BMC Health Services Research

RESEARCH

Open Access

Patient perspectives on adverse event investigations in health care

Rachel I. Dijkstra-Eijkemans[1*], Linda J. Knap[2,3], Nieke A. Elbers[4,5], Roland D. Friele[2,3] and Antony Pemberton[4,6]

Abstract

Background Over the last decade attention has grown to give patients and next of kin (P/N) more substantial roles in adverse event investigations. Adverse event investigations occur after adverse events that resulted in death or severe injury. Few studies have focused on patient perspectives on their involvement in such investigations. The present study sets out to investigate how P/N and patient representatives (client councils and the Patient Federation Netherlands) view the involvement of P/N in adverse event investigations, particularly whether and why they want to involved, and how they want to shape their involvement.

Methods The study features qualitative data on three levels: interviews with P/N (personal), focus groups with representatives of client councils (institutional), and an interview with the Patient Federation Netherlands (national). Researchers used inductive, thematic analysis and validated the results through data source triangulation.

Results The initiative taken by the hospitals in this study provided P/N with the space to feel heard and a position as legitimate stakeholder. P/N appreciated the opportunity to choose whether and how they wanted to be involved in the investigation as stakeholders. P/N emphasized the need for hospitals to learn from the investigations, but for them the investigation was also part of a more encompassing relationship. P/N's views showed the inextricable link between the first conversation with the health care professional and the investigation, and the ongoing care after the investigation was finalized. Hence, an adverse event investigation is part of a broader experience when understood from a patient perspective.

Conclusions An adverse event investigation should be considered as part of an existing relationship between P/N and hospital that starts before the investigation and continues during follow up care. It is crucial for hospitals to take the initiative in the investigation and in the involvement of P/N. P/N motivations for involvement can be understood as driven by agency or communion. Agentic motivations include being an active participant by choice, while communion motivations include the need to be heard.

Keywords Adverse event investigation, Patients and next of kin, Patient involvement, Learning, Agency and communion

*Correspondence:
Rachel I. Dijkstra-Eijkemans
r.i.dijkstra@uu.nl
[1]Tilburg Law School, Tilburg University, PO Box 90151, Tilburg 5000 LE, the Netherlands
[2]Netherlands Institute for Health Services Research (NIVEL), PO Box 1568, Utrecht 3500 BN, the Netherlands
[3]Tranzo Scientific Center for Care and Wellbeing, Tilburg University, PO Box 90153, Tilburg 5000 LE, the Netherlands
[4]Netherlands Institute for the Study of Crime and Law Enforcement, PO Box 71304, Amsterdam 1008 BH, the Netherlands
[5]VU University Amsterdam, De Boelelaan 1105, Amsterdam 1081 HV, the Netherlands
[6]Leuven Institute of Criminology, KU Leuven, Herbert Hooverplein 9, Leuven 3000, Belgium

Introduction

Unfortunately, patients and their next of kin (further: P/N) have experienced health care harm all over the world. Sometimes such harm is the consequence of an avoidable adverse event, for example in the case of wrong-site surgery. When a (serious) adverse event occurs, Dutch health care organizations are obliged to conduct an official, internal investigation. Such adverse events are defined by law as "unintended or unexpected events, related to the quality of health care, that have led to either the death of a client or severe injury" (Article 1 Healthcare Quality, Complaints and Disputes Act). By conducting adverse event investigations, health care organizations aim to learn and to compensate and for P/N to heal [1, 2].

Increasing attention has been given to offering P/N a more substantial role in adverse event investigations [3–6]. Following legislation passed in 2016, it is mandatory for hospitals in the Netherlands to involve P/N in these investigations (Article 10 [3] Healthcare Quality, Complaints and Disputes Act). The mandatory involvement of P/N indicates a move towards a more solid position for P/N (article 8.2 Executive Order of the Healthcare Quality, Complaints and Disputes Act) and broader goals for adverse event investigations than (just) quality improvement. Subsequently, patient involvement in such investigations increased from 15 to 85% [5]. Patient involvement can vary between submitting a question to being interviewed by the investigating committee [7–9].

To understand why P/N are involved in adverse investigations, Kok et al. identified two main motivations: a moral justification (to do the right thing) and an epistemological justification (to learn from their experiences) [5]. P/N have unique knowledge that could contribute to learning and their involvement could support P/N in their healing and understanding of what occurred [5, 6, 10]. Friele et al. considers these aspects along the lines of instrumental and relational value [11]. Involving P/N for either of these goals has sparked concern among health care organizations regarding legal risks, additional trauma, emotional impact and (psychological) readiness of P/N [6]. Regardless, little is known about the P/N's own motives to indeed participate.

As designated stakeholders, P/N might have their own expectations and motivations about if, when, and how they want to contribute to adverse event investigations. Motivations for participation might also reflect Friele's notion of instrumental or relational value [11]. This distinction traces the so-called "Big Two" of social motivation: agency and communion [12]. These concepts could support a more thorough understanding of how and why P/N want to be involved in adverse event investigations and what they hope to gain. Agency motivations concern "individual striving, competence, power and instrumentality", while communion-related motivations include "social relatedness, warmth, expressiveness and affiliation" [12]. However, how to involve P/N in the investigation remains a topic of discussion in Dutch hospitals [8].

Generally, Dutch hospitals assemble internal investigation committees. The committees consist of an average of five internal members. These members usually include the head of the patient safety department, a medical specialist, a nurse, and a medical specialist specifically appointed to deal with patient safety [13]. This is different from Norway for example, where the investigative committees consist of regulatory inspectors [14]. In the Netherlands the committees examine whether an adverse event indeed occurred by investigating medical records and interviewing the health care professionals and P/N involved [8]. According to hospital managers and incident investigators patients were generally interviewed once in the course of the hospital investigation [5]. This practice differs from Scotland, where patient involvement varies between submitting questions to sharing observations [7]. Each hospital communicates the results in an investigative report to the Dutch Health and Youth Care Inspectorate within six to eight weeks after the adverse event [5, 15]. In 2021 the Inspectorate received 810 notifications of adverse events in medical specialist care [16].

