

# Patient and family engagement in incident investigations: exploring hospital manager and incident investigators' experiences and challenges

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## Abstract

**Objective:** There is growing recognition among health care providers and policy makers that when things go wrong, the patient or their families should be heard and participate in the incident investigation process. This paper explores how Dutch hospitals organize patient or family engagement in incident investigations, maps out incident investigators' experiences of involving patients or their families in incident investigations and identifies the challenges encountered.

**Methods:** Semi-structured interviews were conducted with managers and incident investigators in 13 Dutch hospitals. Study participants (n = 18) were asked about the incident investigation routines and their experiences of involving affected patients or family members. Interview transcripts were coded and analysed using thematic content analysis.

**Results:** Our findings reveal that patient or family involvement in incident investigations is typically organized as a one-time interview event. Interviews with patients or their families were considered to be valuable and important in their own right and seen as a way to do justice to the individual needs of the patient or their family. Yet, the usefulness and validity of the patient or family perspective for incident investigations was often seen to be limited, with the professional perspective afforded more weight. This was particularly the case when the patient or their family were unable to provide verifiable details of the incident under investigation. Study participants described challenges when involving patients or family members, including in relation to the available timeframe for incident investigations, legal issues, managing trust and working with intense emotions.

**Conclusions:** We propose that by placing patient and family criteria of significance at the centre of incident investigations (i.e. an 'emic' research approach), hospitals may be able to expand their learning potential and improve patient-centeredness following an incident.

## Keywords

incident reporting and analysis, patient-centred care, serious incidents

## Introduction

Patient centeredness in health care has become a widespread goal. Initiatives to achieve patient participation vary widely and can be found in many aspects of health care delivery, including patient safety. Emerging incident disclosure frameworks highlight the importance of the patient's or their family's experiences, needs and rights.<sup>1–5</sup>

There is growing recognition among health care providers, policy makers and scholars that when things go wrong,<sup>3</sup> patients or their families should also be heard and participate in the incident investigation process.<sup>6–10</sup>

The literature discusses two main lines of reasoning as to why patients or their families should be involved

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in incident investigations. First, a moral justification emphasizes the rights and needs of an affected individual and their family. It argues that their involvement is an ethical imperative, is necessary for acceptance, supports the grieving process and reestablish bonds of trust.<sup>8,11,12</sup> The second is an epistemological justification which recognizes the epistemic value of the patient or family perspective; that is, the existence and validity of knowledge attributed to their experience. The epistemological justification draws on concepts of system-based learning and patient-centred health care. It recognizes that all actors are experts in their own right and that patients and their families bring valuable knowledge that can inform learning from what has gone wrong, thereby improving patient safety.<sup>13,14</sup> It also explicitly recognizes that there is a patient or family perspective and that this can differ from the professional perspective.<sup>15–17</sup> The patient or family experience can thus offer key insights that might otherwise be overlooked.<sup>18</sup>

While recognized as an important issue, there are few published descriptions of processes that explicitly consider the patient or family perspective in responding to patient safety incidents.<sup>19,20</sup> Empirical data on how hospitals organize and experience patient or family engagement in incident investigations remain scarce,<sup>6</sup> and the degree to which the moral or epistemological justifications resonate through these practices remains unclear. This study aims to contribute to closing this gap by exploring how Dutch hospitals organize patient or family involvement in incident investigations and how this is experienced by those responsible for incident investigations.

### *Patient and family engagement in serious incident investigations in the Netherlands*

In the Netherlands, a newly passed law (January 2016) mandates hospitals to involve patients and their families in incident investigations.<sup>4</sup> Dutch hospitals are required to implement internal incident monitoring systems and to report serious incidents to the Dutch Health Care Inspectorate (HCI), the national regulatory body. Dutch law defines serious incidents as unintended or unexpected events that are related to the quality of care and that have caused the death of or serious harm to the patient. They are internally investigated by cause analysis (RCA), or similar form of investigation in an attempt to learn from what went wrong. Hospitals have eight weeks to investigate the event and submit the investigation report to the HCI. The HCI actively monitors patient and family engagement, seeing it as ‘a necessary ingredient for hospitals to optimally learn from what has gone wrong’<sup>21</sup> (epistemological justification) while also considering

involvement to be ‘an external check on the investigation’s validity’.<sup>22</sup>

The legislative framework in place means that the patient or family incident investigation engagement rate in Dutch hospitals is likely to be high. Indeed, HCI data show that the proportion of incident investigation reports that documented some form of input from the patient or their family increased from 15% in 2013 to almost 85% in 2016 (Figure 1). However, what remains unclear is what precisely patient and family engagement in incident investigations in Dutch hospitals entails, how the patient or family perspective is being used in investigations and the challenges that are being encountered by managers and incident investigators in involving patients or their families.

