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What's going well: a qualitative analysis of positive patient and family feedback in the context of the diagnostic process

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Abstract

Objectives: Accurate and timely diagnosis relies on close collaboration between patients/families and clinicians. Just as patients have unique insights into diagnostic breakdowns, positive patient feedback may also generate broader perspectives on what constitutes a "good" diagnostic process (DxP).

Methods: We evaluated patient/family feedback on "what's going well" as part of an online pre-visit survey designed to engage patients/families in the DxP. Patients/families living with chronic conditions with visits in three urban pediatric subspecialty clinics (site 1) and one rural adult primary care clinic (site 2) were invited to complete the survey between December 2020 and March 2022. We adapted the Healthcare Complaints Analysis Tool (HCAT) to conduct a qualitative analysis on a subset of patient/family responses with ≥20 words.

Results: In total, 7,075 surveys were completed before 18,129 visits (39 %) at site 1, and 460 surveys were completed prior to 706 (65 %) visits at site 2. Of all participants, 1,578 volunteered positive feedback, ranging from 1–79 words. Qualitative analysis of 272 comments with ≥20 words described: Relationships (60 %), Clinical Care (36 %), and Environment (4 %). Compared to primary care, subspecialty comments showed the same overall rankings. Within Relationships, patients/families most commonly noted: thorough and competent attention (46 %), clear communication and listening (41 %) and emotional support and human connection (39 %). Within Clinical Care, patients highlighted: timeliness (31 %), effective clinical management (30 %), and coordination of care (25 %).

Conclusions: Patients/families valued relationships with clinicians above all else in the DxP, emphasizing the importance of supporting clinicians to nurture effective relationships and relationship-centered care in the DxP.

Keywords: diagnostic safety; patient engagement; relationship-centered care

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Introduction

Extensive research focuses on diagnostic errors, but few studies examine what good diagnostic processes (DxPs) look like, especially from the patient or family perspective. Patients and families are the connecting thread between healthcare encounters and see things beyond a single provider's view. In this role, they are "boundary spanning" and offer valuable feedback on positive or negative events that transpire at the interfaces of different healthcare settings [1, 2]. Just as patients contribute unique insights into diagnostic breakdowns, they may have unique views about what works well in the DxP that may be distinct from those of clinicians [3, 4]. Because healthcare professionals and patients/families coproduce healthcare, multiple perspectives can help create a full picture of good DxPs [5].

Evaluation of positive feedback may help identify regular successes in care and specific clinician behaviors or organizational processes that improve care and patient experience [6–9]. While many institutions receive both unsolicited compliment letters and solicited feedback through

patient satisfaction surveys, these data are not routinely aggregated or used for organizational learning [6, 10]. In addition, positive feedback from patients and families may not be conveyed to clinicians and teams, missing the chance to strengthen diagnostic teams, combat burnout and amplify what matters most to patients in the DxP.

The objective of this exploratory study was to evaluate patient/family perspectives about "what's going well" in the context of the DxP. Using a pre-visit online survey designed to engage patients/families in diagnosis we aimed to (1) categorize and characterize patient/family comments, and (2) qualitatively compare features of "what's going well" between primary care and subspecialty patients.

Methods

Participants

In order to study patients undergoing DxPs, we focused on visits with active symptoms. We also studied patients with chronic conditions because they may have more complicated DxPs, including visits to multiple providers or institutions. Our study aimed to evaluate all patients undergoing a diagnostic evaluation for active symptoms. We did not restrict our population to initial visits (or a specific part of the diagnostic process) for a given problem because prior studies indicate that patients can identify diagnostic breakdowns in every step of the diagnostic process, and we therefore anticipated that they could also likewise contribute important information at every step of the diagnostic process [3].

Pre-visit surveys were sent to eligible patients between December 2020 and March 2022 in three medical and surgical subspecialty clinics in an urban academic pediatric hospital (site 1) and in a primary care clinic in a rural academic hospital (site 2), up to seven days prior to a scheduled visit. (13) Site 1 specialty clinics serve a population of patients referred for specific diagnoses, second opinions, or ongoing symptoms. At site 1, patients or their parents/proxies (herein "families") were eligible to participate if they had a visit during the study period. At site 2, adult patients with ≥1 health condition who had ≥2 visits in the past year were eligible to participate. In order to focus on symptomatic patients, we excluded annual wellness and preventive visits.