Existing scholarship on the involvement of P/N in adverse event investigations in Scotland, Norway and the Netherlands shows elements that P/N experience as "good". P/N underline the importance of being heard, being included in the investigation, and being made aware of hospitals' learnings [7, 14, 15]. P/N also emphasize an explanation of the investigation, a tailormade approach, and adequate responses to questions or concerns [7, 17]. This research aims to further explore these patient perspectives on their involvement in adverse event investigations. Specifically, the study aims to enrich the understanding of whether and why P/N want to be involved, and how they want to shape their involvement as stakeholders to the investigations in light of the "Big Two" of social motivation: agency and communion.

Methods

Aim, design and participants

A qualitative research design was chosen, including interviews and focus groups. The study employs data source triangulation to include a variety of perspectives and to validate the findings [18]. The data are collected on three levels: P/N (personal perspective), representatives of client councils at sixteen Dutch hospitals (institutional perspective), and a key representative of the Patient Federation Netherlands (PFN) that represents over 200 patient organizations (national perspective).

Ethical approval was given by the Tilburg Law School Ethics Review Board.

Participant recruitment

Participant recruitment: Patients and Next of Kin

The recruitment of P/N was part of a larger study [11] and followed a step by step approach because researchers could not approach participants themselves due to privacy regulations. Researchers reached out to all 74 hospital boards in the Netherlands for participation in the broader study, of whom 37 participated. All 37 were asked to approach P/N and 20 hospitals indeed approached them.

The recruitment of P/N is based on a convenience sample because of the way researchers had to approach P/N, potentially causing selection bias. Each participating hospital (#20) was asked to approach eight P/N. Each P/N's adverse event investigation was finalized at least six months and at most 18 months before this research to support recent cases where patient involvement was mandatory. Not all hospitals were able to approach eight P/N given the low number of adverse events so they approached fewer potential participants or widened their scope to earlier adverse event investigations. The information letter compiled by the researchers was distributed by the hospitals. It contained all information pertaining to the study, a topic list for the interview, and a registration form that P/N could send directly to the researchers. The topic list informed the line of questioning and had five main topics: respondents' demographic characteristics, the specifics of the adverse event, respondents' involvement with the adverse event investigations, respondents' experiences with the adverse event investigations, and person-centered aftercare. Researchers sent out reminders to all hospitals and asked the two participating academic hospitals to approach an extra eight P/N because of their higher frequency of adverse event investigations.

Participant recruitment: Representatives of Client Councils

Researchers sent out digital invitation letters to the client councils connected to the 74 hospitals. Client councils are mandatory and serve as representative bodies to health care institutions to serve the best interests of patients and clients (Article 3 Participation of Clients in Health Care Institutions Act 2018). In total two focus groups were held with sixteen representatives of client councils, one digital ($n=12$) and one live ($n=4$). To keep the number of participants reasonable (max twelve) we conducted two focus groups instead of one. Three additional representatives wanted to participate, but their registration was filed after the focus groups were concluded and data saturation had been reached.

Participant recruitment: Patient Federation Netherlands

Researchers approached the PFN directly and received contact information of one key representative who advises on patients' interests and was most suitable to the topic. The PFN represents over 200 patient organizations and aims to give patients a voice, for example in politics or at health care insurance agencies. Figure 1 shows a flow chart of all participant recruitment.

Data collection

The interviews with P/N were conducted by three researchers (RD and LK or intern – see acknowledgements) from December till February 2022–2023. Researchers conducted eleven semi-structured, face-to-face interviews with seventeen P/N until data saturation was reached. No new themes emerged from the last interviews. The cases were spread geographically across the Netherlands. Interviews took place at the participant's house or at a conference center in one occasion. Informed consent was given prior to the interview.

Three researchers (RD and RF or intern) conducted the focus groups with client council' representatives and the interview with the PFN in October-November 2022. The two focus groups were conducted digitally ($n=12$) and live ($n=4$), based on the preference of the participants. The interview with the PFN had an open structure and was done digitally by two researchers (RD and RF). The interviews with P/N took between 52 min and 70 min, the interview with the PFN took 45 min, and both focus groups lasted 60 min. All data were recorded, transcribed verbatim, and anonymized. Researchers sent out a resume of each interview or focus group to the participants for validation, asking for active approval by e-mail or passive approval by not responding and therefore not disputing the contents. No one withdrew from participation.

The main interview question was: how do P/N or their representatives view the involvement of P/N in adverse event investigations? Additionally, how did P/N experience their own involvement? Questions during the interviews and focus groups centered on five themes. For the interviews, the first line of questions concerned demographics and the background of the adverse event. The second part considered the beginning of P/N involvement with adverse event investigations. For example, how was the communication regarding the adverse event investigation and your role in it? Third, questions focused on P/N's experiences with the investigation process, resulting in questions such as: how did you experience your own role during the adverse event investigation? And as follow up, how did you feel you were heard? Fourth, P/N were asked about the closing of the adverse event investigations. For example, how were you kept informed about the progress of the adverse event investigation? The final