## **Methods**

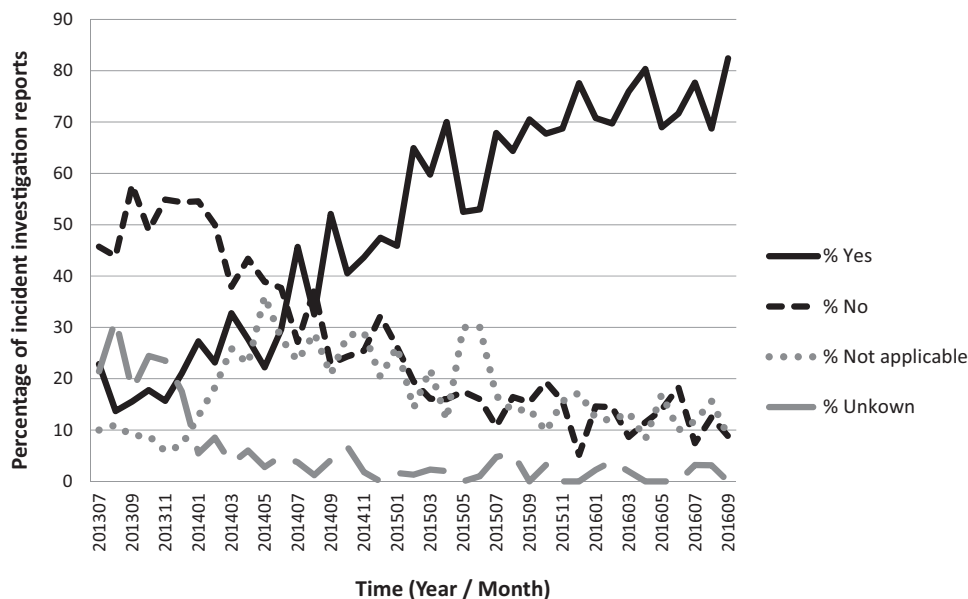
### *Sampling*

Sampling was conducted in two stages. In the first stage, we purposively selected 10 (out of a total of 93) hospitals. These were geographically evenly spread throughout the country and included academic teaching, tertiary and general hospitals. Included hospitals scored excellent, average or poor with regard to the quality of their incident investigation reports, as documented by the HCI (Table 1). Our initial aim was to continue sampling until no new insights emerged from the data,<sup>23</sup> but preliminary analysis suggested that saturation had already been reached within the small initial sample of 10 hospitals. We randomly approached three additional hospitals; this did not reveal any further insights, confirming that we had reached data saturation.

### *Data collection*

This study targeted individuals responsible for or involved in incident investigation in Dutch hospitals. Secretariats from the sample were contacted by telephone to inquire who was responsible for incident investigations within their organization. Following this, we approached 19 eligible individuals for an interview via email, which provided details of the study’s objective and specified confidentiality standards, namely, that all data would be fully anonymized to facilitate open and transparent communication. Stressing these norms was particularly relevant as one of the authors (IL) is employed by the HCI. One potential study participant declined participation.

Interviews were conducted by the first author (JK), who had no prior relationship with study participants, but had met one participant at an international patient safety conference. Interviews followed an interview guide, exploring key topics of interest (Table 1).



**Figure 1.** Documented involvement of patients or families in incident investigations in the Netherlands. Solid black line denotes percentage of incident investigation reports received by the HCl that have received input from the affected patient or their family. Source: HCl's incident investigation monitoring database (accessed December 2016), unpublished data. HCl: Dutch Health Care Inspectorate.

