

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

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Abstract

Background: diagnostic uncertainty is ubiquitous. Its communication to patients requires further investigation.

Aims: To determine: 1) What is known about how and why diagnostic uncertainty is communicated in acute care; 2) evidence of the effects of (not) communicating diagnostic uncertainty in the acute setting; 3) associated ethical issues.

Methods: systematic review of Medline, Web of Science and SCOPUS for (acute or emergency care) AND (diagnostic uncertainty) AND (ethics OR behaviours). Critical interpretive synthesis and ethical analysis were conducted.

Results and conclusion: Nine studies (primarily surveys and interviews) were identified. Doctors are not trained in communicating diagnostic uncertainty and perceive it to have negative effects on patients; however not communicating diagnostic uncertainty can disempower patients, resulting in delayed/missed diagnoses or inappropriate use of resource.

Keywords

Diagnostic uncertainty, diagnosis, uncertainty in medicine

Key Messages

- Diagnostic uncertainty is ubiquitous in the acute and emergency care setting, but there is not consensus on how, or to what extent, it should be communicated to patients.
- There is some evidence that diagnostic uncertainty is not always communicated in the acute care setting, for a number of reasons.
- There is a lack of empirical data backing up perceptions that disclosure about diagnostic uncertainty could be harmful to patients.
- There is a need for more explicit empirical and ethical analyses, which carefully examine the issues relating to the communication of diagnostic uncertainty on patient experience and clinical outcomes.

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Introduction

Diagnosis is not a single event but a process: “an iterative cycle of information gathering, interpretation and synthesis to develop a set of working diagnoses and ultimately a final diagnosis”.¹ Uncertainty, which is often maximal at the beginning of this process, is present throughout.

Uncertainty in medicine has been widely examined,^{2–6} but the specific concept of “diagnostic uncertainty” has received relatively less attention; a universal definition is lacking.⁷ Diagnostic uncertainty is ubiquitous in the acute/emergency medical setting; the differential often starts wide and is narrowed down through investigation and clinical assessment. A definitive diagnosis is not always reached: one study found that 37% of Emergency Department (ED) patients are discharged with a ‘symptom-based diagnosis’.⁸ It is important to differentiate between diagnostic uncertainty – which is common in many acute presentations – and Medically Unexplained Symptoms (MUS), where

the patient has persistent symptoms for which no organic cause has been identified.⁹

Although diagnostic uncertainty is common in the acute setting, there is not consensus on in what manner, or to what extent, it should be communicated to patients. Its communication requires doctors to balance their responsibility to (i) alleviate anxiety, (ii) make decisions based on clinical expertise, and (iii) provide full disclosure in order to respect a patient’s decision-making autonomy.^{10, 11} Maintaining the right balance in these three matters is crucial to building a relationship of trust with the patient. This is an issue of growing importance, particularly in the context of increased emphasis on shared decision-making in acute settings.^{12, 13} Indeed, new guidance from the GMC recommended that if doctors are uncertain about the diagnosis, they should explain this to the patient.¹⁴

Simpkin and Armstrong published a narrative review of communicating all aspects of uncertainty (prognostic, scientific and diagnostic), highlighting

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

the need for more research in this field.¹⁵ In primary care, the management of diagnostic uncertainty has been examined.^{16, 17} In acute secondary care – which is distinct in terms of acuity of illness, access to investigations and reduced continuity of care, as well as the training that clinicians receive – there is no such analogous review.

We therefore reviewed the literature to answer the following research questions:

1. What is known about *how* and *why* diagnostic uncertainty is communicated in emergency and acute secondary care?
2. What evidence exists on the effects of (not) communicating diagnostic uncertainty in this setting?
3. What are the ethical issues associated with (not) communicating diagnostic uncertainty in this setting?

In order to ensure generalisability of findings, we focussed on those studies which examined uncertainty surrounding general presentations (e.g. chest pain), rather than a specific single diagnosis (e.g. myocardial infarction).

Methods

The review was registered on the PROSPERO database (CRD42018110298). A systematic review framework was employed to ensure a robust and replicable searching strategy and clarity of data extraction. Critical interpretive synthesis¹⁸ and ethical analysis were used to analyse a complex body of literature that combined both qualitative and quantitative studies spanning multiple disciplines.

Identification of studies

Through trial searches, broad search criteria were utilised to capture all relevant literature that referenced: (acute or emergency care) AND (diagnostic uncertainty) AND (ethics OR communication). Ovid MEDLINE(R), Web of Science (Core Collection) and Scopus, were searched from inception to May 2018, and repeated in July 2020. Full search criteria can be seen in Appendix A.

Inclusion criteria

All primary research study designs in English were considered which addressed (either explicitly or implicitly) diagnostic uncertainty and either communication or ethics, which were set in, or primarily concerned with, acute secondary care.

Exclusion Criteria

Abstracts/conference proceedings were excluded. Studies were excluded which were set wholly outside of acute secondary care, or which focussed on: uncertainty about the diagnosis of a single specific

pathology; uncertainty in other contexts, (e.g. therapeutic, scientific or prognostic uncertainty); medically unexplained symptoms; communication between health care professionals.

Study selection

JH screened all titles identified in the first search. CLC screened all titles identified in the updated 2020 search, and ZF co-screened 10% of all papers to ensure consistency. JH or CLC and ZF screened abstracts of those studies which had been highlighted as having potential for inclusion. JH, CLC and ZF identified further studies for inclusion by reference mining. Any disagreements were resolved through face-to-face discussions.