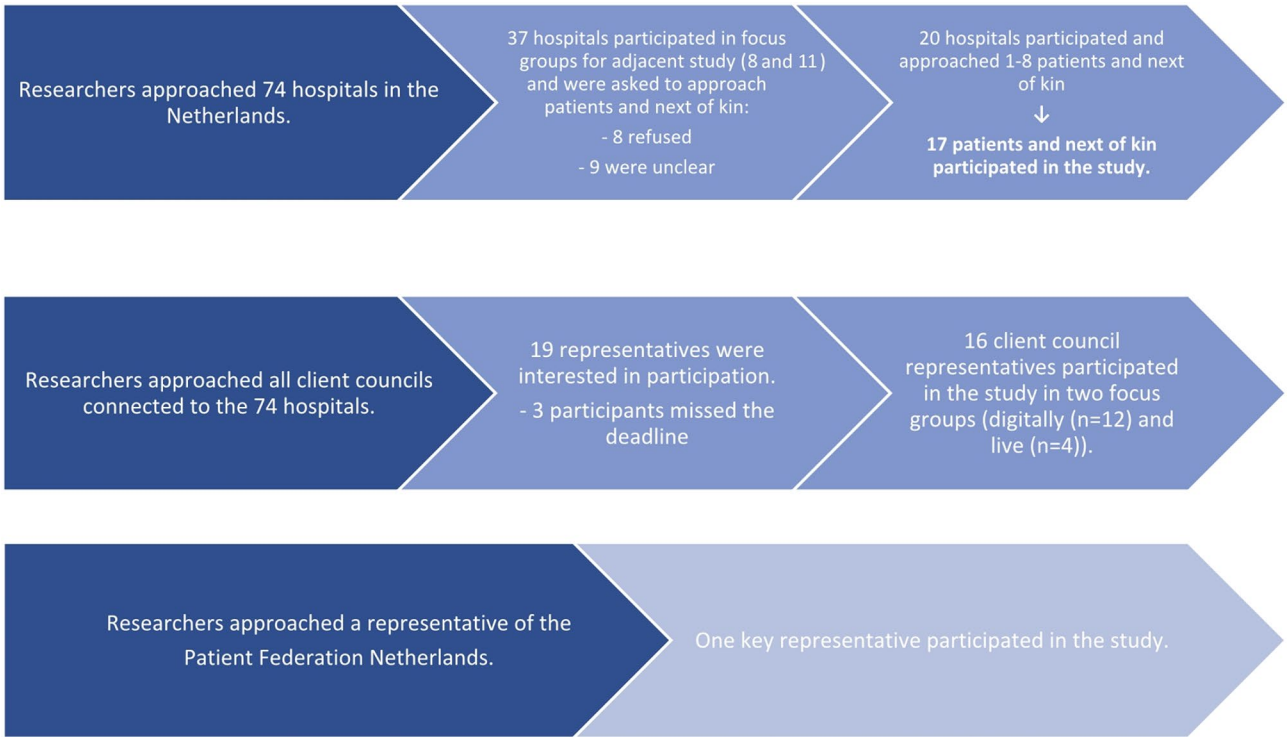

Fig. 1 Recruitment of respondents

theme considered person-centered aftercare after the investigation was finalized. These questions centered for example on the extent to which P/N had experienced aftercare. For the focus groups, each of the five themes was brought up as starting point for an in-depth discussion. We have added the translated questions that we asked the P/N as Supplementary file 1.

Analysis

In analyzing the interviews with P/N and the PFN and both focus groups, the first and second author (RD and LK) followed Braun and Clarke's six phases of thematic analysis [19]. The analysis was inductive, data-driven and done using MaxQDA software. Both authors (RD and LK) extracted themes from the data and crossmatched them to see whether all important themes were flagged and included in the results. The focus in all analyses was on views, experiences where applicable, and reflection (depicting the patient perspective).

Both authors (RD and LK) first read through all transcripts (phase one) and applied a first round of open, initial codes to the data (phase two). Then they combined and regrouped codes to form themes (phase three). They reviewed and cross-matched the themes (phase four) and finalized them (phase five). This article reports the main results relevant to the research question (phase six) and is in line with Tong's 32-item checklist [20]. This filled-in checklist is added to the article as Supplementary file 2. The article contains quotes to illustrate the results and Table 1 shows an example of how themes were extracted from the data (interviews and focus groups). All quotes have been translated from Dutch to English by the first author.

Results

Respondents' characteristics

Respondents can be subdivided into three groups: P/N, client council representatives, and the PFN. P/N identified as male (seven) and female (ten). The adverse events occurred in a multitude of hospital departments, including gynecology, urology, oncology, neurology, gastroenterology, internal medicine, and cardiology. For an overview of P/N and their specific cases, see Table 2. Representatives of the client councils identified as male (five) and female (eleven), see Table 3. The representative of the PFN identified as female, see Table 3.

Six main themes emerged that were paramount in what P/N, client council representatives and the PFN considered important. The identified themes were: P/N as legitimate stakeholders: recognition on hospital initiative (3.2); P/N as stakeholders that choose how to participate (3.3); the investigative report as a symbol of being a stakeholder (3.4); understanding adverse event investigations as primarily aimed at learning (3.5); the inextricable link between the first conversation and the investigation

Table 1 Example of data analysis, final theme "P/N as stakeholders that choose how to participate"

Data extract →	Initial coding (phase two) →	Searching for themes (phase three) →	Reviewing themes (phase four) →	Final theme (phase five)
"Because we sifted through the adverse event investigation report, really to the letter, to the comma […]" (#11A and B)	Feeling of wanting to contribute and ask questions	Active participation in the investigation	Ideas about your own role	P/N as stakeholders that choose how to participate
"It is best if they do their own internal investigation without me asking all sorts of questions. Because what kind of questions should I ask?" (#5)	Feeling no need to contribute to the investigation.	Consciously passive during the investigation		
"She said: 'well, do you want to participate? And I said: 'yes, I do want to participate.' Of course, that is the main question.'" (#1)	The main question is whether I want to participate.	Important to be able to say whether and how you want to be involved.	Everyone is different and has different needs	
"I knew that [the investigation] was going to happen, and that was enough for me." (#10)	Knowing that the investigation would happen was sufficient.	Having no insight into the investigation was OK.		
"[…] we find it important, at such an adverse event investigation, that you listen to the individual needs of patients and next of kin" (focus group 1)	The individual matters.	Listen to individual needs.	Listening to individual needs	
"Who is sitting across from you and what is important to that person?" (focus group 2)	People are different.	Consider what is important for different people.		
"[…] it is the most important that you ask the patient what he or she needs" (Patient Federation Netherlands)	Ask the patient what he or she needs.	Needs can be different, make sure to discover them.	Listen to individual needs.	

