Article

Patient perspectives on how physicians communicate diagnostic uncertainty: An experimental vignette study†

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Abstract

Objective: We evaluated the effects of three different strategies for communicating diagnostic uncertainty on patient perceptions of physician competence and visit satisfaction.

Design/Setting: Experimental vignette-based study design involving pediatric cases presented to a convenience sample of parents living in a large US city.

Participants/Intervention(s): Three vignettes were developed, each describing one of three different ways physicians communicated diagnostic uncertainty to parents—(i) explicit expression of uncertainty (‘not sure’ about diagnosis), (ii) implicit expression of uncertainty using broad differential diagnoses and (iii) implicit expression of uncertainty using ‘most likely’ diagnoses. Participants were randomly assigned to one of the three vignettes and then answered a 37-item web-based questionnaire.

Main Outcome Measure(s): Outcome variables included parent-perceived technical competence of physician, trust and confidence, visit satisfaction and adherence to physician instructions. Differences between the three groups were compared using analysis of variance, followed by individual post hoc analyses with Bonferroni correction.

Results: Seventy-one participants completed the vignette questions. Demographic characteristics and scores on activation (parent activation measure [PAM]) and intolerance to uncertainty were similar across the three groups. Explicit expression of uncertainty was associated with lower perceived technical competence, less trust and confidence, and lower patient adherence as compared to the two groups with implicit communication. These latter two groups had comparable outcomes.
**Conclusion:** Parents may react less negatively in terms of perceived competence, physician confidence and trust, and intention to adhere when diagnostic uncertainty is communicated using implicit strategies, such as using broad differential diagnoses or most likely diagnoses. Evidence-based strategies to communicate diagnostic uncertainty to patients need further development.

**Key words:** diagnostic uncertainty, doctor–patient communication, patient perspective, diagnostic error, vignette-based questionnaire

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**Introduction**

Diagnostic uncertainty is omnipresent in clinical practice [1–6]. For true shared decision-making and information exchange with patients, communication of diagnostic uncertainty is essential [7, 8]. Practice guidelines and the recent National Academies of Science, Engineering and Medicine report ‘Improving Diagnosis in Health Care’ recommend that physicians should share their working diagnosis with patients including an explanation of the degree of uncertainty associated with the diagnosis [9, 10]. However, the task of communicating diagnostic uncertainty to patients is challenging, and previous studies have reported some undesirable effects of such communication on patients [11–15].

Although one study found that patients were more satisfied when physicians communicated diagnostic uncertainty [7], most report the opposite findings. For instance, simulated video-tape studies with patients have found communicating diagnostic uncertainty is associated with low visit satisfaction scores, decreased adherence to doctors’ instructions, low trust and decreased confidence in the doctor [16]. Other studies using patient surveys and standardized patient visits have also found less patient satisfaction, lower patient confidence in the physician and lower perceived competence of the physician when diagnostic uncertainty was communicated to patients [17–21].

How physicians should communicate diagnostic uncertainty effectively to patients is unknown [11, 20]. Patients may be receptive to this type of communication if it is delivered in a way that avoids some of the undesirable consequences described above [7, 20, 22, 23]. If communicated very openly, patients may appreciate the honesty or may react negatively to the doctor’s lack of knowing what health problem they have. Conversely, strategies that communicate in a more subtle fashion could suggest to patients that while actual diagnosis may not be known yet, several possibilities are being considered (e.g. using differential diagnosis). To our knowledge, the impact of communication of diagnostic uncertainty on parents of pediatric patients is unknown and has not been studied. Our objective was to evaluate the impact of three different strategies of communicating diagnostic uncertainty to parents on their perceptions of physician competence, perceived trust and confidence, visit satisfaction and adherence to clinical instructions.

**Methods**

**Study setting, participants and design**

We used an experimental, vignette-based study design involving pediatric cases presented to a convenience sample of parents. The study sample consisted of parents participating in a parent and family advisor email listserv at a large pediatric academic center and parents participating in two parent social-media groups. Local Institutional Review Board approval was obtained.

We created three vignettes, each describing the same clinical scenario of a parent presenting to a new pediatrician with abdominal pain. The pediatrician communicates diagnostic uncertainty to the parent through one of three different strategies (Table 1). Each scenario then provides reassurance to the parent and discusses the further plan for diagnosis. The vignettes varied only with respect to how diagnostic uncertainty was communicated according to one of three strategies: (i) explicit expression of uncertainty (‘not sure’ about diagnosis), (ii) implicit communication of uncertainty using broad differential diagnoses ( Implicit communication of uncertainty using differential diagnoses) and (iii) implicit communication of uncertainty using most likely diagnoses.