Data extraction

A standardized data extraction form was developed and piloted. Data included: country of origin and the medical setting; methodologies used; limitations and biases; results. Data was cross-checked by the three reviewers and any disagreements were resolved by discussion.

Methods of analysis

The heterogeneous nature of the research identified by the searches did not lend itself to meta-analysis. A critical interpretive synthesis¹⁸ and ethical analysis were performed in addition to the systematic review. A full account of both the merits of and processes involved in critical interpretive synthesis can be found here.^{18, 19} An inductive approach was used to identify recurring themes and develop a synthesizing argument. Ethical analysis was conducted first using the ‘four principles’ (beneficence, nonmaleficence, autonomy and justice)²⁰ as a guide; further emerging ethical issues were identified and discussed.

Results

A summary of the screening and identification process can be seen in the PRISMA diagram in Figure 1. 10 publications (based upon 9 separate studies) were identified, all of which were primary research: 3 mixed methods, 1 quantitative study and 5 qualitative studies. There was a western bias to the literature: 6 studies originated from North America, 2 from Europe and 1 from Australia.

The key data extraction from each article can be seen in Table 1.

We present the results of the review with regard to each of our research questions:

What do we know about how and why diagnostic uncertainty is communicated?

There is a relative lack of research that directly and specifically examines *how* diagnostic uncertainty

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

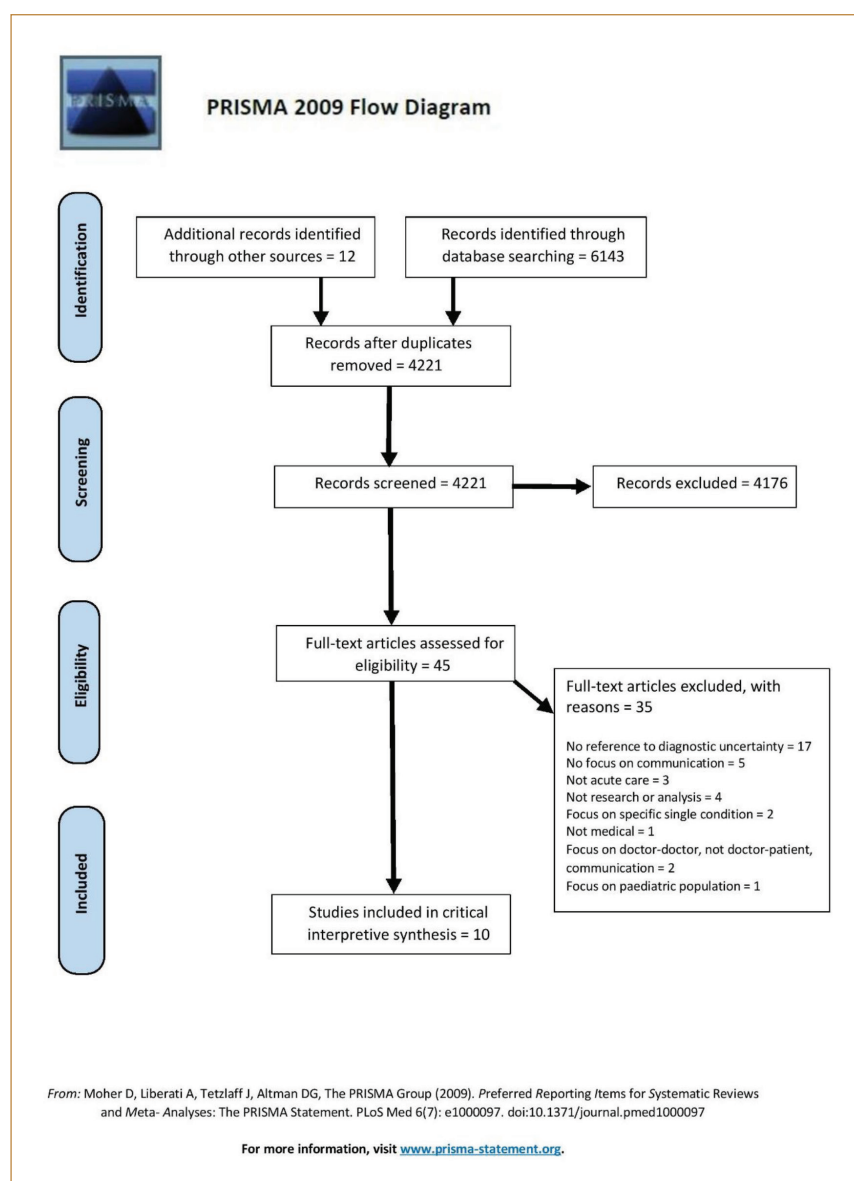


Figure 1. PRIMA diagram.

is communicated in practice: for example, there were no studies reporting observed doctor-patient communication, and no research measured how frequently doctors communicate information about diagnostic uncertainty. One study interviewed patients and healthcare staff to try to understand their experiences of the communication of diagnostic uncertainty.²¹

Several papers examined *why* diagnostic uncertainty is (not) shared with patients.¹⁹⁻²³

Reasons for communicating diagnostic uncertainty to patients:

1. To empower patients

Some doctors expressed ideals about informing patients, for example to help them “have more

ownership over their healthcare”.²¹ A study using semi-structured interviews with emergency physicians supported this idea: one participant commented, “I think if we have these conversations it gives the patient some understanding about what we’re doing... sorta brings them into more of an active role rather than a passive role in their care.”²² Patients expressed a desire for information: “I would like to know everything about my health. I’d like everything. I don’t want the doctor to just say, ‘Oh, yes, you can go home, you’re fine.’ I’d really like to know what’s wrong with me or what’s not wrong with me.”²¹

Both patients and doctors feel that information about presumptive diagnosis, diagnoses on the differential which have been excluded,

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

Table 1. Key data extracted from eligible studies.