Survey items and implementation

The OurDX ("OurDiagnosis") survey was co-developed by patients/families, clinicians, patient engagement and safety experts, and was specifically designed to engage patients/families in the DxP. The survey was iteratively tested and refined over approximately nine months with feedback from patients, family members, a user-centered design expert, a patient experience officer, and clinicians. Further details of the development of the OurDx survey are available in other publications [3, 11, 12]. The survey had three domains: (1) "What matters to you" (visit priorities); (2) "Tell us about your health" (recent symptoms) and (3) "Getting it right" (common DxP problems or delays such as communication, tests/referrals), and an additional positively framed open-ended question: "Is there something in particular that is going well for you in your care?" The latter question was the focus of this study. The survey invitation and the survey itself was labeled "OurDX" ("Our Diagnosis") and linked to information about OurDX and the diagnostic process, including more general principles about how and why patients/families should engage in diagnosis. The survey and FAQs are freely available [12, 13].

Site 1 implemented the pre-visit survey using Tonic Health, Murray, UT, which provided the patient/family an email link for the survey. Site 2 used the MyChart Epic patient portal (Epic Systems Corporation, Verona, WI). At both sites, survey responses flowed to the electronic health record (EHR) for clinician review prior to or during the visit. Clinicians could choose to incorporate some or all patient contributions to the DxP (such as priorities and history) into the visit note.

Qualitative analysis

We established our preliminary codebook adapting the Healthcare Complaints Analysis Tool (HCAT) framework to anchor our qualitative analysis of the "what's going well" responses in three domains: Relationships, Clinical Care, and Management (we adapted the term "Environment" to avoid confusion with clinical management) [14], and establishing subcategories from HCAT and themes defined in the literature. Three researchers (SL, FB, SB) applied the preliminary codebook to a randomly selected subset of 200 participant comments [6]. We used an inductive and deductive approach, identifying new subcategories emerging from the data during the initial coding. We used an iterative process of coding comments, discussion, and establishing consensus, updating of the codebook and repeating the process until we achieved saturation (no new emergent subcategories) and finalized our codebook. We coded as many categories and subcategories that were present in each comment and coded comments that could not be categorized (i.e., "great" or "wonderful") as "not applicable."

We used Gwet's Agreement Coefficient 1 (AC1) as the most appropriate measure for interrater reliability because some of the coding categories were used more frequently than others [14]. We also reported the kappa statistic because it is a commonly used and recognized statistic for interrater reliability and it is more conservative [15]. We considered agreement coefficients 0.61–0.8 as good agreement and 0.81–1.00 as excellent agreement. Among the three coders the AC1 (95 % CI) and kappa (95 % CI) was, respectively: (0.92(0.89, 0.95) and 0.78(0.70, 0.85)), (0.89(0.86, 0.92) and 0.71(0.63, 0.79)) and (0.91(0.88, 0.94) and 0.72(0.64, 0.80)). Given good to excellent interrater reliability, two researchers (SL, SB) then coded the study sample.

During our initial coding, we noted that some comments were too short to code beyond the broad categories of Relationships, Clinical Care, and Environment. Therefore, we focused our qualitative analysis on responses with ≥20 words. In addition, because we noticed that several comments specifically expressed gratitude – a feeling associated with, but not descriptive of, the specific attributes of what was going well – we separately searched the dataset for key words including "grat" (grateful, gratitude), "thank" (thankful, thank you, thanks), and "apprec" (appreciative, appreciate, appreciated) to quantify comments expressing gratitude.

Data analysis

In addition to qualitative analysis, we used descriptive statistics to report participant demographics from administrative data and frequency counts related to OurDX survey responses. Chart review was conducted on randomly selected patients with a structured data extraction form in REDCap [16, 17]. Results (i.e., proportion of patients

with active symptoms) are reported descriptively. We used chi-squared analysis to compare "what's going well" categories between participants in subspecialty vs. primary care. Data analysis was completed using SAS software, version 9.4 (SAS Institute Inc., Cary, NC).