**Table 1.** Interview guide.

	<i>Introduction</i>
	<ul style="list-style-type: none"> <li>• General acquaintance</li> <li>• Repeat purpose study</li> <li>• Repeat confidentiality norms</li> <li>• Informed consent/permission auto-recoding</li> </ul>
Topic 1	Incident investigation team Participants: how many? Who is involved? etc. Organization: formal/informal activities Own role/responsibilities
Topic 2	Incident investigation routine/work protocol Experiences Challenges
Topic 3	Patient/family engagement Process description Experiences Challenges
	<i>Wrap up</i>
	<ul style="list-style-type: none"> <li>• Other points to discuss?</li> <li>• Member-check appointment made</li> </ul>

We carried out a total of 15 semi-structured interviews, involving 18 participants in 13 hospitals (Table 2). Interviews were carried out face-to-face; they lasted between 50 and 90 minutes. Interviews were audio recorded following consent and transcribed verbatim. Participants were invited to receive a copy of the transcript to validate or amend their accounts. Nine respondents did request the transcript, but none requested any changes.

### Data analysis

Data were analysed using thematic content analysis. This involved categorizing data based on recurrent patterns and deviant cases found within the earlier defined topics from the interview guide (Table 2).<sup>23</sup> Transcripts were first coded inductively (open coding) in Microsoft Word by JK. The inductive codes were transferred to tables, ordering related interview extracts. In the second coding phase, the content in these tables was reexamined to search for and define patterns. The identified patterns were discussed (JK and RB) to agree on the credibility of our interpretations.

Our analysis was presented at the Third International Disclosure Conference (Amsterdam, October 2016), attended by many of the study participants. The presentation and succeeding discussion provided a member-check platform as participants publicly reflected on our analysis. The discussion established that our analysis reflected the reported involvement practices and experienced challenges.

Quotes presented in this paper were translated into English. They were selected to illustrate our analytical findings. The selected quotes were shared with study participants to obtain permission for use and validate our translation.

### Ethical approval

This study did not require approval from national or local ethical committees as Dutch law (WMO act)

**Table 2.** Study participants and interview details.

Hospital details			Study participants			Interview details	
Hospital No. type	Average quality of incident analysis report vs. national average (0–100%) <sup>a</sup>	Gender	Occupation	Role in RCA investigation process	One-on-one/duo	Length (min)	
1 Academic	75 /78	Female	Manager	RCA investigator/committee member	o	80	
2 Tertiary	90 /82	Male	Director/medical professional	Committee chair	o	63	
3 Tertiary	88 /80	Female	Manager	Committee chair	o	75	
4 Tertiary	91 /81	Female	Manager	RCA investigator	o	87	
		Female	Quality and safety advisor	Committee chair	o	58	
5 Tertiary	84 /81	Female	Medical professional	RCA investigator	o	59	
6 General/tertiary	78 /81	Female	Manager	Committee chair	o	91	
		Female	Assistant manager	RCA investigator/committee member	o	62	
7 Tertiary	78 /81	Female	Manager	Committee chair	d	61	
		Male	Manager/medical professional	Committee secretary	d	61	
8 Academic	76 /81	Male	Assistant manager	RCA investigator/committee member	d	70	
9 General/tertiary	76 /81	Male	Manager/medical professional	Committee chair	o	52	
10 General	70 /80	Female	Manager	Committee chair	o	76	
11 Tertiary	70 /82	Female	Legal advisor	Committee secretary/ RCA investigator	o	72	
12 General/tertiary	75 /81	Female	Manager	Committee secretary/ RCA investigator	o	75	
		Female	Manager	Committee secretary	d	75	
13 Tertiary	83 /82	Female	Assistant manager	RCA investigator/committee member	d	75	

<sup>a</sup>Incident analysis reports are scored by the HCI (0–100%) to monitor the quality of the incident investigation. Data present the moving average over five years at the time of this study as recorded by the HCI. Source: HCI's incident investigation monitoring database (accessed Feb–Aug 2015), unpublished data.

