not simply risk miscommunication, but can structurally silence families.

Lack of access to trained, in-person medical interpreters can further diminish the voices of patients and families. Since the COVID-19 pandemic, remote methods of interpretation have left providers and patients with forms of communication that are often technologically flawed and lack personal connection.⁷ Despite their reliance on remote forms of interpretation in most clinical environments, many providers lack confidence in interpretation for high-acuity communication, such as at the end of life.⁸ This gap leaves patients with NELP vulnerable to miscommunication, exclusion, and reduced credibility.

EVIDENCE-BASED PRACTICE AND INFORMATIONAL POWER

While it is central to modern medicine, evidence-based practice can reinforce testimonial injustice when it situates certain kinds of evidence as inherently more credible than others.

Testimonial injustice can occur when a speaker's knowledge is unfairly discredited, or the credibility of lived experience is questioned over "objective" scientific data. A parent's close observation of their child's subtle changes may be disregarded because those forms of knowledge do not align with the standards of evidence-based medicine. This dynamic is particularly evident in cases when patients report symptoms that are not easily quantifiable or do not fit established diagnostic criteria, which can cause their experiences to be undervalued or dismissed.

Furthermore, an emphasis on standardized clinical guidelines and protocols in evidence-based practice can marginalize individual patients' narratives, especially when a narrative conflicts with an established medical model.⁹ Such marginalization can be compounded for patients who are from linguistically diverse backgrounds, as language barriers can further hinder the recognition and validation of their experiences. The reliance on interpreters, whether professional or familial, introduces additional complexities, as the nuances of a patient's testimony may be lost in translation, leading to potential misinterpretations and further epistemic injustice.

The medical record not only reflects, but can construct reality in healthcare. Providers' language choices in documentation can undermine patients' credibility—for example, describing a patient as "noncompliant" without acknowledging systemic barriers. Such records perpetuate epistemic injustice across encounters, as subsequent providers inherit biased framings.¹⁰ Providing patients access to medical notes is one mechanism to reduce epistemic exclusion and is viewed by providers as a way to promote patients' participation in their care.^{11,12}

A paradigm shift in medical practice that values patients' testimony as a legitimate form of evidence is needed to address these issues. This approach involves the integration of patients' narratives into clinical decision-making processes, to ensure they are given equal weight alongside biomedical data. Such a shift would not only enhance the quality of care, but promote a more inclusive and equitable healthcare

system that recognizes the epistemic contributions of all patients, regardless of their linguistic or cultural backgrounds.

PROVIDER-LEVEL CONTRIBUTORS

Gatekeeping, intentional or not, is one way that epistemic injustice occurs and can be perpetuated (as described in the table). Patients' entry into a healthcare system begins with their sharing their embodied experience, which is informed by their cultural narrative and the individual way they understand their experience. Providers, by virtue of the structure of the healthcare system and their privileged position in it, have the power to determine what information is clinically relevant, what actions need to be taken, and the pace at which they need to occur. Physicians' gatekeeping is not limited to overt disbelief or bias. It can be the product of, and manifest as, structures that prioritize biomedical data and rely on rigid clinical guidelines and metrics-motivated, time-pressured encounters that leave little room for narrative or culturally mediated forms of knowledge. This gatekeeping can inadvertently perpetuate inequities, particularly for NELP families, which raises epistemic and ethical concerns about fairness, autonomy, and the best interests of the child.^{1,13}

The gatekeeping of information is particularly pronounced in high-stakes pediatric contexts such as neonatal (NICU) and pediatric intensive care (PICU), where clinicians often possess significantly greater decisional power than family members do.^{14,15,16} In these settings, physicians must make rapid, life-altering decisions under conditions of uncertainty, which can unintentionally marginalize parents' voices. Providers may perceive themselves as balancing parental authority with the child's rights and best interests, yet, in practice, a power imbalance often results in the use of biomedical reasoning or established clinical guidelines that can reduce the power of parents' beliefs. Fast-paced, high-acuity environments can leave limited time for providers to explore parental goals, cultural values, and understanding of risk, which can privilege medical expertise over