Ethics

The study was approved through a single Institutional Review Board process (protocol IRB-P00034869) and Data Use Agreements were established between participating organizations.

Results

Of all 7,535 submitted OurDX surveys, 7,075 were submitted before 18,129 visits (39 % response rate) at site 1 and 460 were submitted prior to 706 eligible visits (65 % response rate) at site 2. Nearly all patients (95 % at site 1, 99 % at site 2) had active symptoms documented in the EHR at the time of the visit on chart review. In total, 1,575 (21 %) of all surveys included voluntary positive comments, ranging from 1–79 words. Among these, 272 comments (submitted for 267 unique patients, Table 1) had word counts ≥20, which formed our dataset for qualitative analysis. Overall, 60 % of comments focused on Relationships, 36 % described Clinical Care, and 4 % described Environment; 7 % comments were not applicable. In total, 66/272 (24.3 %) of patient/family comments expressed gratitude. The most common attributes within each category are described below.

Table 1: Patient characteristics of participants who submitted positive feedback in the total study population and in the pediatric subspecialty clinics and adult primary care clinic.

Variables	Total study population (n=267)	Pediatric subspecialty clinics (n=217)	Adult primary care clinic (n=50)
Age, years			
<18	196 (73.4 %)	196 (90.3 %)	0
18–44	22 (8.2 %)	17 (7.8 %)	5 (10 %)
45–64	12 (4.5 %)	4 (1.8 %)	8 (16 %)
65+	37 (13.9 %)	0	37 (74 %)
Gender			
Male	138 (51.7 %)	119 (54.8 %)	19 (38 %)
Female	129 (48.3 %)	98 (45.2 %)	31 (62 %)
Race			
White	212 (79.4 %)	163 (75.1 %)	49 (98 %)
Black/African–American	7 (2.6 %)	7 (3.2 %)	0
Other	12 (4.5 %)	12 (5.5 %)	0
Asian	6 (2.3 %)	6 (2.8 %)	0
Unknown	30 (11.2 %)	29 (13.4 %)	1 (2 %)
Ethnicity			
Not Hispanic or Latino	217 (81.3 %)	167 (77.0 %)	50 (100 %)
Hispanic or Latino	13 (4.9 %)	13 (6.0 %)	0
Unknown	37 (13.9 %)	37 (17.1 %)	0
Language			
Non-English	5 (1.9 %)	5 (2.3 %)	0
English	262 (98.1 %)	212 (97.7 %)	50 (100 %)

Relationships

Patients most commonly described the characteristics of clinicians and teams and their relationships with patients. Nearly two-thirds (63 %) described physicians, and one-third (34 %) reflected the whole clinic or organization. A few (12 %) described non-physicians, including nurses, physician assistants, nutritionists, audiologists, social workers or child life specialists, and front desk staff such as schedulers. Relationships most often focused on the following attributes (Table 2).

Thorough and competent attention

Nearly half (46 %) of Relationship comments highlighted providers who were knowledgeable, informative, thorough, attentive, efficient, or professional.

> *"[Doctor] spent a lot of time at my first visit with me and was very detailed in listening to my symptoms and taking notes. She seems very professional and approachable but also knowledgeable. Her nurse was fantastic and also very detailed. I felt in good hands and cared for, which was not my experience at my previous hospital.*

When working through more complex DxPs, participants underscored how much they valued providers who were committed to reaching an explanation.

> *"So far everyone with [Organization] (all 5–7 departments we've worked with!) have been so caring and thorough. We really appreciate everyone's diligence to help us find answers."*

Clear communication and listening

Roughly forty percent of comments highlighted communication between clinicians/staff and patients, among providers in multidisciplinary care, and within the whole practice. In addition to effective communication with patients, participants underscored the importance of feeling heard by others.

> *"We really felt like our concerns regarding [Name's] breathing were always taken with t[he] concern [and] with the seriousness we saw."*

Table 2: Relationship attributes and examples in patient and family comments.