RCA: root cause analysis; HCI: Dutch Health Care Inspectorate.

determines such approval is not required for reflective interview studies.<sup>24</sup>

## Results

Study participants from all 13 hospitals (n = 18) included in the study reported that they would seek patient involvement during incident investigations and all but one actively sought input from family members when the patient was (emotionally) not able to participate or was deceased. All study participants noted that the majority of patients or their families wished to be involved in the investigation process. Our analysis of the data identified a number of key themes. These were: the practical

organization of patient or family involvement; motivations for involving patients or families; and experienced challenges of involving a patient or their families in incident investigations. We report on each theme in turn.

### *Patient or family involvement is a one-time event*

Study participants explained that it was a common practice for an incident investigation team to be formed within the hospital immediately after a serious incident had been discovered. Teams would typically comprise of two to five trained incident investigators with diverse clinical (doctor, nurse) and non-clinical (administrative support staff)

backgrounds. Most study participants reported that incident investigators on these teams would conduct these investigations on a voluntarily basis, in addition to their day-to-day work. A typical investigation would start by examining medical file(s) to describe the problem, followed by defining the questions that the investigation should answer and the sources to be consulted to understand the causal factors that have contributed to the problem:

Depending on the type of incident we decide what it is we need to know. General research questions are formulated. And (...) we determine who we need to speak to. We plan interviews with these actors and (...) we involve the patient or their next of kin. (...) We contact them and ask if they would like to be interviewed or just wish to receive the end report. (RCA Investigator, no. 7)

There was widespread agreement that patient or family involvement in the investigation process would generally constitute a one-time interview event rather than ongoing engagement. Study participants noted that a patient or family interview may last anywhere between 30 minutes and two hours. Practices vary between hospitals, however, for example in the way they communicate with patients or their families affected by the incident. Some formally invite the patient or their family by sending a letter or leaflets to inform them about the investigation process and purpose. Others use a more informal approach, communicating with the patient or their family face-to-face or on the phone. Interviews with patients or their family are conducted at the hospital, in people's own homes or by telephone. Some hospitals strictly adhere to one location while others are more flexible, choosing the location of the interview in line with the patient's or their family's preferences. Also, hospitals differ in sequencing the process; that is, the point when the patient or their family is being interviewed. Study participants from two hospitals expressed a strong preference for starting the process with input from the patient or their family to allow them to share their experiences first, while the majority would conduct the interview at a time of practical convenience i.e. when personal schedules of involved participants matched. Hospitals also vary in the range of hospital staff involved in the interview of the patient or their family. Typically, interviews comprise two incident investigators and the patient or a family member. Occasionally, a quality manager, member of the hospital board or medical specialist who was not involved in the incident may join. The presence of a complaints officer is also becoming more common, to lead the interview or serve as a support person for either the patient/their family or investigator(s).

### *Motivations for patient or family engagement in incident investigations*

All study participants stated that they valued patient and family engagement in incident investigations. Several participants specifically highlighted their appreciation of the HCI, which had helped or forced hospitals to overcome the 'hurdle' of engaging patients and their families during investigations:

R: We must compliment the HCI, (...) it is a good thing they enforce this [patient and family engagement]. It has really improved the quality.

I: In what way?

R: Well you do hear [during the patient or family interview] several things that you won't find in the official internal documentation or hear from the medical staff. They [patient and family] have a different perspective. (Committee Secretary, no. 8)

This quote also speaks to one of four motivations that incident investigators identified for involving the patient or their family as incident investigations, which we discuss in turn.

*Verifying operational details and/or inspiration to 'look further'.* Patient and family engagement was considered meaningful when it allowed investigators to verify technical details or when patients or their families were able to offer new 'facts':

We often receive information from patients that place the doctors' or nurses' accounts in new light. Just the other day we had a case in which they [the nurses] said 'Those people [patients or their families] did not call the hospital' but then the patient handed us [investigators] a phone bill specifying that he [the patient] did call. (...) So the nurses' accounts were verifiably incorrect. (Committee Secretary, no. 13)

Such 'verifiable' input could then 'push investigations into new directions' (Committee Secretary, no. 13). The interviews revealed that when patients or their families were not able to provide or confirm such details, that is, they had not 'witnessed' the actual incident, their input was perceived to be less useful for the investigation. Study participants from only two hospitals (notably the same two hospitals where the investigation process begins with an interview with the patient or their family) argued that patient or family input was always seen to be relevant. Firstly, where there are large discrepancies between the patient's or family's account and that of professionals, recommendations could be made towards improving internal communication practices. Secondly, a patient's or their family's account of the incident can



sometimes prompt investigators to look further than the ‘factual’ technicalities of the incident:

R: The other day we investigated an incident, which was brought to our attention via a complaint. (...) The central research question in our investigation was, ‘was care delivered according to protocol?’ Obviously the patient wasn’t happy. (...) Everyone [investigators] was zooming in on the protocol but it was vague, could be interpreted from different angles. One professional thought this, the other expert and complains commission thought that. (...)