**Table 1** Vignettes used for the study consisting of a common clinical scenario, one of the three communication strategies and a common future plan for diagnosis

<table>
<thead>
<tr>
<th>Common clinical scenario</th>
<th>1 of 3 different strategies to communicate diagnostic uncertainty</th>
<th>Common future plan for diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assume you just moved to another part of the country for work. Your child has been experiencing pain in his/her belly for about 3 weeks. You are at a local pediatrician’s office for a third visit in 2 weeks. At the first visit, the doctor asked you about your child’s previous illnesses and examined your child. The pediatrician also ordered some laboratory tests and imaging, which did not point to any particular disease. At the second visit, the doctor ordered some more tests, which were completed before your visit today. During this visit, you tell the doctor that your child still has pain in his/her belly.</td>
<td>During the following discussion, the doctor says that:</td>
<td>However, the doctor tries to comfort you and comes up with a detailed plan to try to figure out what is causing the belly pain. This plan includes additional visits and tests in the next 2 weeks.</td>
</tr>
<tr>
<td>he/she is not sure what might be causing your child’s belly pain. (Explicit communication of uncertainty)</td>
<td>your child’s belly pain could be caused by Disease A, Disease B or Disease C. (Implicit communication of uncertainty using broad differential diagnoses)</td>
<td>your child’s belly pain is probably due to Disease A. (Implicit communication of uncertainty using most likely diagnoses)</td>
</tr>
</tbody>
</table>
expression of uncertainty using broad differential diagnoses (it could be Disease A vs. Disease B or Disease C) and (iii) implicit expression of uncertainty using 'most likely' diagnoses (it is probably Disease A). The three strategies were based on expert input and shared decision-making literature [5, 10, 15, 16]. The vignettes were iteratively developed with input from a multidisciplinary research team of physicians, patient advocates, health service researchers, a cognitive psychologist, a communication expert and a social worker. Participants were randomly assigned to receive one of the three vignettes followed by a questionnaire (Fig. 1).

**Questionnaire development and administration**

We developed a 37-item questionnaire using existing literature [16, 24–27], and input from the research team. Our outcome variables included (i) perceived technical competence of the physician (2 items), (ii) overall visit satisfaction (1 item), (iii) perceived trust and confidence in the physician (3 items) and (iv) adherence to clinical instructions (1 item) (see Appendix). Participant responses were captured on a 4-point Likert Scale ranging from Disagree Strongly to Agree Strongly. Only items with high reliability and good to excellent internal consistency across multiple studies were chosen [16, 24–27].

To account for patient activation level for each participating parent, we used the Parent/Patient Activation Measure (Parent PAM-10 licensed by Insignia Health©) [28, 29]. The parent PAM-10 consisted of a set of 10 questions captured on the materials received from Insignia Health© regarding the use of parent PAM-10. In the literature, PAM has been found to be highly reliable and valid across different populations and age-groups, and has been used in over 350 research studies internationally [28–32].

We used the Intolerance to Uncertainty Scale (IUS-12) to measure each parent participants’ tendency or intolerance to uncertainty due to its high reliability and good internal consistency in multiple studies [33–35]. Responses were captured on a 5-point Likert Scale ranging from ‘Not at all characteristic of me’ to ‘Entirely characteristic of me’. The IUS-12 score was calculated between 0 and 120 reflecting extremes of total tolerance and intolerance, respectively. We also collected information about the parents’ perception of uncertainty in medical decision-making (i.e. whether parents agree that many decisions in medicine are based on insufficient information) using a sub-scale used in previous literature [16].

We used two strategies to account for parent participants’ pre-existing relationship with his/her physicians. All vignettes used in our study highlighted that the ‘parent participant had moved to a new city and they were seeing their new pediatrician for the third time in 2 weeks’. We also asked participants about their perception of their current relationship with their actual pediatricians (using a 5-point Likert Scale from excellent to poor).

For all participating parents, we collected information about the age of their children, health status of the children and parent demographics (age, gender, race and educational status). Parent participants with multiple children were instructed to think about their youngest child while filling out the questionnaire to ensure that participants were not biased by their healthcare experiences with the sickest or most demanding child. Youngest were chosen instead of oldest (or any) to homogenize the groups as much as possible and to ensure children considered were less likely to be adult children.