Relationship attribute	n (%)	Example
Thorough and competent attention	75 (46.0)	[Doctor] and his staff are awesome! I enjoy [Name's] visits because they are so knowledgeable, yet explain things so well to a non-medical person. I trust their opinions and advice and feel that my son is in great hands with the care he receives My conversation with the social worker on [date] and with the child life specialist on [date] have been very helpful. I didn't even know these services existed before I put [Name] on the wait list for a developmental evaluation
Clear communication and listening	66 (40.5)	I have always felt very listened to and cared for from [Doctor] and feel very fortunate that she is my doctor. She has always been very attentive, responsive, and wonderful to work with "Good communication from the office. We've only had to call the office once with a question regarding blood work, but our question was handled quickly in the office called back to give us an answer … I think it's the only Doctor's office I call that has a human answering the telephone" He listens and explains things well so that we can make informed decisions about her care
Emotional support and human connection	63 (38.7)	[Doctor] always goes above and beyond to help us with [Name's] care and to answer questions. [Doctor] is also very realistic and gives us all the information, which we really appreciate. [Doctor] is always very patient, kind, and understanding about what [Name] needs at appointments [Doctor] is the best medical advocate I have at [Hospital]. She does a great job at communicating with my [treatment] teams in other departments & also keeps me informed about my current health status. Also, the nurses & other staff do a great job when I come in, making me very comfortable
Accessibility and promptness	49 (30.1)	[Doctor's] call backs when paged are quick and issues are resolved. Medications are prescribed when needed. We are always reassured if we have any other issues to call anytime Working with [Doctor] has been the answer to managing [Name's] Alzheimer's and gives me access to immediate [next steps for my] problems or worries
Non-specific praise related to providers or staff	29 (17.8)	We love [Name's] doctor. Wonderful experience with [Doctor] and his team
Patience	19 (11.7)	[Doctor] and his team are very attentive to [Name] and always take the time to answer all our questions and come up with a plan that we are all comfortable with The nurses … have been amazing at giving [Name] extra time to adjust to what they are going to do. The doctors have also been really great about giving [Name] space and telling him what they are going to do
Transparency and trust	15 (9.2)	[Doctor] is an excellent responsive and attentive doctor who always makes time for his patients. He is very astute in his deductions regarding health matters, and also has empathy for his patients. I trust his judgement and advice The hospital seemed very organized and knew exactly how to handle situations. When I met the doctors, I knew right away I could trust what they were doing and talking about. They took very good care of my son and I. They were on top of what they were looking for
Other attribute[a]	17 (10.4)	I love [Name's] doctors and feel like everyone is working really hard to figure out what's going on with him The PCP is checking in frequently and providing support in any way she can

[a]Other attributes described providers who proactively engaged patients and families, "went the extra mile," and checked in with patients after the visit.

A participant highlighted bidirectional communication as the foundation to shared decision making, and patients viewed effective communication as an *active* effort to include patients/families.

> *"Transparency has been good, as well as putting medical terms into ones I can understand. I really appreciate that time was taken to explain things to me so that I could actually understand what [Doctor] was saying."*

Parents highlighted education and explaining to children what will happen next.

> *"The [Doctor] is wonderful and explains things very well. He also explains things to [Name] in a way that it becomes a 'life lesson' [versus a] short term fix."*

Some participants highlighted the importance of good communication while experiencing slower or uncertain diagnostic processes.

> *"Audiologists were very knowledgeable and patient with [Name]. Although results are inconclusive and we have to return, I felt that the audiologist explained everything really well and was thorough in her examination."*

Emotional support and human connection

Nearly 40 % of comments described clinicians who were kind, supportive, compassionate, or helped patients feel comfortable. Some commented on long-standing relationships with

Table 3: Clinical care features and examples in patient and family comments.