I: The investigators were stuck?

R: Yes. Our focus on the protocol just wasn’t going to help. So we turned it around and asked: ‘did we place this patient’s needs first? And did we follow up on those needs?’ (Committee Chair, no. 4)

In this example, the patient’s experience prompted the investigators to move beyond the technical specifics of the incident and embraced it as a driver for broader improvements.

Interview participants from other hospitals appeared to place less weight on individual patient’s (or their family’s) emotions, opinions or observations. An exemplary quote conveys this tendency:

Sometimes we identify discrepancies [between what the patient or their family and the health care professional says] but yeah, that’s where it ends because, well you can’t verify it with facts, it’s something someone says, it’s the patient’s point of view. (Committee Chair, no. 6)

Embracing the patient’s or their family’s story and learning from their accounts appear to be difficult. As the quote reveals, incident investigators do recognize that there is such a thing as a patient or family perspective, but in most cases the professional perspective seems to carry more weight.

*Providing space to share experiences and emotions.* All study participants emphasized the value of patient or family involvement to provide a platform that allows them to share their experiences and feelings.

It is of particular importance that you provide patients or family members with space to share their experience. Because you want them to be satisfied, despite what has happened. (Committee Chair, no. 7)

Clearly, inviting patients or their family for an interview does not only serve the purpose of gathering (practical) information for the investigation; the interview functions as a space for the recollection of events. However, in line with our earlier observation, the recollection of events by

patients or their families is not always framed as ‘useful’ input for the incident investigation:

What I’ve noticed is that the information provided by the patient is mostly not taken up in the report (...). They just share their experiences. (Committee Chair, no. 6)

*Providing information and answering questions.* Many study participants explained that the interview with patients or their families also functions as a formal opportunity to respond to questions and/or provide information. Depending on who is present at the interview, queries regarding the investigation process and goal, as well as related medical questions, can be answered:

It [the patient or family interview] is a moment to inform them [patients or their families] that the hospital is doing an investigation and why this investigation is done. We explain that we wish to learn from what has happened and are not out to assign blame. It’s sort of like expectation management, so that when they [patients or their families] receive the end report they know what to expect of it and won’t be like ‘but the report doesn’t tell me if I also have an increased risk of having a brain haemorrhage’. That’s not what the investigation is for but patients or their families don’t know this. (...) So we take the time to attend to questions. (RCA Investigator, no. 3)

*Displaying empathy and regaining trust.* Study participants highlighted the value of interviews with the patient or their family as providing an opportunity to show empathy, which may help to restore trust:

Purely the fact that we [hospital], that you listen to them [patients or their families] and that we make the effort to listen to them. That works therapeutically. They [patients or their families] feel like they are taken seriously, like ‘well, that our hospital does all this for us’. (Committee Secretary, no. 13)

The interview provides an opportunity where hospital representatives can demonstrate sincerity. One study participant noted that doing this well can be a way to help restore or improve a hospital’s reputation, and a means to avoid legal claims: ‘It’s worth gold!’ (Committee Secretary, no. 8). Thus, engaging patients and their families serves the hospital’s own interests as well as that of affected patients and their families.

### *Challenges faced by hospital incident investigators*

Although patient and family engagement were believed to be important and valuable, study participants highlighted several challenges. First, patient and family engagement can create legal challenges as incident investigations can take place in parallel to financial claims and complaints proceedings. Study participants reported the challenge of the need to keep all parties informed of various proceedings that occur in parallel. It may also impose considerable strain on patients and their families, as well as investigators, to deal with the wide range of actors involved in different processes and proceedings.