Gatekeeping as a Contributor to Epistemic Injustice in Pediatric Settings

Clinical Context	Example	Testimonial Injustice	Hermeneutical Injustice
Language and communication systems	Provider skips interpreter for “quick” updates Simplifies communication with only yes/no questions	Parents’ testimony discounted as less necessary Parental contributions perceived as incomplete	Without interpreter mediation, parents lack linguistic resources to make lived experience intelligible in medical decision making Interpreters treated as ancillary as opposed to care team members
Clinical documentation	Only “objective” findings recorded in the chart Subtle parental observations omitted from the chart Limited documentation of interpreter use	Experiential knowledge seen as less credible than “data” Parents’ accounts dismissed as “subjective” or “emotional” Consistent use of interpreters diminished	Electronic health records/templates lack categories for relational/cultural knowledge Notes often lack relational information Lack of integration of interpreters as part of the care team
Rounds and care conferences	Providers talk in shorthand with colleagues, then summarize to parents Providers report objective data with limited contextualization	Parents receive a credibility deficit—treated as passive listeners rather than contributors Perpetuating epistemic privilege by use of “medical language”	Parents cannot fully access or respond to the medical discourse, limiting shared understanding
Time-constrained clinical encounters	Time limits cut off parental narratives Child not directly addressed	Parental insights downgraded in favor of efficiency Child’s perspective ignored	Parent is powerless to control communication Pediatric frame privileges parent/provider voices, leaving child’s experiential knowledge unexpressed
“Best interest” decisions	Providers treat parental reasoning as emotional versus their own “objective” biomedical stance	Clinicians’ knowledge is privileged while parents’ testimony is discounted as biased or emotional	Cultural/spiritual/religious frameworks that shape parental decisions don’t fit biomedical categories, leaving their reasoning unintelligible
Diagnostic workups	Parent’s “gut feeling” not pursued until labs confirm something	Parental expertise in recognizing early signs of illness dismissed	Experiential, embodied knowledge doesn’t fit biomedical categories and remains marginalized

lived experience. Reliance on evidence-based predictions of “poor” outcomes can reinforce this, and grant clinicians not only the authority to define medically appropriate options, but also the power to judge parents’ choices.^{17,18}

Gatekeeping under time pressure may lead to forgoing the use of interpreters. In Amira’s case, one can imagine myriad preferable ultimate outcomes that would likely have occurred in Amira’s case if an interpreter was used in

trained interpreters is not only a practical communication tool, but is a moral imperative to avoid epistemic harm.

The use of relational interpreters in health-care communication (such as bilingual family members, friends, or nonclinical staff) is common in pediatric settings, despite professional guidelines that discourage their use based on concerns about accuracy, confidentiality, and potential bias.^{17,26} There is evidence that rela-

Efforts to improve interpreter use in the PICU, such as standardizing technology, standardizing placement of interpretation devices in patients’ rooms, and educating providers, have been successful.

the discussion of ECMO. Despite data that indicate that the use of professional interpreters can improve communication (errors and comprehension), clinical outcomes, and satisfaction that approaches levels of satisfaction for English-speaking patients,¹⁹ the routine use of professional interpreters in pediatric settings remains low (40 to 50 percent).²⁰ Providers often make deliberate choices about the use of professional interpreters, in their use in general and the particular modality of interpretation, based on time constraints and acuity of information.^{21,22,23} Providers may use bilingual staff, family members, or gestures instead of trained interpreters, especially when they feel time pressure or perceive the clinical interaction as “simple,” and so lower their communication standards with NELP patients and families. Trainees describe the “hidden curriculum” in healthcare that offers poor role models in appropriate and ethical engagement with interpreters.²⁴ Efforts to improve interpreter use in the PICU, such as standardizing technology, standardizing placement of interpretation devices in patients’ rooms, and educating providers, have been successful.²⁵ The routine use of