Clinical care feature	n (%)	Example
Timeliness of appointments, tests, response to calls/messages	30 (30.6)	I really appreciate how quickly I got a response when I called and left a message asking for help with [Name's] mouth breathing. I received a call back a few hours after I left a voicemail with instructions and feedback going forward I really appreciate being able to email when my son has an oozing ear and can get prescription ear drops for him the same day without needing to bring him in. As a working parent, this allows me to get my son the help he needs immediately I've never had an office be so responsive and timely with follow-up and scheduling
Effective clinical management	29 (29.6)	My cancer treatment has gone very smoothly … a big challenge during COVID. Someone is always available to answer questions I have more energy and endurance, easier deep breathing, no daily fevers since [date](!), and have gained some desired weight. My primary care doctor has been central to arranging for me to get various tests, and needed procedures and to see other specialty departments when that would be advantageous to my health We finally have answers and a solution since transferring to [Hospital]
Non-specific praise related to care	26 (26.5)	We have loved the care and concern provided by cardiology Very pleased with our audiology experiences thus far, looking forward to hearing [Doctor's] assessment of what may have caused this
Coordination of care	24 (24.5)	The coordination of multiple appointments by each scheduler we have spoken with is appreciated We are very pleased with how organized the [clinic] team and procedures for assessment have gone at [Hospital]. It is very organized, perhaps the most organized medical team we have ever experienced The compassion shown to him since his diagnosis and post-surgery has been helpful. The continued medical team collaboration in their efforts to aide [Name] in his recovery from brain surgery
Whole person care	12 (12.2)	The "big picture" understanding of my daughter situation, since the very first moment
Good clinical follow up/careful monitoring	11 (11.2)	[Doctor] does a great job of communicating between visits as well as during our times in the clinic Received excellent care and f/u in non-invasive Cardiology with phone calls to me in FL to see how I was doing with new meds and halter monitor and f/u on diagnosis and treatment – exceptional service! We are very grateful for [Doctor] for following [Name] so closely and helpful us to coordinate and navigate her care. Her and her team have been wonderful from the beginning
Other features[a]	11 (11.2)	She has helped me navigate missing school and pain management as well as referring me to different specialist to get to the root of my pain

[a]Additional features included use of cancellation/notification lists for appointment access, contingency planning such as what to do if symptoms worsen, and broad thinking that considers the impact of ongoing symptoms or diagnostic work-up on missed school or work.

clinicians, who served as dedicated advocates for patients. However, patients/families meeting a provider for the first time also highlighted caring and supportive attributes.

> *"[The] on-call provider was called during the weekend and was very helpful, friendly, and called in a prescription quickly. They made a note to have the office call during business hours to check in on our child and they called right away on Monday morning. It's comforting to know my daughter has a compassionate care team!"*

Additional attributes

Participants described clinicians who were accessible or prompt, not rushed, and transparent or trustworthy. Trust was often coupled with good communication and listening. "Other" relational attributes most commonly described providers who proactively engaged patients and families, "went the extra mile," and checked in with patients after the visit.

Clinical care

This category focused on the details of care, (as opposed to the attributes of people delivering the care). Common features (Table 3) included:

Timeliness

Timeliness of appointments, tests, and responses to calls was noted by 31 % of participants, and often included multiple individuals and coordination of care.

> *"Excellent handling of urgent case – quick and timely review of existing records, very near-term scheduling of appointment and follow-up scans (with maximum convenience to us as well), immediate initiation of necessary treatment … We feel we are getting outstanding care and are extremely appreciative!"*

Several other participants underscored thoughtful consideration of the patient/family's time and experience.

> *"… short wait time when calling to schedule and staff is always pleasant. We see tons of departments at [Hospital] and [Clinic] is one of the easiest to work with!"*

Some noted the willingness to quickly diagnose and treat patients with chronic conditions.

> *"[Doctor] always fits [Name] in very soon after we report that she is having vertigo so she doesn't have to suffer too long"*

Effective clinical management

About 30 % of comments highlighted clinical improvement, making a diagnosis (especially after a protracted evaluation), or outlining clear next steps.

> *"The fact that we have a plan [going] forward and have something to target for remediation of the medical condition is a very promising situation rather than [just saying] 'I am not sure'".*

Coordination of care

One-quarter (25 %) of comments mentioned effective coordination including specialist referrals, testing, discussion among clinicians, and keeping the "big picture" in mind to synthesize multiple appointments and perspectives into a cohesive diagnostic or treatment plan. Patients were especially grateful for coordination of care that demonstrated consideration for patient's time.