Title and authors	Aims	Setting	Article type, research methods, data collection and analysis	Key results
Primary research				
<i>Emergency Medicine Resident Perceptions About the Need for Increased Training in Communicating Diagnostic Uncertainty</i> Rising, Papanagnou, McCarthy, Gentsch and Powell (2018)	To demonstrate the current gap in educational training with regards to communicating diagnostic uncertainty.	US National survey conducted across multiple EDs.	Type: Mixed methods – <i>Qualitative and quantitative</i>. Methods: Survey of 263 EM resident trainees (basic demographic questions, followed by four questions with accompanying open-ended comment boxes related to experiences). Analysis: Simple descriptive statistics, with three researchers analysing and coding qualitative responses by group consensus. Limitations: It was impossible to measure which residents received the survey, and response rate was not recorded. As such there may have been a self-selection bias.	• 43% of EM residents reported often or always encountering challenges when discharging patients with diagnostic uncertainty. • 53% of EM residents reported sometimes encountering challenges when discharging patients with diagnostic uncertainty. • EM resident trainees described patients as leaving “angry, frustrated, confused, upset, unsatisfied, unhappy, disappointed and concerned” if they were not given a definitive diagnosis. • 62% of EM residents reported having been not at all or minimally trained to communicate diagnostic uncertainty during medical school. • 37% of EM residents reported having been trained “fairly well” or better to communicate diagnostic uncertainty during residency. • In both cases, where training was received it was largely informal. • 51% of EM residents expressed a strong desire for more training in how to approach communicating diagnostic uncertainty.

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

<i>The Chest Pain Choice Decision Aid</i> Hess, Knoedler, Shah, Kline, Breslin, Branda, Pencille, Asplin, Nestler, Sadosty, Stiell, Ting and Montori (2012)	To test whether, in the context of chest pain, use of a decision aid to facilitate a patient-centred discussion would increase patient knowledge, increase engagement in decision making, and decrease the proportion of patients who decide to be admitted to the observation unit for stress testing.	US Saint Mary's Hospital ED at the Mayo Clinic	Type: Mixed methods – <i>Qualitative and quantitative</i>. Methods: Prospective randomised study with a parallel, 2 arm design whereby 204 patients with chest pain received either a decision aid (101) or usual care (103) and follow up after 30 days. Analysis: Outcome was measured by patient knowledge in an immediate post visit survey, as well as patient engagement in decision making (as assessed by OPTION criteria) and proportion of patients deciding to undergo cardiac stress testing. Limitations: The trial was conducted in a single centre. There was no power to detect a difference in major adverse cardiac events between groups.	Decision aid patients, in comparison to patients who did not use the decision aid, had: • Greater mean knowledge (more correct answers; 3.6 vs 3). • Greater mean engagement in decision making (higher OPTION scores; 26.6 vs 7). • Decided less frequently to undergo CST (58% vs 77%).
Title and authors	Aims	Setting	Article type, research methods, data collection and analysis	Key results
Primary research				
<i>Discharge Communication in Patients Presenting to the Emergency Department with Chest Pain: Defining the Ideal Content</i> Ackermann, Heierle, Bingisser, Hertwig, Padiyath, Nickel, Langerwitz and Bingisser (2015)	To determine the ideal content of ED discharge communication with chest pain from both the patient and provider perspectives, and to elicit patient perspectives on the information required at discharge.	Switzerland University Hospital of Basel ED.	Type: Mixed methods – <i>Qualitative and quantitative</i>. Methods: Cross-sectional study of 47 physicians and 51 chest pain patients; first EP and patient views were assessed quantitatively through their evaluation of a list, and then patient views were assessed qualitatively through face-to-face interviews. Analysis: Simple descriptive statistics compared quantitative EP responses to subsequent patient responses. Qualitative patient responses were thematically analysed, and a Mann-Whitney U test then demonstrated the distributions of these responses did not differ significantly from those of EPs. Limitations: EPs and patients are unlikely to be in complete agreement with regards to ideal content. The study acknowledges that standardisation can never replace individualised communication.	• 4 out of 5 items endorsed as important content by >50% of EPs were endorsed by >75% of patients. • 84% of patients voiced a need to receive information on their diagnosis, including the significance of the presumptive diagnosis and the association of symptoms with the suspected diagnosis.