tional interpreters can play complex roles beyond literal translation, including contextualizing medical information, advocating for patients, and facilitating relational trust between families and clinicians. When this happens, patients may be more able to articulate their experiences, clarify concerns, and participate more fully in shared decision making, particularly when standard clinical communication does not account for linguistic or cultural differences.^{1,27,28} However, reliance on nonprofessional interpreters can introduce risks of omission or filtering, which underscores the need to balance relational benefits with accuracy and professional standards of interpretation.²⁶ Conversely, some literature reports that relational interpreters serve as critical cultural bridges in contexts when linguistic and cultural discordance might otherwise silence patients’ voices, and may contribute to more equitable health-care interactions, when appropriately supported.^{29,30,31}

The use of medical jargon can alienate patients and obscure their contributions. The use of specialized and technical terminology is common in most patient-provider encounters, even

though patients prefer the use of laypersons' language and see doctors who use less jargon as more caring, empathetic, and approachable.^{32,33} This tension is heightened for NELP patients when an interpreter substitutes medically incorrect terminology due to a lack of familiarity with technical language.³⁴ Studies report that patients often feel disempowered when medical language dominates encounters and providers seem to question the patient's or a parent's credibility, which leaves little room for the reciprocal sharing of knowledge.^{35,36} In Amira's case, time pressure to make a complex decision without the use of an interpreter led to her parents' misunderstanding of the risk. Given the opportunity to respond to clinicians' statements or ask questions, her parents may have felt confidence in the clinical team when Amira's clinical status changed. Following her devastating hemorrhage, her parents then lost trust in the healthcare team when decisions about withdrawing ECMO surfaced. Loss of trust in such contexts may lead families to be

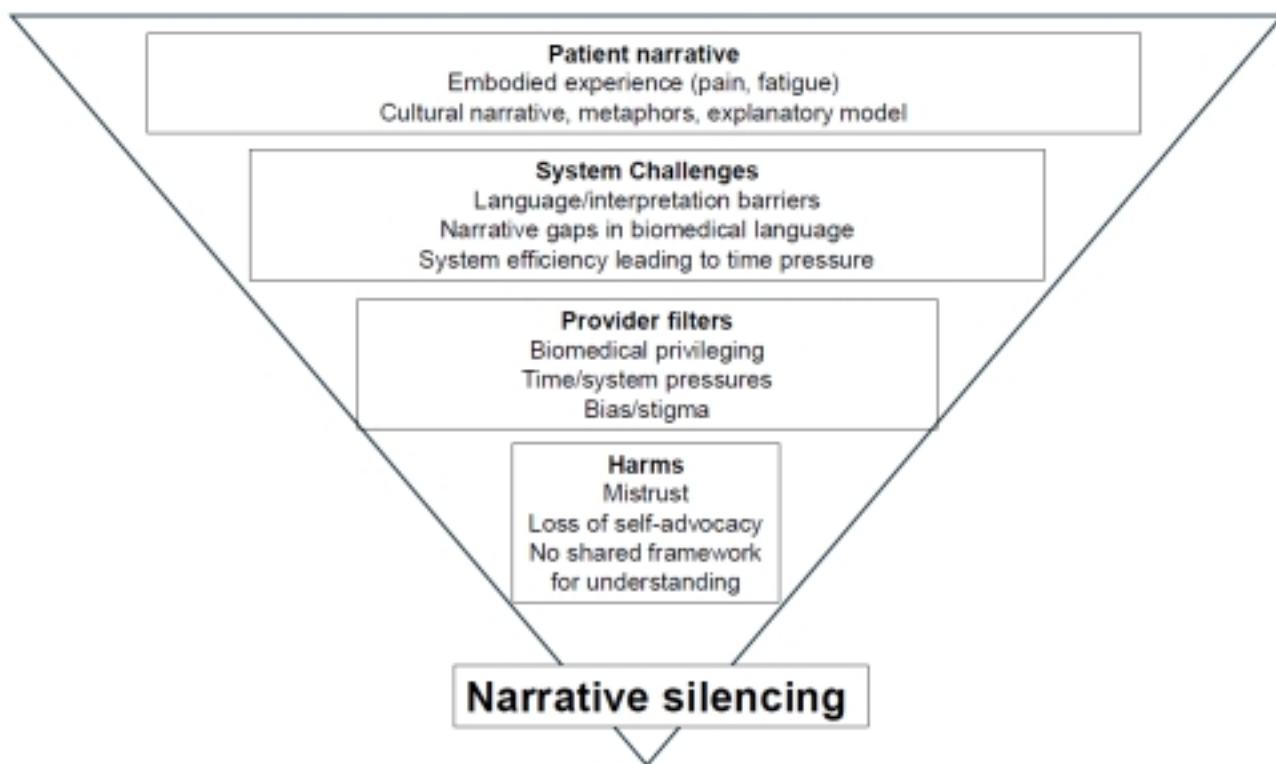
unable or unwilling to engage in shared decision making or to decline clinicians' recommendations.