> *"An excellent experience was that you were able to get me an appointment with [Doctor] and communicated it while I was on the table at the PT (physical therapy). Someone saw in the chart that I was at that appointment, called there to pass me the message that I could see [Doctor] later that morning. That was coordinated and thoughtful, I felt seen and cared for in this complex system."*

Patients noted coordination of care among providers who were all invested in reaching a diagnosis.

> *"[Doctor] and the [general medicine] team have been wonderful … working with OB/GYN about getting me into see my GYN so that everyone can figure out what's going on with my periods."*

Additional features

Some participants specifically noted "whole person care," and good clinical monitoring as important features of Clinical Care. Additional features included use of cancellation/notification lists for appointment access, contingency planning such as what to do if symptoms worsen, and broad thinking that considers the impact of ongoing symptoms or diagnostic work-up on missed school or work.

Environment

Very few comments (n=10) described environmental factors. When mentioned, patients/families highlighted facilities, such as clean exam rooms, large/multi-site organizations (and appointment access), the convenience of telehealth, and facilitated communication through the patient portal.

Primary care vs. subspecialty clinics

Comments from primary care and subspecialty clinics showed the same relative category rankings (Relationship > Clinical Care > Environment), although relationship comments were even more frequent in primary care (85.5 vs. 53.5 %, $p<0.001$). There were no significant differences in the frequency of sub-category attributes within Relationship or Clinical Care, with the exception of emotional support and human connection, which was more common in primary care than subspecialty care (51.1 vs. 33.6 %, $p=0.038$; Table 4). The total number of Environment comments (n=10) was too small for clinically meaningful statistical comparison.

Discussion

This explorative qualitative study of adult and pediatric patients/families living with chronic conditions provided important early insights into what patients viewed as going well in the context of the DxP. Above all else, relationships were most important to patients/families. While this may be expected for primary care patients who have established relationships with providers, we observed the same result among patients of specialist providers who may have new or intermittent relationships with patients. This suggests that it is not just the duration of the relationship, but other aspects that promote positive feelings of support and caring. While some clinicians are uncomfortable with emotion, our findings suggest that emotional engagement (alongside thorough and competent attention, clear communication and listening) may be important, particularly in more challenging DxPs, and among primary care patients [16, 18–20].

Many patient comments about "what's going well" reflected the opposite of what patients/families have described as diagnostic breakdowns in other studies [3, 19]. For example, in a study representative of the US population, the most common patient-reported contributing factor to self-reported diagnostic error was not feeling listened to [17]. In our study, patients/families lauded providers who took their concerns seriously and made them feel heard. Rather than report delayed work-ups (as described in patient-reported

Table 4: Comparison of positive comment categories and subcategories between subspecialty and primary care (n=272).

	Total n (%)	Site 1 n (%)	Site 2 n (%)	p-Value
Going well categories[a]				
Relationship	163 (59.9)	116 (53.5)	47 (85.5)	**<0.0001**
Clinical Care	98 (36.0)	73 (33.6)	25 (45.5)	0.103
Relationship	n=163			
Thorough and competent attention	75 (46.0)	58 (50.0)	17.00 (36.2)	0.1085
Clear communication+listening	66 (40.5)	51 (44.0)	15.00 (31.9)	0.1557
Emotional support and human connection	63 (38.7)	39 (33.6)	24.00 (51.1)	**0.0383**
Accessible and prompt	49 (30.1)	33 (28.5)	16.00 (34.0)	0.4804
Non-specific praise	29 (17.8)	21 (18.1)	8.00 (17.0)	0.87
Patient/not rushed	19 (11.7)	15 (12.9)	4.00 (8.5)	0.4256
Transparency and trust	15 (9.2)	10 (8.6)	5.00 (10.6)	0.7662
Other	17 (10.4)	12 (10.3)	5.00 (10.6)	0.9557
Clinical care	n=98			
Timeliness	30 (30.6)	25 (34.3)	5.00 (20.0)	0.1822
Effective clinical management	29 (29.6)	21 (28.8)	8.00 (32.0)	0.7599
Coordination of care	24 (24.5)	17 (23.3)	7.00 (28.0)	0.6363
Whole person care	12 (12.2)	7 (9.6)	5.00 (20.0)	0.1705
Good clinical follow up/careful monitoring	11 (11.2)	9 (12.3)	2.00 (8.0)	0.554
Non-specific clinical	26 (26.5)	18 (24.7)	8.00 (32.0)	0.473
Other	11 (11.2)	10 (13.7)	1.00 (4.0)	0.1849

[a]We did not compare Environment comments because the (n=10) was too small for clinically meaningful statistical comparison.

diagnostic breakdowns), they recognized the value of timely tests and referrals [21, 22].