Second, the timeframe within which an investigation is to be carried out can be problematic. As noted earlier, hospitals have to report to the HCI within eight weeks from when the incident has been discovered. While incident investigators interviewed for this study were positive about the strict timeline, this can pose challenges for effective patient and family engagement as it leaves little room for working at the patient's (or their family's) pace.<sup>18</sup> Several study participants explained that in case of a patient's death they would 'wait for the funeral to pass' (Committee Secretary, no. 8; Committee Chair, no. 10) but then they would 'really have to get going' (RCA Investigator, no. 3). This may result in patients or their families not being willing or able to take part in the investigation. The restricted timeframe may also limit opportunities for effective learning from the patient's or their family's stories, as it allows investigators to speak to them only once.

Third, study participants highlighted the challenge of managing patients' and their families' expectations about how their input will be used. Failing to do so may cause additional distress or even distrust. Study participants noted that this can be problematic when patients or their families seek answers from the investigation that it may not be able to provide. Moreover, as one participant explained, where patients or their families share personal experiences or provide alternative accounts to those of the professionals, but this input is not considered in the final investigation report, this may make patients or their families feel unheard (Committee Chair, no. 6).

Finally, study participants highlighted the challenges of having to deal with emotions. Managers interviewed for this study noted that interviews with patients or their families were not difficult as such as incident investigators are often clinical staff that are equipped with the tools to give 'bad news' (Committee Secretary, no. 11; Committee Secretary, no. 12). However, incident investigators themselves noted the difficulty of dealing with their own emotions, as well as those of patients and their families, which can

range from anger, sadness, guilt, betrayal and helplessness. One investigator recalled a particularly emotional interview:

For me it almost felt as a threatening situation. I was relieved that we [the investigators] were with the two of us. He [bereaved family member] looked at me in a way that made me think 'I hope he doesn't find out where I live'. You know? But at the same time, I also felt so sorry for him. (RCA Investigator, no. 13)

Our findings suggest that the diverse emotions surfacing during interviews with patients and their families may require (additional) support or improved investigator competencies.

### **Discussion**

Our study set out to explore how patient and family involvement in incident investigations is organized in a sample of Dutch hospitals and how hospital staff involved in investigations experience this involvement. We found that patient and family involvement is typically limited to a single interview event. Patient or family interviews confront incident investigation teams with several challenges, but they are largely regarded as adding value to the investigation process. Motivations for patient engagement in incident investigations include that consulting the patient or their family allows investigation teams to verify operational details and/or prompts investigators to look for further information or beyond the incident under investigation. Further, the patient or family interview provides space for patients and their families to share their experiences and emotions; allows hospital investigators to provide patients and their families with information and/or to answer outstanding questions; and it creates a platform where the hospital, through the investigation team, can demonstrate empathy and regain trust.

#### *The nature of participation*

The supportive governmental regulatory policy<sup>5</sup> has led to patient or family involvement becoming a routine part of incident investigations in the Netherlands. This is a positive development that aligns with the norms set by open disclosure frameworks and the patient-centeredness movement more generally.<sup>1,2,4-8,10,14,19,20,25,26</sup> Patients or their families are consulted on and provided with information, but they are not actively taking part in the investigation process. Indeed, participation in terms of reviewing data, providing feedback about (preliminary) findings and reports are increasingly called for in literature,<sup>5-7,20</sup> is not common. Although patient participation is predominantly viewed from within this 'more is better' paradigm,<sup>5,26,27</sup> we would argue that whatever the nature or

intensity of involvement, the underlying justifications for patient or family participation must be considered first.

### *Justifications for engaging patients or their families in incident investigations*

We have suggested that engaging patients or their families in incident investigations provides opportunity for patients and their families to share their experiences and emotions and for hospital investigators to provide further information and/or answer outstanding questions. It also creates a means to demonstrate empathy and regain trust. These motivations reflect what has been described as the moral justification, whereby hospitals aim to do justice and cater to the individual needs of patients and their families. Patient and family engagement is seen to be important based on the underlying principle that it is the right thing to do. The patient interview provides an opportunity, a space where the hospital can ‘do the right thing’ in a difficult and emotionally charged situation.