After initial refinement of questionnaire items, the research team and five additional health services researchers reviewed the vignettes and the questionnaire for readability, clarity and ease of completion in a web-based environment. The vignettes and questionnaire were then pilot-tested with 15 patient participants who were not included in the main study. The focus of the pilot was to improve readability, to ensure participant understanding of the vignettes and to test the mode of administration. Subsequently, one of the authors (VB) conducted cognitive interviews to identify issues related to wording, question order and vignette navigation. Both the vignettes and the questionnaire were then refined in an iterative manner based on input provided by the pilot participants. Wording, question order and visual design issues identified were subsequently addressed.

The questionnaire was administered through a commercial internet questionnaire administration service ( surveymonkey.com). The service generated a common survey link (URL) that was sent electronically to participants and provided details about the study (i.e. a questionnaire to understand doctor–patient communication). After consent was obtained electronically, the internet questionnaire administration service randomly assigned participants to view one of the three vignettes and complete the common questionnaire (Fig. 1). Estimated completion time for the final 37-item questionnaire was 5–15 min. No compensation was provided to parent participants for completing the questionnaire.

**Data analysis**

Data were downloaded from the internet questionnaire administration service ( surveymonkey.com) and analyzed using STATA 12 (College Station, TX). One-way analysis of variance (ANOVA), Pearson’s chi-square or Fisher’s exact tests were conducted to compare demographic characteristics of the participants (parent age, gender, race and educational status), child age and health status, relationship with pediatrician, parent activation score, intolerance to uncertainty scores and perception of uncertainty in medicine. Items captured on the 4-point Likert Scale (Disagree Strongly to Agree Strongly) were correspondingly converted into scores of 1–4. A sub-scale score was calculated for each of our outcome variables ( perceived technical competence of the physician, trust and confidence, visit satisfaction and adherence) by averaging the individual item scores for all constituent items. Because the scale was ordinal, a higher score was considered relatively more favorable while making comparisons between the groups. In the

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**Figure 1 Study flowchart.**
absence of rigorous literature evidence to guide us with our research question, we had no *a priori* hypotheses regarding which communication methods would related to a better or worse outcomes. Minimum sample size per group was calculated to be 20 to obtain a power of 0.80, assuming $\alpha = 0.05$ (two tailed test). Post hoc analyses using ANOVA with Bonferroni corrections were used to compare the subscale scores across the three groups. All possible pairwise post hoc comparisons were conducted.

**Results**

Between May 2016 and April 2017, 71 parents participated in our vignette study. Vignettes with explicit communication and implicit communication using broad differential diagnoses had 25 participants each, while the ‘most likely diagnoses’ vignette group had 21. Participants across the three groups were similar with respect to parent activation levels (PAM, $P = 0.73$), self-tolerance to uncertainty scores ($P = 0.21$), perception of uncertainty in medicine ($P = 0.37$), relationship with pediatrician ($P = 0.32$), child’s age ($P = 0.18$), child’s health status ($P = 0.80$) and other demographics (Table 2).

We found significant statistical differences among the three groups on three of the outcomes of interest: perceived technical competence of the physician ($P = 0.007$), trust and confidence ($P = 0.002$) and patient adherence ($P = 0.003$). For visit satisfaction, we found no statistically significant differences ($P = 0.059$; see Table 3). Overall, groups with implicit communication (either using differential diagnoses or most likely diagnoses), were relatively more favorable on the three outcomes of interest: perceived technical competence, trust and confidence and adherence, in comparison to the group with explicit communication. The absolute score was not interpreted but differences in the score represented a more favorable response. For example, the mean scores for perceived technical competence of the physician for the implicit groups (differential diagnosis—2.62; most likely diagnosis—2.52) were 0.58 points and 0.48 points higher respectively, compared to the mean score for the explicit group (2.04), revealing a more favorable relative response. More details in Table 3.

Post hoc tests using the Bonferroni correction test (see Table 3 for details) revealed that outcome variables perceived technical competence and trust and confidence were less favorable relatively in the explicit group when compared to both implicit groups ($P = 0.009$ and $P = 0.048$; $P = 0.005$ and $P = 0.010$, respectively). For adherence to instructions, implicit group with differential diagnosis was relatively favorable compared to explicit group ($P = 0.003$). Both implicit groups were similar with respect to perceived technical confidence, trust, visit satisfaction and adherence.

**Discussion**

We evaluated parent perceptions of three different strategies that pediatricians could use to communicate diagnostic uncertainty about their children’s illnesses. Our findings suggest that parents react less negatively to implicit expressions of diagnostic uncertainty using broad differential diagnoses or most likely diagnoses over explicit expressions. We did not find any differences in their reactions to the methods of implicit expression of diagnostic uncertainty, i.e. using either a differential diagnosis or the most probable diagnosis.