In addition, patients/families described being actively engaged, included, and informed by clinicians. Parents in particular viewed the doctor as a teacher, providing "lifelong lessons" for them and their child. They underscored the importance of coordination between providers and seeing the "whole person" or "big picture" rather than a small slice of fragmented care. They noticed providers who respected their time and experience, checked-in or followed-up closely, and were committed to seeing the diagnosis through. Many of these attributes, or their absence, are not routinely measured but are important to patients when things go well.

Finally, our results highlight the potential role of virtuous cycles in healthcare with about one in four comments expressing gratitude [23]. Acknowledgement of a good deed has the potential to promote future good deeds, if shared with clinicians [6]. Research demonstrates that expressions of gratitude are associated with increased clinician self-esteem, pride in work and satisfaction, and can promote a healthy work environment, which could potentially help decrease burnout and dissatisfaction with work in healthcare [24–26]. In addition, gratitude has been associated with enhanced team performance. Notably, patient gratitude for providers carried greater weight than gratitude from colleagues [26].

Roles of teams

While many comments focused on the relationship or experience with an individual clinician, one-third of comments described positive interactions with a care team, in some cases across different specialties, or with the clinic as a whole. As healthcare organizations increasingly rely on teams of clinicians and staff to coordinate and manage a patient's care, the composition of the team responsible for the DxP has evolved and expanded from the classic patient and provider dyad to a team involving multidisciplinary expertise, including nurses, advanced practice providers and allied health professionals [27]. Diagnostic team membership is often fluid as members may shift as the patient's needs or provider coverage changes over time [28]. This expansion and dynamic nature of the diagnostic team can have a significant impact on patient safety, as cognitive contributions to the DxP are distributed across the various care team members (including patients/families) and effective collaboration among members requires them to have a

shared mental model about the process and shared accountability toward a diagnostic outcome [28]. Patient comments of "what's going well" as they relate to the whole care team, including observations on collaboration across specialties, may reflect instances of effective "*teaming*" where members of the team collectively promote the patient's perception of feeling heard and constructive collaboration [29].

Implications for diagnostic safety

First, because patients/families prioritize relational attributes, organizations should consider resource allocation to help promote relationship-centered care, supporting providers in their efforts to nurture relationships and emotional engagement [7, 18, 30]. Second, organizations should cast a broader definition of diagnostic excellence that includes emotional safety [31, 32]. Consistent with prior studies where patients emphasize "feeling safe," good DxPs were strongly influenced by interpersonal interactions and relational aspects of care including empathy, respect, and emotional intelligence [31, 33]. Participants described "feeling in good hands" and trusting providers who demonstrated not only competent attention but also clear communication and palpable, human caring. Third, although clinicians often focus on their own individual behavior, some patients may view positive attributes as characteristics held by teams (i.e., the caring of teams, the kindness of teams). In this case, the behavior of one clinician may affect the patient/family's perception of others, and vice versa. This interdependence may not be fully perceived by individual clinicians or staff members and should be emphasized in the context of team training and awareness [34].

Finally, patient/family comments in this study differentiated between *listening* and *feeling heard*, with important implications for diagnostic safety. Active or "empathic" listening, currently emphasized in healthcare, is necessary but not sufficient to feeling heard. In Roos' conceptual model, in addition to clinician behaviors (i.e., non-judgmental listening, humble inquiry, paraphrasing and summarizing), patients must first be able to speak freely (i.e., empowered by voice), and must also *perceive* clinician responsiveness (attention, empathy, and respect), each described by participants in this study [35]. Together, these help establish "common ground" or shared understanding between patients/families and clinicians; perhaps the foundation for a shared mental model of the DxP. In this adaptation of the Roos model for the DxP (Figure 1), the primary locus of feeling heard shifts away from clinician behavior alone to clinicians, patients – and perhaps most importantly – the interpersonal or relational domain between patients and clinicians [35–37]. This difference is subtle but critical. Because "not feeling heard" is emerging as an important patient-reported contributing factor to patient-perceived diagnostic error, a better understanding of this concept may be central to safety efforts [11, 17, 19, 38]. If feeling heard resides in the space between patients and clinicians, diagnostic excellence needs a relational model, skillset, and measure. Future research should also explore the relationship between feeling heard and feeling safe.