Table 2 Demographics of patients and next of kin

Interview	Patient and/or next of kin	Gender	Age	Short case description
1	Patient	Female	40–60 years	Patient undergoes a severe operation after a missed diagnosis.
2 A and B	Patient and husband	Female and male	> 60 years	Severe heart attack after following the advice of her physician.
3 A and B	Patient and wife	Male and female	> 60 years	Malfunctioning device resulting in severe pains.
4 A and B	Patient and wife	Male and female	> 60 years	Patient undergoes intestinal surgery after a missed diagnosis.
5 A and B	Patient and wife	Male and female	40–60 years	Invasive heart surgery after an earlier heart attack was overlooked.
6	Wife	Female	> 60 years	Patient undergoes intestinal surgery after trauma was overlooked.
7	Wife	Female	> 60 years	Damage to digestive tract, eventually resulting in the death of the patient.
8	Husband	Male	> 60 years	Patient undergoes surgery. Scepsis led to the death of the patient.
9 A and B	Patient and wife	Male and female	40–60 years	Patient suffers from a severe tumor due to a missed diagnosis.
10	Patient	Female	> 60 years	Physician starts to operate on the wrong side, no irreparable damage.
11 A and B	Husband and son	Male and male	> 60 years 20–40 years	Patient undergoes surgery but her deteriorating condition is not properly diagnosed, resulting in the patient's death.

Table 3 Demographics of client council representatives & Patient Federation Netherlands

Focus groups Client Council Representatives	Number of participants	Gender
1 (digital)	12	8 female, 4 male
2 (live)	4	3 female, 1 male
Interview Patient Federation Netherlands Representative	**Number of participants**	**Gender**
1	1	Female

(3.6); understanding adverse event investigations as part of a broader experience (3.7).

P/N as legitimate stakeholders: recognition on hospital initiative

P/N appreciated that the adverse event investigations started with the hospitals taking initiative (#2A and B, 4 A and B, 5 A and B, 8, 9 A and B, 10, 11 A and B). The hospitals in this sense took ownership of the problem and legitimated the P/N's positions as stakeholders to the investigations. Most P/N were asked to come in for one or more interviews with the investigating committee and a closing conversation with the responsible health care professional. Both were important elements for P/N (#1, 3 A and B, 4 A and B, 5 A and B, 7, 8, 9 A

and B, 10, 11 A and B). Being able to tell the story in your own sequence and pace felt good (#4, 8, 9 A and B). As one patient recalled: *"Actually, the story I am telling you now, they let me tell it then, they had lots of patience. They did not make me feel like a layman [...]."* (#3) One patient explained that she did not feel she had to *"defend"* her position and was heard (#10). The transparency of the investigation provided one patient with the feeling of being taken seriously (#1). Client councils also considered that merely listening or having an actual conversation with P/N are two distinct things and they sometimes missed the latter.

P/N as stakeholders that choose how to participate

P/N were specific regarding whether and how they wanted to be involved as stakeholders during the adverse event investigations. This shows different views on their roles as partners in the investigations. Some P/N valued an active role and considered themselves potentially contributing stakeholders during the investigations. They prepared for the meetings with the investigation committees (#1, 11 A and B) and wanted to contribute (#4A and B, 11 A and B). To one patient it felt logical to be involved, given that he was the subject of the investigation (#5A). One patient particularly considered setting the agenda together: *"They should have said: 'Let's set the agenda together and what are your items and what are our items?' [...] I don't sit here to contribute nothing"* (#1). Similarly, another P/N felt that adding questions to the report would have *"improved the quality of the report"* (#11B). Generally speaking, many P/N appreciated the potential to ask questions (#4A and B, 5 A and B, 7, 8, 9 A and B, 11 A and B). This was also pointed out by the PFN as an important element of the proceedings. Client council representatives generally emphasized the value of patient participation.

However, some P/N actively chose to refrain from participating or asking questions and did not consider themselves stakeholders that needed to be involved. Sometimes P/N (#5B, 6, 10) did not feel that they could add valuable information: *"What would you or I be able to add to the investigation?"* (#5B). Another patient considered that it was valuable and sufficient to know that the investigation was being done (#10). Also, one patient and her husband who were not heard by the investigation committee did not miss this (#2A and B).

The differences in whether and how P/N wanted to be involved emphasizes the value of a tailormade approach. Listening to individual needs and really hearing and recognizing the patient was also reiterated by the client councils (focus group 1 and 2) and the PFN. They emphasized the value of an approach *"tailored to the needs of the patient or next of kin"* (focus group 1).

The investigative report as a symbol of being a stakeholder

Generally, P/N felt that it was very logical for them (as stakeholders) to receive the final investigative report. This is not mandatory for hospitals in the Netherlands to provide. All P/N received the final report, except for two P/N (#3A and B, 10). One of them mentioned that she would probably not understand 80% of the report, even if she would have received it (#10). The other P/N (#3A and B) had notified the committee that they did not want to receive it. They were preoccupied by follow up care and had other things on their minds.