Our findings suggest that parents prefer when physicians imply that a diagnosis is not certain by using differential diagnoses or the most likely diagnosis as compared to explicitly acknowledging that they are ‘not sure’. To our knowledge, this is the first attempt to compare different strategies of communicating diagnostic uncertainty in clinical practice from the parent’s perspective. Because little is known

| Table 2 Comparing participant characteristics among the three groups |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Explicit expression of diagnostic uncertainty ($n = 25$) | Implicit expression using differential diagnoses ($n = 25$) | Implicit expression using most likely diagnosis ($n = 21$) | P-value (using ANOVA*, Pearson’s chi-square Statistic or Fisher’s Exact Test) |
| Parent Age (mean, in years) | 36.3 | 38.8 | 41.4 | 0.13 |
| Parent Gender (in %) | | | | 0.35b |
| Male | 16.0% | 8.3% | 4.8% | | |
| Female | 84.0% | 91.7% | 95.2% | | |
| Race (in %) | | | | 0.06^ |
| White | 68.0% | 75.0% | 95.2% | | |
| Non-White | 32.0% | 25.0% | 4.8% | | |
| Parent Educational Status (in %) | | | | 0.06^ |
| High school or undergraduate | 44.0% | 75.0% | 47.6% | | |
| Graduate Degree | 56.0% | 25.0% | 52.4% | | |
| Child Age (mean in years) | 4.2 | 6.7 | 7.8 | 0.18 |
| Child’s Health Status (% describing as Excellent) | 28.0% | 33.3% | 23.8% | 0.80b |
| Relationship with pediatrician (% describing as Excellent) | 36.0% | 50.0% | 28.6% | 0.32b |
| Self-Tolerance to Uncertainty Score (mean score based on IUS-12) | 26.2 | 29.2 | 29.8 | 0.21 |
| % who believed medical decisions have uncertainty (Agree or Strongly Agree) | 44.0% | 25.0% | 33.3% | 0.37b |
| Parent Activation Score (mean) (higher score indicates more patient activation) | 72.7 | 71.5 | 69.8 | 0.73 |

*ANOVA was used to evaluate group differences, unless indicated by Footnotes b or c (see below).

bPearson’s chi-square statistic was used to evaluate differences between groups.

Fisher’s Exact Test statistic was used to evaluate differences between groups.
about how physicians communicate diagnostic uncertainty to their patients, physicians often rely on personal experiences and self-made strategies when tasked with such communication [11, 19, 20]. For example, one clinic-based study in Oregon found that physicians explicitly expressed uncertainty in 71% of clinical visits [7], which we found as more negatively perceived by parents in our study. These findings are important in light of increasing emphasis on making care more patient-centered and improving patient experience [36-40].

Our work has important implications for understanding and improving physician–patient communication related to diagnosis. Managing uncertainty has been discussed as a critical aspect of patient-centered communication [31, 32]. Patients are known to have complex cognitive, emotional, and behavioral responses to uncertainty [11, 41]. Previous research has suggested a possible association between physician–patient communication and long-term health outcomes [17, 41-44]. Although the impact of communication of diagnostic uncertainty on patient outcomes has not been studied yet, previous studies have shown negative patient perceptions following such communication (e.g., lack of confidence, low visit satisfaction, worry or concern) [16-20, 22, 45]. The undesirable impacts of such communication could possibly extend into other long-term patient outcomes and this link should be studied further. While we found preliminary evidence in support of implicit expressions such as using the differential diagnoses or the most likely diagnosis for communicating diagnostic uncertainty, further research should unravel how uncertainty is best communicated to patients in order to optimize outcomes.

Few studies that have discussed steps for sharing diagnostic uncertainty with patients suggest generating hope or opportunity for patients and its potential to improve patient satisfaction if such communication is accompanied by positive talk, empathy, and partnership building [7, 45, 46]. Other studies have found that supplemental training programs focusing on improving physicians’ communication skills improve patients’ perceptions of the visit [23, 47]. Although these findings are encouraging, strategies that physicians use to communicate diagnostic uncertainty while maintaining patient confidence still need to be defined and evaluated. The recent National Academies of Science, Engineering and Medicine publication ‘Improving Diagnosis in Health Care’ has also emphasized the importance of such communication by including failure to communicate an explanation of a patient’s health problem(s) to the patient in its definition of diagnostic error, and has also highlighted that ‘the working diagnosis should be shared with the patient, including an explanation of the degree of uncertainty associated with a working diagnosis’ [9]. Efforts to better educate patients about diagnostic uncertainty and to prime them to reduce their intolerance to uncertainty may also need to be explored.