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

<i>Quantifying patient-physician communication and perceptions of risk during admissions for possible acute coronary syndromes</i> Newman, Ackerman, Kraushar, Lederhandler, Masri, Starikov, Tsao, Meyers and Shah (2015)	To evaluate communication between patient and physician about these risks by ascertaining the content of discussion surrounding disposition decision.	US 2 academic, inner city EDs.	Type: <i>Quantitative</i> Methods: Matched-pair surveys of 425 patients admitted for possible ACS and their physicians, using descriptive statistics. Analysis: Matched-pair analysis of survey responses, including simple agreement values. Limitations: Unable to find validated instruments for the exploratory survey, which may have left it imperfect or ambiguous. There may also have been a Hawthorne effect on physicians.	• Patients were found to overestimate the risk of myocardial infarction (8% relative to 5% by physicians). • Patients over-estimate the potential benefit of hospital admission (estimate of mortality at home versus hospital of 80% vs 10% relative to 15% and 10% by physicians). • Patient risk estimations were found to be generally less accurate after the patient's discussion with their physician. • The authors argue that most patients can be risk stratified to a less than 1% chance of an adverse event, although no patients can be stratified to zero risk. "In the face of this uncertainty there is considerable resources devoted to pursuing further evaluation".
Title and authors	Aims	Setting	Article type, research methods, data collection and analysis	Key results
Primary research				
<i>Uncertainty and the Shaping of Medical Decisions</i> Beresford (1991)	To identify the sources of uncertainty in clinical practice and consider how this can impact medical decisions.	Canada Variety of urban healthcare settings.	Type: <i>Qualitative</i> Methods: Semi-structured interviews with 25 Canadian physicians. Analysis: Thematic analysis of interviews. Limitations: The author did not clearly describe their methodology and nature of analysis. There was also only a small number of participants.	• Physicians reported over-testing in the search for a degree of diagnostic certainty that is unnecessary and unobtainable. In some cases, this was in order to assure patients, whilst in others it was due to a fear of litigation. • Under time pressure, physicians also admitted patients inappropriately in order to avoid the risk of sending home a patient who should have been admitted.
<i>Patients' Experiences of Cancer Diagnosis as a Result of an Emergency Presentation: A Qualitative Study.</i> Black, Sheringham, Spencer-Hughes, Ridge, Lyons, Williams, Fulop and Pritchard-Jones (2015)	To capture in detail the experiences of patients whose cancer was diagnosed following an ED visit to understand how emergency presentations arise and identify where there is scope to improve outcomes.	UK Service evaluation by London Cancer, covering the population of North-Central London and North-East London and West Essex.	Type: <i>Qualitative</i> Methods: 27 patients were interviewed to assess their experiences of healthcare services before diagnosis. Analysis: Thematic analysis of interviews. Limitations: A limited number of potential participants were approached for interview.	• Patient concerns about discovering they have cancer, and about the harms or embarrassment of investigations, may have acted as particular incentives to adhering strongly to a benign diagnosis once given.

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

<i>The Physician-as-Stakeholder: An Exploratory Qualitative Analysis of Physicians' Motivations for Using Shared Decision Making in the Emergency Department</i> Schoenfeld, Goff, Elia, Khordipour, Poronsky, Nault, Lindenauer and Mazor (2016)	To identify and explore factors that may motivate EPs' engagement in SDM.	US EPs from several regions.	Type: <i>Qualitative</i> Methods: Semi-structured interviews with a purposeful sample of 15 EPs. Analysis: Thematic analysis of interviews. Limitations: Perceived barriers were not included in this analysis. Pre-existing assumptions and social desirability bias may have influenced data collection.	• All participating EPs believed that patients benefited from SDM in terms of satisfaction, engagement, or education. • EPs noted that using SDM in scenarios would lead to increased resource utilisation or decreases in testing. • EPs often initiate SDM because of a conscious agenda, such as avoiding tests and interventions with minimal benefit or possible harm, or sharing and mitigating uncertainty. This often occurs where the standard of care was in direct opposition to what the physician felt was best for that particular patient, so rather than unilaterally diverging from the standard of care, the physician used SDM to explain the situation and obtain input from the patient regarding their values, preferences and often risk tolerance.
Title and authors	Aims	Setting	Article type, research methods, data collection and analysis	Key results
Primary research				
<i>Physician-identified barriers to and facilitators of shared decision-making in the Emergency Department: an exploratory analysis</i> Schoenfeld, Goff, Elia, Khordipour, Poronsky, Nault, Lindenauer, Mazor (2020)	To explore physician-identified barriers to and facilitators of SDM in the ED	US EPs from several regions.	Type: Primary research – <i>Qualitative</i> Methods: Semi-structured interviews with a purposeful sample of 15 EPs. Analysis: Thematic analysis of interviews. Limitations: Pre-existing assumptions and social desirability bias may have influenced data collection. Only examined physician-identified barriers - physicians may not recognise the same barriers that patients, nurses or other involved parties feel are important.	• EPs described the following barriers: time constraints, clinical uncertainty, fear of a bad outcome, certain patient characteristics, lack of follow-up and other emotional and logistical stressors. • EPs noted that risk stratification methods, the perception that SDM decreased liability and their own improving clinical skills facilitated their use of SDM. • The culture of the institution could play a role in discouraging or promoting SDM, and patients could encourage SDM by specifically asking about alternatives.

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

<i>Managing Uncertainty During the Communication of Diagnostic Test Information Between Patients and Clinicians in Australian Emergency Care</i> Miao, Dahm, Li, Thomas, Georgiou. (2020)	To understand patient and clinician perspectives/ experiences of the communication of diagnostic test results in ED, and to understand the management of uncertainty in the discussion of these results.	Australia EPs and patients from two metropolitan and one regional ED in New South Wales	Type: <i>Qualitative</i> Methods: Semi-structured interviews with EPs and patients who had received pathology laboratory or radiology testing while in ED Analysis: interviews analysed using inductive thematic analysis, then a normative theory of uncertainty management Limitations: limited generalizability beyond the examined context and population. Patient interviews occurred in ED, so were somewhat limited by practical considerations, (including convenience rather than purposive sampling of ED patients, and necessity for shorter structured patient interview protocols)	• Themes of “Ideals,” “Service Efficiency,” and “Managing Uncertainty” were inductively identified as influencing the communication of diagnostic test information. • Systemic tensions between themes accounted for when diagnostic test information communication occurred, was deferred or avoided. • For example, need to balance managing patient emotion around uncertainty with ideals – EPs reported purposefully maintaining uncertainty when discussing potentially “life-limiting abnormalities” in diagnostic tests. • EPs use communication strategies such as progressive disclosure or foreshadowing of diagnostic test information until results could be delivered face-to-face with enough certainty. • EPs also purposefully maintain uncertainty on discharge if a definite diagnosis has not been reached as protection against premature closure or error. • Some EPs also maintain uncertainty around diagnosis and avoid absolute terms to protect from litigation. • EPs often only discuss abnormal investigation results or discuss higher risk investigations due to time restraints. • Patients report negative conceptualisation of uncertainty, with desire for more information to reduce uncertainty around diagnosis.
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Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