The positive meaning of the report for some P/N was recognition because it provided transparency (#1) and a feeling of being taken seriously (#5A and B), or it reflected the patient perspective (#9A): *"[...] the report was certainly written from my perspective"*. Sometimes the report even had symbolic value merely by its existence. The patient in this case did not feel like she needed to read it to understand its importance (#1). For some P/N the report meant an emotional confrontation with the adverse event (#5A and B, 11 A and B). Client council representatives agreed with the value of sharing the report and underscored ownership of the report by P/N (focus group 1). Though sometimes they considered that a summary would be sufficient, with the option to receive the full report upon request (focus group 2).

Oftentimes P/N did not particularly mention whether or not the adverse event eventually was confirmed in the report. However, in two cases P/N did not agree with the final outcome of the report (#6 and 11). One spouse (#6) felt that the whole report was simply a *"denial"* of the adverse event, particularly because the health care professional had said different things in an earlier conversation. Two next of kin (#11A and B) did not grant their approval for the final report that concluded that a *"potential adverse event"* had taken place. The adding of *"potential"* led to a lot of anger. They continued correspondence with the hospital until the *"potential"* element was retracted, which cost a lot of energy. They did not know whether the Inspectorate was made aware of the changed outcome.

Understanding adverse event investigations as primarily aimed at learning

Many P/N considered it to be crucial that the health care organization and professional had learned from the adverse event and that changes were made to prevent reoccurrence (#1, 2 A and B, 3 A and B, 4 A and B, 5 A and B, 7, 9 A and B, 11 A and B). For example, a spouse recalled: *"We only wanted them to show us what they would change so that there would be no more victims"* (#9B). Client councils also considered that adverse event investigations are less relational and more preventative in nature, but thought this might conflict with patients'

needs (focus group 1). The PFN was explicit about the need to be transparent about changes made, ideally beyond just mentioning them in the report.

Some P/N felt reassured that changes were made as a result of the adverse event investigation (#2A, 3 A and B, 4 A and B, 5 A and B, 7, 8, 9 A and B, 10, 11 A and B). For example, several reports included improvement measures and specified what had been done already (#4A and B, 5 A and B, 8, 11 A and B). In some cases the health care professional was very specific and thorough with regards to communicating how he or she had learned and would prevent reoccurrence (#10).

In other cases, P/N did not have specific knowledge of the changes made (#3A and B, 7, 10). And finally, some P/N felt they did not have sufficient insight into improvements and changes made or even experienced a lack of changes (#1, 2B).

The inextricable link between the first conversation after the adverse event and the investigation

P/N identified their (continued) contact and connection with the health care professional and started with their experiences of speaking with the first responder – many times the same health care professional. This disclosure conversation was therefore inextricably linked to the adverse event and the subsequent investigation. During the disclosure conversations, P/N considered openness about the events to be crucial (#4A and B, 5 A and B, 7, 10). Taking responsibility and admitting that something went wrong was also highly appreciated, sometimes as recognition (#1, 2 A and B, 5 A and B, 10): *"When you are prepared to say: 'sorry, this did not go well and I want to take responsibility for this', then you immediately open the way"* (#10). This patient asked her physician to perform the next surgery despite the adverse event. She did so to find closure together and for her physician to move on. Some P/N emphasized that it is human to make mistakes and some P/N sympathized with the professional (#2A and B, 3 A and B, 4 A and B, 5 A and B, 8, 9 A and B). Some P/N reiterated the trust they still had in the hospital (#7, 9 A and B).

Client council representatives and the PFN also underlined the necessity of openness and honesty during disclosure talks, even though this might be hard for health care professionals (focus group 2). Client council representatives and the PFN considered the importance of *who* conducts the conversation with P/N, leaning towards a combination of the health care professional with an independent patient contact person. Generally, consistent communication should be *"top of mind"* (focus group 1). This was also underlined by P/N. The PFN emphasized the value of equal partners in the conversation. P/N considered it to be positive that health care professionals did not hide behind their co-workers and external circumstances (#2A and B, 10). A different response might have triggered a different, angrier reaction (#2A and B, 10): *"If he had slipped off all this [responsibility, red.] on someone else, then it would have been something else entirely"* (#2A).

Understanding adverse event investigations as part of a broader experience

Apparent in many of the cases was the continuing need for health care, even after the investigation was finished, and the major impact of the adverse events on the lives of P/N. The adverse events meant a prolonged duration or intensification of the care needed, for example oncological or surgical care due to a missed diagnosis (#1, 9 A). The continuing substantive care and poor health as a result of the adverse event meant that many of the P/N were preoccupied with surviving or caring for their loved ones during the time of the adverse event investigations. Despite its felt importance, P/N had other things to deal with: *"We did not concern ourselves with it (the investigation, red.) because we were busy with other things – his recovery, his rehabilitation"* (#5B).

Therefore the relationship between P/N and health care provider oftentimes continued. With regards to this relationship, P/N expressed how they appreciated a heightened level of (customized) care (#1, 2 A and B, 4 A and B, 5 A, 10). P/N felt like they – unofficially – received a bit of preferential treatment, for example extra attention (#2A and B, 5 A) or fast follow up appointments (#4A and B). One patient phrased this as: *"[…] now I am a VIP patient"* (#2A). Client councils also highlighted the value of *"customized caring"* (focus group 1), but the PFN stressed that there are limits to aftercare in terms of time lapsed. Some P/N missed extra sensitivity after the adverse event (#1, 9). For one patient follow up care felt rude and reactivated the endured trauma (#1). It made her feel like the hospital had learned nothing. She would want an "*exclamation mark behind [her] name"* to not be overlooked.

All P/N were aware of the option to file a complaint or claim, but only one spouse indeed hired a lawyer (#6). The spouse and her family felt that the hospital was unjustly denying what had occurred. In another case the next of kin wanted to take some more time to decide on further proceedings (#11A and B). All other P/N consciously refrained from further proceedings for a variety reasons. Some did not want all the fuss and the *"circus"* (#4A) of extra proceedings (#2A and B, 4 A and B, 5 A and B, 9 A and B, 10), the *"negative energy"* (#1) or questioned what you would gain (#2A and B, 4 A and B, 9 A and B). One patient ironically said *"this is not America"*(#3A).