Our study findings can inform future work to explore what impact parent–physician communication has on clinical practice outcomes, such as diagnostic errors and patient adherence. A large multi-site pediatric survey found that diagnostic errors are common in pediatric clinical practice and result in considerable harm [48]. Inappropriate management of diagnostic uncertainty could potentially result in diagnostic errors. For example, suppression of uncertainty and lack of considering differential diagnoses for the patients’ problems could result in premature closure and missed diagnoses. Physicians find it challenging to acknowledge and make decisions when diagnostic uncertainty is present [49]. This is additionally complicated by patients’ lower tolerance for explicit uncertainty. However, in the era of patient-centered care, physicians and patients will need to embrace communication of diagnostic uncertainty [50–52]. Communication of diagnostic uncertainty can provide a shared understanding of the patient’s health problem and
managing patient’s expectations for future care. This shared understanding could help patients better engage in the diagnostic process including mindfulness of the evolution of the diagnostic process and emergent care plans. Effective communication could also help prevent delays seen in patients returning too late to the physician for worsening health issues [53]. Our study participants perceived the use of differential diagnosis during the communication of uncertainty less negatively, and thus further exploration of such communication is warranted.

Our study has several limitations. First, we used a convenience sample of parent participants for our study and any generalizability to patients of other medical specialties or to the general population is limited. We also recruited several parent/family advisors, who may have different levels of activation and/or information sharing expectations than the general population. However, this study is one of the first attempts to evaluate the impact of any strategy to communicate diagnostic uncertainty and lays the foundation for future studies in this area. Second, we used text-based vignettes for our study, which might not convey subtle changes in tone, phonetics and body-language akin to that observed in patient–physician communication in the real world. Use of validated audiovisual tools or standardized patients could help in better understanding patient perceptions. However, vignette-based studies have been found to accurately test patients’ perceptions of physicians and evaluate satisfaction with patient–physician encounters and have been commonly used in the literature [54, 55]. Moreover, vignettes were exactly similar for all the three groups except the text related to communication of diagnostic uncertainty. Third, we explored only three distinct strategies of communicating diagnostic uncertainty in practice although several other strategies exist and could be used [4, 22, 56]. Physicians could even combine different strategies to effectively communicate diagnostic uncertainty in the real world. Fourth, we were limited by our sample size in our ability to look for associations or interactions between the different factors. Fifth, in a vignette study we could not assess the potential moderating effects of the physician–patient relational history and only studied a new relationship. Future research should examine how patients/parents react differently to expressed uncertainty in established patient–doctor relationships. Sixth, we used a common reassurance statement for all scenarios in order to minimize its influence on outcome variables. This approach may not be ideal and additional research on use of reassurance in such situations is warranted. Lastly, specific measures used in the study (e.g. to measure uncertainty in medicine) were adapted from a previously validated study [16], and may need further validation.

Conclusion
We found that parents of pediatric patients may react less negatively (i.e. less negative perception of physician’s competence, better trust and confidence, and more intention to adhere) when communication of diagnostic uncertainty was implicit using broad differential diagnoses or most likely diagnosis, compared with strategies that used explicit communication. Because uncertainty is so common in medical practice, additional work is needed to understand how communicating uncertainty affects health outcomes. Our study provides an initial foundation for future development of evidence-based guidance on how physicians can effectively communicate diagnostic uncertainty to patients.

Supplementary material
Supplementary material is available at International Journal for Quality in Health Care online.

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Contributors’ statement
Dr. Viraj Bhise: Dr. Bhise conceptualized and designed the study and the data collection instrument, conducted initial analyses, drafted the initial manuscript and approved the final manuscript as submitted. Dr. Ashley Meyer: Dr. Meyer conceptualized and designed the study, provided critical feedback on the data collection instrument, reviewed and revised the manuscript and approved the final manuscript as submitted. Dr. Shailaja Menon: Dr. Menon provided feedback on the data collection instrument, reviewed the manuscript and approved the final manuscript as submitted. Dr. Geeta Singhal: Dr. Singhal provided expert input and critical feedback on the data collection instrument, reviewed the manuscript and approved the final manuscript as submitted. Dr. Richard Street: Dr. Street provided expert input and critical feedback on the data collection instrument, reviewed the manuscript and approved the final manuscript as submitted. Dr. Traber Giardina: Dr. Giardina provided expert input and critical feedback on the data collection instrument, reviewed the manuscript and approved the final manuscript as submitted. Dr. Hardeep Singh: Dr. Singh conceptualized and designed the study, provided expert input on the data collection instrument, critically reviewed the manuscript and approved the final manuscript as submitted. All authors agree to be accountable for all aspects of the work.

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