Title and authors	Aims	Setting	Article type, research methods, data collection and analysis	Key results
Primary research				
<i>Development of the Uncertainty Communication Checklist: A Patient-Centered Approach to Patient Discharge From the Emergency Department</i> Rising, Powell, Cameron, Salzman, Papanagnou, Doty, Latimer, Piserchia, McGaghie, McCarthy. (2020)	To develop the Uncertainty Communication Checklist for use in simulation-based training and assessment of emergency physician communication skills when discharging patients with diagnostic uncertainty.	US Patients and expert focus group members from variety of centres in US.	Type: <i>Qualitative</i> Methods: Used the established 12-step Checklist Development Checklist framework to develop the checklist. 3 categories of participants were involved in the checklist development: the study team, expert panel members, and focus group patient participants. Analysis: The authors developed a preliminary instrument based on existing checklists, clinical experience, literature review, and input from an expert panel comprising health care professionals and patient advocates. They then refined the instrument based on feedback from 2 waves of patient focus groups, resulting in a final 21-item checklist. Limitations: Selection bias in patient participants – those who agreed to partake in checklist development may not be processes involving group dynamics, such as focus groups and expert panel sessions, may be influenced by a single forceful opinion and may not represent true consensus. Checklist designed for educational use, not for use during real patient encounters.	- Steps in the checklist include discussing diagnoses that were considered (using both medical and lay terminology), and discussing possible alternate or working diagnoses. - The extensive patient input into the development of the items on the checklist provides some evidence for patient desire for the communication of information surrounding diagnostic uncertainty.

Key: ED = Emergency department, EM = Emergency medicine, EP = Emergency Physician, SDM = Shared decision-making

and the need for further investigation should be included on ED discharge summaries.²³ Furthermore, patients were explicit in their desire for openness about uncertainty: 2 of the 10 most frequently named patient needs elicited in a free generation task were “for the physician to admit if they do not know something”, and “for the physician to be completely honest without concealing details”.

One paper described the development – with patients – of an uncertainty communication checklist for use in simulation-based training. Two of the items on the final checklist were discussing diagnoses that were considered, and discussing possible alternate or working diagnoses.²⁴

2. To mitigate risk, including reducing the likelihood of diagnostic error and/or litigation.

In interviews with physicians, one participant described communicating uncertainty to share the risk of missing a more serious diagnosis, commenting, “I want them to be aware that although the risk is low, there is some little bit of risk there that something bad could happen to this person”.²⁵ Another participant emphasised that the working diagnosis might be wrong, encouraging the patient to return if needed: “I recognize that there are certainly limitations to my intellect or skill set...if something goes in the wrong direction then they knew that I was open to the idea that I wanted them to come back”.²⁵

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

Miao describes some doctors having a positive conceptualisation of uncertainty, explicitly discussing diagnostic uncertainty with patients as a safeguard against diagnostic error (“*I think that’s important that they understand that medicine is not an exact science*”) and litigation (“*If you give absolutes you just open yourself to litigation, so the patients get peeved off; ‘You told me there’s nothing wrong with me’. I would say, ‘low risk’ but not ‘no risk’*”).²¹

3. To manage patient emotion surrounding potentially life-limiting diagnoses.

Some doctors had a positive conceptualisation of uncertainty when communicating the purpose of a test for potentially life-limiting diagnoses. In these situations, doctors might intentionally maintain the uncertainty around the diagnosis or purpose of investigations: “*Sometimes I’ll explicitly and intentionally not tell them what I’m looking for. But I will say; ‘Let’s do some tests and see if we can figure out what’s going on’... Sometimes it’s nicer to kinda ease into that conversation, than to drop the bombshell in the first conversation*”.²¹

Reasons for **not** communicating diagnostic uncertainty to patients

1. Concerns about patient risk intolerance:

Doctors often have negative perceptions about the impact of sharing diagnostic uncertainty with their patients. In a survey of Emergency Medicine residents, comments were focussed on patient expectations, such as “*Patients want definitive answers and inconclusive is the opposite*”.¹ Participants also discussed the perceived need for reassurance of patients in the ED: “*As uncomfortable as we are with uncertainty, our patients are often even more uncomfortable. They WANT reassurance*”.¹ These results are somewhat supported by another study, in which one of the 10 most-frequently patient-reported communication needs was “*to be reassured*”.²³ Other interviews with emergency physicians further support the idea that doctors do not always feel that patients are able to understand, or are willing to engage in, conversations about diagnostic uncertainty. One participant noted: “*There are families who are not as receptive to... grey areas, medical uncertainty, diagnostic uncertainty*”, whilst another said: “*The main thing that stands in my way is the patient’s inability to understand risk*”.²²

Some doctors expressed concern that communicating uncertainty might result in patients losing confidence in them: “*I think that people want to know that the doctor that they*

talked to had found something or was confident in this is what’s going on... [not] ‘maybe it’s this, maybe it’s that?’ I don’t want to sound too wishy-washy”.²² This is supported by reports of perceived mistrust in the medical system among patients who were discharged without a definitive diagnosis.¹