Discussion

This research set out to understand how P/N and patient representatives view patient involvement in adverse event investigations, particularly whether, why, and how they want to be involved. Main results include that P/N appreciated the initiative of hospitals to start adverse event investigations and to include them in these processes as legitimate stakeholders. The hospitals' initiative made people feel heard. P/N generally wanted to know of changes made but they differed in how much they wanted to partake in the investigations. P/N considered the investigations in correlation with their first talks with the health care professionals disclosing the event and with the enduring relationship after the investigations.

Patient perspectives

First, the experiences and views of P/N in this study all correspond to each P/N's position as a stakeholder. This position is not restricted to the adverse event investigation. It rather spans the whole care relationship that starts with the first intake and continues after the investigation is finalized. In these relationships all P/N have a stake, namely their health and safety. The adverse event investigation in this regard is a procedure that is introduced in the *existing* relationship between P/N and the health care provider. It is therefore, from the perspective of P/N in the Netherlands, nearly impossible to evaluate adverse event investigations in a vacuum.

Hence, P/N's experiences of adverse event investigations are highly influenced by the first responder after the adverse event, the interview by the investigating committee, and by the ongoing care after the investigation is finalized. P/N in this study reported positive experiences regarding open and non-defensive conversations with health care professionals, who usually were the first responders disclosing the adverse event. These conversations were not the official start of the investigations, though inextricably linked to them. The importance of an open demeanor was also emphasized by client council representatives and the PFN. It confirms previous findings regarding open disclosure [1] and indeed shows the importance of the professionals' social and human skills [14, 17]. The existence of just (organizational) culture is paramount in this regard, safeguarding an environment in which learning can co-exist with accountability [6, 9, 21]. P/N were interviewed during the course of the investigation, which they appreciated. P/N's positive experiences could explain why P/N in this study generally felt that there was room for their emotions, despite the inherent variety [5]. The ongoing care after the investigation was also important. Peerally et al. have suggested a professionalization of adverse event investigations, meaning specialist expertise, which could indeed support good practices [9]. The present study shows that such professionalization should address all stages, i.e. before, during and after the adverse event investigation. Scholarship regarding (good) open disclosure therefore applies. Notwithstanding differences between different health care settings, parallels can be drawn between P/N views in this study to other forms of (long-term) care such as disability care centers. The continuity of the care relationship is even more prominent in those settings.

Second, the data show that the hospital *initiating* the proceedings was paramount to signal to P/N that they were taken seriously as stakeholders and that they felt heard. The need to be heard resonates with scholarship worldwide [22, 23]. The initiative shown by hospitals in this study solidifies P/N's "place at the table" [10] and we believe it could be considered an exemplary practice. The initiative to start up these investigations lies with hospitals, who in this sense take ownership of the problem. Such initiative lacks in complaints processes and adversarial litigation. For example, at dispute committee proceedings you as a complainant are burdened with filing a complaint [22]. Similarly, filing a civil lawsuit is always dependent on the plaintiff [24]. Scholarship regarding the experiences of P/N in dispute committees, for example, shows a lack of feeling heard [22].

Another relevant aspect related to initiative was the unconditional offer of the report to P/N as stakeholders. P/N felt entitled to the reports dealing with their cases, sometimes simply as a symbol of their involvement, which hospitals should not deny them. Previous work has emphasized legal challenges or fears associated with sharing the report or its use in the media in addition to covert patient conduct [4–6, 15]. However, this study does not show such risks. Respondents, apart from one, did not start follow up, legal processes, despite the fact that (almost) all of them received the investigative reports. On the contrary, the mandatory and valued inclusion of P/N could be seen as preventing these challenges, as was suggested by Wiig [14]. Especially since negative experiences of feeling overlooked and excluded did show an increased risk of legal proceedings [7]. Cultural differences should be born in mind when translating this particular finding to international settings.

Finally, many P/N considered it crucial that the health care organization would learn. In this sense they underlined the original goal of such investigations and echoed earlier findings on the need to be made aware of the changes made for prevention [7, 14, 15, 22]. However, whether or not they wanted to *actively* contribute was a more nuanced affair. A factor in this regard might have been the intensive care needed for some P/N after the adverse event, taking up all energy, or the emotional toll of participation [4, 14]. Given these multiple interpretations regarding involvement, P/N should be considered autonomous stakeholders and given the opportunity to

choose whether or not to participate and in what form. Such autonomy would be hindered by making it contingent on psychological and emotional readiness and screening as suggested by Zimmerman et al. [6, 9]. In a way, the 'conflict' caused by the adverse event between P/N and the health care provider is taken away from them if the P/N is not allowed to participate [25]. The P/N as a victim is a "loser" in this sense, whilst participation in the investigation and thus the conflict could be valuable for healing [25].

P/N motivations to participate in adverse event investigations

The different motivations P/N expressed about being involved in adverse event investigations can be understood in the framework of the Big Two of social motivation: agency and communion [26, 27]. Agency motivations concern "individual striving, competence, power and instrumentality", while communion-related motivations include "social relatedness, warmth, expressiveness and affiliation" [12]. Victimological work discusses the infringement on a victim's agency and communion through crime, which justice processes could potentially help to rebuild [12]. At criminal trials for example, this could be done by a victim impact statement that requires a victim to share his or her victimization experience [28]. From this angle, a health care incident could be construed as an infringement on P/N's sense of agency and communion. Understanding health care incidents as such infringements could illuminate the motivations of P/N to participate in adverse event investigations. Participation in these processes could help restore their sense of agency or communion and therefore support their well-being [29].