PATIENTS' EXPERIENCE

This figure depicts how undervalued lived experience, narrative gaps, and reduced credibility can lead to layered epistemic injustice that results in the narrative silencing of patients' voices. Families who cannot communicate in English not only must contend with the stress of managing complex pediatric illness, but must advocate across linguistic and cultural barriers in an environment that privileges biomedical knowledge over experiential expertise. This may result heightened family stress, potential mistrust of healthcare providers, and, in some cases, inequitable health outcomes for pediatric patients.

Parents' embodied knowledge of their child's illness, be it pain, fatigue, or functional limitations, is often undervalued compared to

Mechanism of Narrative Silencing



a reliance on biomedical evidence of disease.³⁷ In pediatric care, this dynamic is particularly complex. Children with complex medical needs frequently cannot fully articulate their symptoms, which makes their parents the primary conveyors of nuanced signs of illness. These parents often express their observations in laypersons' language or with culturally specific idioms that may not translate to biomedical language or carry any similar meaning, which can lead to their marginalization in clinical decision making.³⁸ When parental testimony is overriden in deference to biomedical narrative, the result is not only diagnostic delay, but possibly moral harm.

NELP parents are often perceived as less credible or less engaged, even when their knowledge is deeply informed by day-to-day caregiving.³⁹ As a result, patients and families are less likely to speak up, less likely to question healthcare professionals' decisions, and are more afraid to ask questions.⁴⁰ This can result in delayed diagnoses, suboptimal management, and increased emotional distress for families, who must navigate a healthcare system that undervalues their insights and struggles to communicate effectively with them. When patients feel disbelieved or excluded, they lose trust in providers and institutions.⁴¹

CONCLUSION

Epistemic injustice in healthcare is not incidental. It can be structurally embedded in systems, workflows, professional norms, and cultural assumptions. It arises from the privileging of biomedical knowledge, time-pressured encounters, and systemic underinvestment in equitable communication. The consequences for patients can be profound, and range from diminished trust to lasting emotional trauma, while providers experience moral distress and compromised therapeutic relationships. In pediatrics, these dynamics are further complicated by the triadic nature of communication and a child's developing voice. Epistemic injustice in this context not only marginalizes parents' cultural and experiential knowledge, but risks silencing children themselves, raising profound

ethical concerns about respect for emerging autonomy, family integrity, and the child's best interests. Mitigating epistemic injustice requires multilevel interventions that include structural reforms to guarantee access to interpreters, training for providers in epistemic and cultural humility, and cultural shifts that recognize patients as co-knowers in healthcare. Only when these injustices are addressed at their roots can healthcare systems begin to honor the epistemic agency of all patients and move toward more just and humane care.

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