2. Lack of training in the communication of diagnostic uncertainty and physician intolerance of uncertainty

Some degree of risk tolerance is required on the part of physician in order to share and mitigate diagnostic uncertainty. However, emergency medicine physicians said that they themselves were uncomfortable with uncertainty, reporting a sense of failure when unable to provide their patients with a diagnosis.¹ A further interview study found that risk-averse emergency physicians were less likely to communicate uncertainty as part of shared decision-making, implying that physician discomfort in the context of diagnostic uncertainty is an important obstacle to its communication.²⁵

Training in the communication of uncertainty is lacking: 62% of US emergency physicians reported minimal to no training during medical school, and only 37% reported being trained “fairly well” or better during residency. Where training *was* received it was largely informal.¹

3. Logistical constraints, particularly time pressure

In Schoenfeld’s study of emergency physicians, nearly every participant highlighted time constraints as a barrier to shared decision-making. Comments included “*Time is perhaps the major constraint*”, and “*you can’t go in there knowing you only have 5 min cause it’s never gonna take just 5 min*”.²² Other logistical barriers included frequent interruptions, challenges due to physical space and difficulties in ensuring reliable follow-up.²² Rising’s study highlighted logistical concerns as a challenge in communicating diagnostic uncertainty, with one participant discussing the difficulties in providing patients who did not receive a definite diagnosis with clear follow-up.¹

An important theme in Miao’s paper was the tension between ideals and service efficiency, with doctors sometimes not honouring communication ideals due to acute setting pressures. One participant noted, “*sometimes when we’re under pressure we don’t do it [communication] as well and we don’t inform them*”.²¹

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

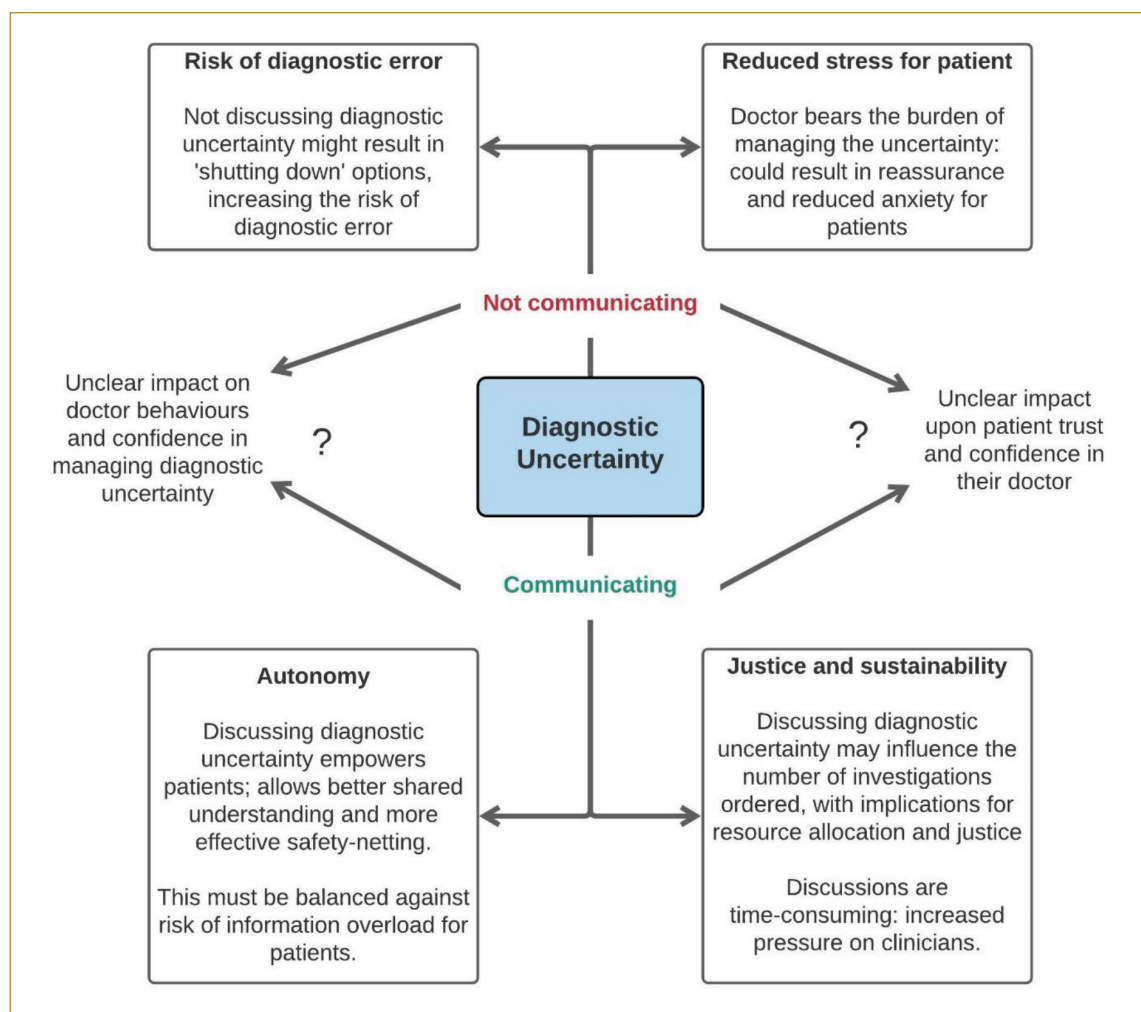


Figure 2. Ethical issues associated with the (non) communication of diagnostic uncertainty.

What evidence exists on the effects of communicating (or not communicating) diagnostic uncertainty?