Respondents in this study show several agency motivations, most prominently the freedom as stakeholders to choose whether or not to participate and in what form. By being offered the choice to be a part of the investigation, respondents show a certain regaining of control, of agency. The initiative taken by the hospitals provided room for this. Some P/N in the study wanted to have an active role, to ask questions, and to actively contribute to the investigation. They prepared thoroughly for their interviews with the investigative committees. Enacting influence in this manner shows agency motivation, the same as demonstrated by victims of crime [28]. Other P/N specifically did not want to participate, which emphasizes their need to choose. Also related to agency is the finding that many P/N felt entitled to the report. P/N as such seem to understand their own position and status [12] as stakeholders that have a right to the investigative report.

The present study also shows communion motivations, which center around relations and making connections. P/N appreciated that they were taken seriously. They oftentimes felt continuously heard throughout the investigation by the health care professional disclosing the adverse event, the investigative committee, and the health care professionals in charge of the follow up care (the notion of a VIP patient). Safeguarding and being mindful of the relationship between P/N and health care provider and offering dialogue are all aspects that support communion, as was apparent with victims of crime [28]. Such communion is even more noteworthy in those instances where P/N felt sympathetic towards the health care professionals: the relationship continues or is reestablished. Lastly, P/N emphasized the need for hospitals to learn from the adverse events and to make sure it would not happen again. This focus on prevention shows a certain care for others, a communion-driven idea that we as humans should not suffer from the same mistakes again.

As described above, P/N motivations to participate in adverse event investigations are fueled by both agency and communion. Respondents often embodied motivations originating in both. Bearing that in mind while shaping the involvement of P/N is important to connect to patients' needs. Not addressing them can incite the opposites of agency and communion: feelings of ineffectiveness and alienation [30]. A tailormade approach provides the space to really tune in and see what P/N need in terms of agency and communion, in an attempt to let the adverse event investigation aid the restoration of these infringed aspects and the well-being of P/N.

Strengths and limitations

This study provides an in-depth exploration of a multilevel patient perspective on patient involvement in adverse event investigations. The findings in the Dutch context could inform similar processes internationally, given that adverse event investigations and learning from adverse events are of interest to health care institutions worldwide. The results were validated through data source triangulation, data saturation, and data analysis by two authors (RD and LK).

A limitation of the study is the risk of selection bias because of the convenience sample of P/N and our inability to approach them directly. The hospitals had to approach them for us, adding an extra layer of potential bias. We might have spoken predominantly with P/N who had a positive experience during the adverse event investigations. In addition, we only spoke with a small sample (eleven cases) and did not encounter P/N from a multicultural background. However, by using data source triangulation we attempted to counter these shortcomings. Particularly because client councils and the PFN can be considered associations where patient perspectives and experiences accumulate and are therefore most

suitable to reflect on the views of P/N. Our focus on the patient perspective meant we explicitly left out the perspective of health care professionals.

Conclusions & implications for practice

As opposed to previous studies, the majority of P/N in the present study seemed content with how the adverse event investigations were conducted and what their roles were. Hospitals in the Netherlands should continue their efforts to actively initiate adverse event investigations and involve P/N. Such ownership of the 'problem', albeit partially fueled by legislative requirements, should inspire health care institutions worldwide. When doing so, hospitals should provide P/N with the emotional and procedural room to choose whether and how to participate and be aware that to P/N the adverse event investigation is only a part of the overarching care relationship. Providing room, means asking P/N about their preferences and making sure the investigation process allows P/N to participate in their own way. This can be fully, partially or not; immediately or later; face-to-face or through written accounts. How to do so while safeguarding legal guidelines, for example regarding terms, is beyond the scope of this paper. It would require a close reading of hospital guidelines on adverse event investigations and the room it leaves for individualized processes.

Given the importance of open and non-defensive communication with the health care professional, attention should be paid to the interpersonal skills of these professionals. In addition, hospitals should be aware of the impact of the first responders – usually the health care professionals – on the subsequent investigations for P/N. Hospitals should make sure their health care staff has the training and skills to conduct these conversations in a sensitive and clear way. Previous findings on how to do open disclosure (well) are paramount.

By addressing the elements outlined above, adverse event investigations can be tailored more closely to the motivations that drive the participation of P/N. P/N as stakeholders can therefore support learning and the safety of other P/N. If participation can be tailored to each individual's specific needs, chances of positive outcomes are greater both in terms of learning and healing.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-024-11522-x.

Supplementary Material 1

Supplementary Material 2

Acknowledgements
We wish to thank Jeffrey de Heij, former intern at Nivel, who made a significant contribution to the participant recruitment and data collection for this study.

Author contributions
RD, NE, RF, and AP had the original idea for the study and developed the proposal. RD, LK and RF collected the data. RD and LK analyzed the qualitative data. RD wrote the first draft of the paper, and NE contributed significantly through proof-reading and commenting on the paper. RD wrote all subsequent drafts of the paper and LK, NE, AP, and RF all commented on these drafts. All authors have read and approved the final manuscript.

Funding
The study was supported by Tilburg Law School (Tilburg University), the Netherlands Institute for Health Services Research (NIVEL), and the Dutch Health and Youth Care Inspectorate.

Data availability
The data that support the findings of this study are available from the Netherlands Institute for Health Services Research (NIVEL) but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of the Netherlands Institute for Health Services Research (NIVEL).

Declarations

Ethics approval and consent to participate
Ethical approval was sought and given by the Tilburg Law School Ethics Review Board at Tilburg University, The Netherlands. All participants signed informed consent to partake in the study prior to the interview. The research was conducted **in accordance with the relevant guidelines and regulations** (Declaration of Helsinki).