We have also shown that engaging patients and their families allows investigation teams to verify operational details, a motivation that is more closely linked to the epistemological justification. This considers the patient or family perspective as valuable to help understand and learn from things that have gone wrong. However, we find that existing processes and routines do not fully do justice to the ‘learning from’ aspiration. Incident investigators interviewed for this study recognized that there is a distinct patient or family perspective on the incident and that this perspective differs from a professional perspective, but it is the latter that is typically accorded more weight in an investigation. This was particularly the case where patients or their families were unable to provide or verify ‘facts’ related to the incident; here, the epistemic value of their input was deemed to be limited.

### *Emic versus etic research approach*

The anthropological concepts of ‘emic’ and ‘etic’ research approaches may help us understand why the epistemic value of the patient (or their family’s) voice in incident investigations is accorded a lower weight. An etic research approach emphasizes the observers’ (researchers’; the outsider) rather than the insider’s explanations, categories and criteria of significance.<sup>28</sup> Preconceived notions of what is ‘true’ and relevant to know lead the fieldwork and are used to decipher a phenomenon. In contrast, an emic research approach emphasizes the insider’s perspective with a focus on the explanations and criteria of significance provided by the members of the phenomenon, i.e. the actors

involved.<sup>28</sup> Emic approaches seek to understand a phenomenon ‘from within’.

Our findings suggest that in most cases, hospital incident investigators appear to adopt (implicitly or explicitly) an etic research strategy: the investigation team decides what it is they need to know and whom they need to speak to, to understand and learn from what has gone wrong. Such an approach devalues the epistemic significance of the patient or family perspective. While incident investigations seek to support the healing process and cater to individual needs, the experiences of patients and their families, their reconstructions of events and ‘low level’ concerns<sup>8</sup> are predominantly framed as less valid or important for the analysis of the incident, unless their insights ‘fit’ with or contribute to the predetermined investigation route. Moreover, most investigations take the investigators’ research questions as a starting point rather than those posed by patients or their families.

The patient or family interview, conducted within an etic researcher strategy, reflects a moral rather than the epistemological justification. Adopting an emic research approach in incident investigations, for instance by interviewing patients or their families at the beginning of the investigation process and maintaining continued involvement and using patients’ questions and concerns to be the starting point of the investigation, would emphasize the epistemic significance of patient (or family) knowledge. However, an emic approach may not necessarily meet all needs of patients or their families, but it would support investigators to embrace the patient or family perspective and help inform their learning from patient or family input, which is likely to provide insights that were previously unrecognized patient safety issues.

### *Study limitations*

The scope of this study is limited as we have focused our exploration on a specific type of health care organization (hospitals) and our sample size was small. Broadening the scope could have possibly furthered our understanding of patient and family involvement processes and the challenges different types of health care organizations are facing in terms of serious incidents and involvement approaches. However, the balanced diversity of our sample, including participants from different hospitals across the Netherlands and the member-check performed at the Open Disclosure conference to validate our analysis, gives us confidence that our findings provide a trustworthy exploration from within Dutch hospitals. We also recognize that patients and families ‘being heard’ and actually ‘feeling heard’ are not necessarily the same thing. This study did provide insights from an institutional perspective



but did not include patients and families affected by incidents. Future research should focus on the patient and family views of incident investigations.

## Conclusions

Our findings provide a better understanding of the practices and challenges of engaging patients or their families in incident investigations in Dutch hospitals. A key finding is that patient and family voices are heard but the value of their input is often downplayed and not used widely as a driver for broader learning.

## Implications

Complementary to earlier calls to investigate how patient or family engagement can play an effective role in patient safety,<sup>5,14,15,25</sup> we recommend that hospitals actively evaluate their patient engagement approaches to understand the degree to which they are meeting the expectations and needs of patients and their families. This is a necessary step to encourage learning from the patient perspective and provide patient-centred care more broadly. It will be essential for policy makers and incident investigators to recognize the approach taken to investigate patient safety incidents. The nature of the approach, emic or etic, determines how investigators assess what it is they see and hear, what they think is important and relevant to learn. Our findings highlight that patient or family engagement on its own does not necessarily lead to increased patient-centeredness,<sup>27</sup> or enable broader learning from mistakes. The patient's and their family's experiences and perspectives must be recognized as valuable in their own right and should be considered as a core part of the investigation process.

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