Effects on patients

Several studies surveyed doctors, providing information on doctors' perceptions of the effect on patients.^{1, 22, 25, 26} Physicians reported that patients expect answers, and believed that patients feel 'angry', 'confused' and 'upset' when they do not receive a definite diagnosis;¹ some doctors felt that communicating uncertainty might reduce patients' confidence in them.²²

We identified four studies surveying or interviewing patients.^{21, 27-29} A patient-centred study of a decisional aid to communicate diagnostic uncertainty and risk in chest pain demonstrated that use of the decision aid did not alter patients' trust in their physicians, countering physician's concerns.²⁸ The use of the decisional aid was also associated with increased patient knowledge, reduced decisional conflict and increased satisfaction with the decision-making process.²⁸

Attempts to communicate diagnostic uncertainty are not, however, always effective. Patients' estimates of 30-day adverse event risk diverged from the physicians' estimates more *after* speaking to a physician, suggesting that communication was "largely ineffective at both achieving accurate risk estimation and aligning physician and patient perceptions".²⁷

Importantly, *not* communicating the extent of diagnostic uncertainty to patients might disempower them, leading to worse health outcomes. Patient interviews found that for some, a working 'benign diagnosis' – without disclosure of the surrounding diagnostic uncertainty – resulted in inappropriate re-evaluation (self-doubt, or dismissal) of symptoms by patients, and delayed re-presentation.²⁹

Effects on resource utilisation and investigation

Where doctors do not adequately communicate diagnostic uncertainty, it can adversely interfere with the allocation of scarce resources. Interviews with physicians,²⁶ and a matched-pair survey of

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

patients and physicians,²⁷ found that in the face of uncertainty there can be an inappropriate increase in resources put into chasing a certain diagnosis (even if it may be unobtainable), at least in part driven by the patient's wish for a "complete diagnosis". However, when uncertainty (in the diagnosis of the cause of chest pain) was shared with an explicit decision aid, resource utilisation was decreased, and unnecessary testing and admissions were reduced.²⁸

What are the ethical issues associated with communicating (or not communicating) diagnostic uncertainty?

No primary ethical analyses of the effects of (not) communicating diagnostic uncertainty in the acute care setting were identified in this review. We therefore performed a secondary ethical analysis of the identified empirical literature; figure 2 outlines some of the important ethical issues arising from the analysis, in particular considering the effects of communicating, or not communicating, diagnostic uncertainty to patients.

If it is accepted that autonomy is a primary tenet of medical ethics, an argument can be made that doctors should communicate as much information as they can to their patients (including uncertainty about their diagnosis); the empirical data supports the idea that this facilitates the patient taking on a more active (and autonomous) role in their own care.^{21, 22, 30} Most importantly, this might empower patients to appropriately re-present in the event of their symptoms changing or not-resolving.^{23, 25}

The assumption that patients should be given information about diagnostic uncertainty is complicated by the fact that patients can not provide informed consent to whether they would want the information without knowing what it is. Furthermore, it is not necessarily true that more information always increases patient autonomy – if the information is overwhelming, overly technical or excessive in detail, it does not support autonomous decision-making.³¹ Concerns that patients may not be able to understand or fully engage in conversations about risk or diagnostic uncertainty are relevant here.²²

Whether communicating diagnostic uncertainty is beneficial or harmful to patients is difficult to state with certainty given the relatively limited and at times conflicting empirical evidence identified in this review.^{1, 21, 22, 28} One harmful consequence of not communicating uncertainty in diagnosis is to "shut down" other options: in Black's study of patients with a late cancer diagnosis, patients who had been given a benign explanation for their symptoms – without the

caveat of uncertainty – did not seek further medical help when their symptoms got worse.²⁹

Finally, doctors have an ethical responsibility to balance the needs of the immediate patient in front of them against the needs of other patients (both present and future) to ensure just healthcare for all^{32, 33} – for example, though fair use of limited resources. The studies identified in this review suggest that diagnostic uncertainty can drive inappropriate over-investigation;²⁶ explicit discussion about diagnostic uncertainty could reduce resource utilisation and unnecessary testing could be decreased.²⁸ The logistical challenges associated with communicating diagnostic uncertainty must also be considered: having such discussions places increased time-pressure on clinicians,^{21, 22} and may necessitate consideration of how to best provide care for multiple patients in an acute setting.

Discussion

Diagnostic uncertainty was shared with patients to promote engagement and to protect both the patient (from diagnostic errors) and the doctor (from litigation). Although doctors expressed concerns that sharing diagnostic uncertainty might erode trust, there was little patient-focused evidence supporting this; some studies suggested that patients *do* wish to be informed about diagnostic uncertainty. Lack of training and logistical constraints limit doctors' communication of uncertainty.

There is a need for more patient-centric research to understand preferences and the effects of (not) communicating diagnostic uncertainty in the acute setting.

Research in other patient populations suggests potential negative effects of communicating uncertainty to patients. A vignette study of parents of paediatric patients examined the impact of expressing uncertainty explicitly ("*not sure*") or implicitly (either by using differential diagnosis terms, or terms such as "*most likely*"). Explicit expression of uncertainty was associated with lower perceived technical competence of the clinician, less trust and less adherence.⁷ Other studies have identified reduced patient satisfaction associated with communicating uncertainty in scientific evidence or with treatment decisions.^{34, 35} We did not identify any analogous studies of adult patients in the acute care setting, nor was there any published data which demonstrated similar effects on patient satisfaction associated with the communication of diagnostic uncertainty specifically. Further research would enable us to better understand what patients want, and the what the effects of communicating

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

(or not communicating) diagnostic uncertainty to them are.