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Received: 19 July 2024 / Accepted: 2 September 2024
Published online: 10 September 2024

References

1. Dijkstra RI, Roodbeen R, Bouwman R et al. Patients at the centre after a health care incident: A scoping review of hospital strategies targeting communication and nonmaterial restoration. *Health Expect* 2021; 1–12; We will refer to calamities as adverse events because this term has been adopted in scholarship in this context, see references #7 and #14.
2. Ramsey L, McHugh S, Simms-Ellis R, et al. Patient and family involvement in Serious Incident investigations from the perspectives of Key stakeholders: a review of the qualitative evidence. J Patient Saf. 2022;18(8):e1203–10.
3. Etchegaray JM, Ottosen MJ, Burress L, et al. Structuring patient and family involvement in Medical Error Event Disclosure and Analysis. Health Aff (Millwood). 2014;33(1):46–52.
4. Grissinger M. Including Patients on Root Cause Analysis Teams: Pros and Cons. *PT* 2011; 36(12): 778–779.
5. Kok J, Leistikow I, Bal R. Patient and family engagement in incident investigations: exploring hospital manager and incident investigators' experiences and challenges. J Health Serv Res Policy. 2018;23(4):252–61.
6. Zimmerman TM, Amori G. Including patients in root cause and system failure analysis: legal and psychological implications. J Healthc Risk Manag. 2007;27(2):27–34.
7. McQueen J, Gibson KR, Manson M, et al. Adverse event reviews in healthcare: what matters to patients and their family? A qualitative study exploring the perspective of patients and family. BMJ Open. 2022;12(5):1–9.
8. Knap LJ, Dijkstra RI, Friele R, et al. The hospital perspective on serious adverse event investigations in health care. Forthcoming; 2024.
9. Peerally MF, Carr S, Waring J, et al. The problem with root cause analysis. BMJ Qual Saf. 2017;26(5):417–22.
10. Etchegaray JM, Ottosen MJ, Aigbe A, et al. Patients as partners in learning from unexpected events. Health Serv Res. 2016;51:2600–14.

11. Friele R, Dijkstra R, Knap L. Hoe ziekenhuizen patiënten en/of naasten betrekken na een calamiteit. Nivel, The Netherlands: Report; 2023.
12. Pemberton A, Aartsen PGM, Mulder E. Beyond retribution, restoration and procedural justice: the big two of communion and agency in victims' perspectives on justice. Psychol Crime Law. 2017;23(7):682–98.
13. Heuver G, Heijboer L, Schilp J et al. March. Organisatie calamiteitenbeleid in Nederlandse ziekenhuizen, https://www.overkwaliteitvanzorg.nl/2016/08/organisatie-calamiteitenbeleid-nederlandse-ziekenhuizen/ (accessed 13 2024).
14. Wiig S, Haraldseid -Driftland C, Tvete Zachrisen R, et al. Next of Kin involvement in Regulatory investigations of adverse events that caused patient death: a process evaluation (part 1 – the Next of Kin's perspective). J Patient Saf. 2021;17(8):e1713–8.
15. Bouwman R, De Graaff B, De Beurs D, et al. Involving patients and families in the analysis of suicides, suicide attempts, and other Sentinel events in Menta Healthcare: a qualitative study in the Netherlands. Int J Environ Res Public Health. 2018;15(6):1104–24.
16. Dutch Health and Youth Care Inspectorate. Cijfers over meldingen, https://www.igj.nl/over-ons/igj-in-cijfers/cijfers-over-meldingen (accessed 13 March 2024).
17. Merten H, Portegijs S, Drückers MLA, et al. Als het mis gaat… Verhalen van patiënten en nabestaanden na het doormaken van een calamiteit. Report, Nivel, The Netherlands, 2019.
18. Carter N, Bryant-Lukosius D, DiCenso A, et al. The use of triangulation in qualitative research. Oncol Nurs Forum. 2019;41(5):545–7.
19. Braun V. Thematic analysis. In: Cooper H, et al. editors. APA handbook of research methods in psychology, Vol. 2. Research designs: quantitative, qualitative, neuropsychological, and biological. USA: American Psychological Association; 2012. pp. 57–71.
20. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
21. Dekker SW, Breakey H. Just culture': improving safety by achieving substantive, procedural and restorative justice. Saf Sci. 2016;85:187–93.
22. Dijkstra RI, Elbers NA, Friele RD, et al. Medical dispute committees in the Netherlands: a qualitative study of patient expectations and experiences. BMC Health Serv Res. 2022;22(1):1–11.
23. Moore J, Mello M. Improving reconciliation following medical injury: a qualitative study of responses to patient safety incidents in New Zealand. BMJ Qual Saf. 2017;26(10):788–98.
24. Moore J, Bismark M, Mello M. Patients' experiences with communication-and-Resolution Programs after Medical Injury. JAMA Intern Med. 2017;177(11):1595–603.
25. Christie N. Conflicts as property. Br J Criminol. 1977;17(1):1–15.
26. Abele AE, Wojciszke B. Agency and Communion from the perspective of Self Versus others. J Pers Soc Psychol. 2007;93(5):751–63.
27. Horowitz L, Wilson KR, Turan B, et al. How interpersonal motives clarify the meaning of interpersonal behavior: a revised circumplex model. Pers Soc Psychol Rev. 2006;10(1):67–86.
28. Willinsky CL, McCabe A. Agency and communion in sexual abuse survivors' narratives. Narrat Inq. 2021;31(1):236–62.
29. Kragting M, Augesteijn F, Elbers N, et al. Evaluatie wet uitbreiding spreekrecht slachtoffers en nabestaanden in het strafproces. NSCR, The Netherlands: Report; 2023.
30. McCabe A, Dinh KT. Agency and communion, ineffectiveness and alienation: themes in the life stories of latino and southeast Asian adolescents. Imagin Cogn Pers. 2016;36(2):150–71.

Publisher's note