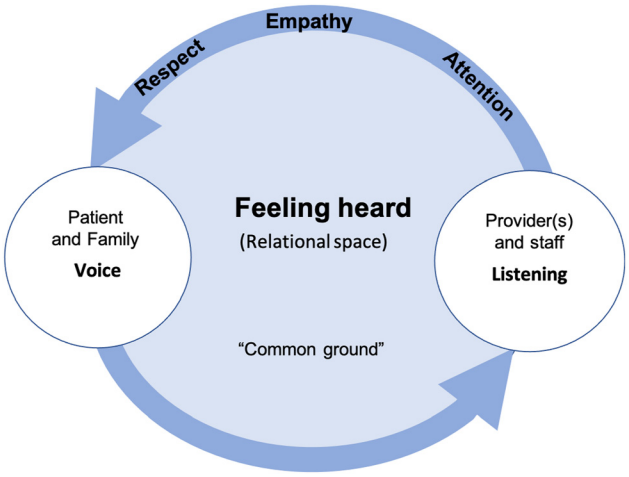

Figure 1: Adaptation of Roos' model on "feeling heard" [35] for the diagnostic process.

Limitations and additional future research

Our study enrolled patients/families from two academic institutions, limiting the generalizability of results. The response rates, while similar to other published online surveys, were modest [39, 40]. Although our study included patients from both urban and rural settings as well as pediatric and adult patients, site 2 was comprised of predominantly older, white and English-preferring patients who used the online patient portal, potentially biasing results. The distribution of participants at the two sites reflected the greater number of participating clinics at site 1, and results may therefore more closely represent pediatric experiences, despite overall similar distribution of response categories. Use of the patient portal is known to be more limited for some patient populations [41–43], likely biasing participation as a result of "the digital divide." Although site 1 employed methodology that did not rely on the patient portal, it still necessitated an email address. Larger studies with more diverse populations are needed. The study was conducted during COVID-19 surges, which may have affected

the speed and efficiency of diagnostic processes, as well as response rates.

In addition, the "what's going well" question was open-ended by design and did not specifically ask about the DxP in an effort to keep the survey brief and avoid terms that may be confusing or unfamiliar to some patients. However, it was embedded in the OurDX survey which focused on the DxP by asking about recent symptoms and potential problems/delays related to the patient's main concern. We confirmed that nearly all participants in chart review had active symptoms. Patient comments show face validity in that many were describing their diagnostic journey. Nonetheless, our findings should be viewed as hypothesis-generating. Future research should focus more specifically on the DxP as understood and experienced by patients/families.

This study did not assess clinical outcomes. Future studies could measure what patients view as good DxPs and their association with DxP safety outcomes. Additionally, future research may include examination of patient feedback in other settings such as urgent care, emergency departments, or inpatient admissions. This work should also encourage studies of burnout reduction and enhancement in team performance through sharing of positive patient feedback and gratitude with clinicians.

Conclusions

In this explorative study, above all else, patients/families value their relationships with healthcare providers and care teams. Patient positive comments may help elucidate what a good DxP looks like, emphasizing largely unmeasured relational attributes (such as emotional support, feeling heard, engagement, respect for patient time and experience), alongside more commonly recognized aspects of clinical care (competence, timeliness, coordination of care). One-quarter of patient/family comments volunteered gratitude, which when shared with clinicians may help combat burnout, amplify positive behaviors, and enhance team performance.

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Research ethics: Research involving human subjects complied with all relevant national regulations, institutional policies and is in accordance with the tenets of the Helsinki Declaration (as revised in 2013), and has been approved by the a single Institutional Review Board (IRB-P00034869).

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