Mis- and delayed diagnosis and the need for legal analysis

In Black's study, "shutting down" options too early was associated with delayed diagnosis. In a study of diagnostic error more generally, the single most common cognitive cause was *"the failure to continue considering reasonable alternatives after an initial diagnosis was reached"*.²⁹

The concept of 'safety netting' – telling patients under when to come back – is well established,³⁹ but less established is the practice of explicitly relating this to the broader differential diagnosis. In primary care, the importance of explicitly discussing diagnostic uncertainty as part of the safety-netting process has been recognised, for example by sharing any uncertainty surrounding the working diagnosis and describing reasons for any investigations.³⁷ This is also common in acute medicine, but was not examined in any of the studies identified.

Empirical analysis of mis- or delayed diagnosis would enable a more thorough investigation of what has been communicated by doctors to their patients (and how those communications have been interpreted).

The associated ethical issues are underexplored and require further analysis, with support from additional empirical studies.

The need to share information with patients to facilitate autonomous decision-making has been highlighted by many.^{20, 38-40} The question of what information doctors are legally compelled to disclose to patients in the context of treatment options was altered by the Montgomery judgment: doctors are now under a duty to *'take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments'*.⁴⁰ How much doctors should communicate about diagnostic uncertainty has not been subjected to the same legal or ethical analysis, and, as Richard et al note in their analysis of disclosure in medicine, *"the doctor is torn between the need to provide*

the patient with information so that considered independent decisions can be made, and the desire to ensure the patient's well-being by minimising suffering".⁴²

Withholding information by the clinician in the belief that its disclosure would lead to patient harm or suffering has some precedent, in the concept of 'therapeutic privilege'.⁴³ Historically, some clinicians would withhold or generalise certain information thought to pose a threat to patient welfare, for example distressing diagnostic or prognostic information. This perception, that patients would rather not be informed if they have a seriously distressing or life-limiting diagnosis, has been widely demonstrated to be false in empirical studies.⁴⁴

Strengths and Limitations

This was a comprehensive review of the literature on communicating diagnostic uncertainty in acute and emergency care. However, the nature of the studies identified were heterogeneous and allowed only descriptive analysis. All of the studies were conducted in western cultures; care should be taken before extrapolating to other cultures. No doctor-patient interactions were observed in the eligible studies; most reports are therefore of perceived rather than actual interactions.

Conclusions and Further work

We propose that there is a need for more explicit empirical and ethical research, which carefully examines the issues relating to the communication of diagnostic uncertainty on patient experience and clinical outcomes. It may be that – like the old practice of not disclosing information about a cancer diagnosis – not disclosing information about diagnostic uncertainty is demonstrated to be contrary to many patients' actual preferences.

More research would enable evidence-based training to equip the acute physicians of the future to communicate uncertainty in diagnosis safely and appropriately.

Conflict of Interest

The authors do not have any conflict of interest relating to this work.

Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

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Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature.

Appendix A: search strategy

Overview

Searches run original May 2018

Searches updated 1st July 2020

	Original hits	New hits since May 2018
Medline via OVID	1435	381
Web of Science Core Collection	812	334
Scopus	2565	616
Total	4812	1331
Total deduplicated	3383	838

Medline via OVID

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to June 30, 2020

1. (acute adj2 (unit* or medic* or care or healthcare or admission* or setting*)).mp.
2. exp Emergency Service, Hospital/ or (emergenc* adj2 (unit* or ward* or department* or care or admission* or service*)).mp.
3. 1 or 2 (189541)
4. exp ETHICS/ or ethic*.mp.
5. exp Physician-Patient Relations/ or exp Communication/ or communicat*.mp.
6. 4 or 5
7. (decision* adj2 mak*).mp. or exp Decision Making/ or clinical reasoning.mp.
8. exp Diagnosis, Differential/ or differential diagnosis.mp.
9. (uncertain*.mp. or exp UNCERTAINTY/) and (diagnos*.mp. or exp diagnosis/)
10. 7 or 8 or 9
11. 3 and 6 and 10

((2018605* or 201806* or 201807* or 201808* or 201809* or 201810* or 201811* or 201812* or 2019* or 2020*).dp. or (2018605* or 201806* or 201807* or 201808* or 201809* or 201810* or 201811* or 201812* or 2019* or 2020*).ez. or (2018605* or 201806* or 201807* or 201808* or 201809* or 201810* or 201811* or 201812* or 2019* or 2020*).ed.)

Web of Science (Core Collection)

(TS= ((decision near/2 mak*) or (clinical reasoning))) OR (TS= (differential diagnosis)) OR (TS=(uncertain* near/5 diagnosis))

And

(TS= (ethic* or communicat*))

And

(TS= ((acute near/2 (unit* or medic* or care or healthcare or admission* or setting*))) OR (TS= (emergenc* near/2 (unit* or ward* or department* or care or admission* or service*)))

Scopus

(TITLE-ABS-KEY ((((acute W/2 (care OR healthcare OR admission* OR unit* OR medic* OR setting*))))) OR TITLE-ABS-KEY ((emergenc* W/2 (care OR unit* OR ward* OR department* OR care OR admission* OR service*)))) AND (TITLE-ABS-KEY ((ethic* OR communicat*))) AND (TITLE-ABS-KEY (((decision W/2 mak*) OR ("clinical reasoning"))) OR TITLE-ABS-KEY (("differential diagnosis")) OR TITLE-ABS-KEY ((uncertain* W/5 diagnosis*)))

Results = 2565