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Journal of
Clinical Nursing WILEY

From identifying patient safety risks to reporting patient complaints: A grounded theory study on patients' hospital experiences

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Abstract

Aim: To explore how patients with hospital experience construct patient safety, from the identification of a patient safety risk to the decision to file a complaint.

Background: Patients play an important role in the prevention of adverse events in hospitals, but the ability of patients to act and influence their own safety is still challenged by multiple factors. Understanding how patients perceive risk and act to prevent harm may shed light on how to enhance patients' opportunities to participate in patient safety.

Design: The research design of this study is qualitative and exploratory.

Methods: Twelve participants who had experienced Swedish hospital care were interviewed between June 2022 and July 2023. The method of analysis was constructivist grounded theory, focusing on social processes. The COREQ checklist for qualitative research was followed.

Results: Four categories were constructed: (1) defining the boundary between one's own capacity and that of the hospital, (2) acting to minimize the impact on one's safety, (3) finding oneself in the hands of healthcare professionals and (4) exploring the boundaries between normality and abnormality of the situation. This process was captured in the core category of *navigating the path of least suffering*. This illustrated how the participants constructed meaning about patient safety risks and showed that they prevented multiple adverse events.

Conclusions: Provided that participants were able to act independently, they avoided a multitude of adverse events. When they were dependent on healthcare professionals, their safety became more vulnerable. Failure to respond to the participants' concerns could lead to long-term suffering.

Relevance to Clinical Practice: By responding immediately to patients' concerns about their safety, healthcare professionals can help prevent avoidable suffering and

exhaustive searching for someone in the healthcare system who will take their needs seriously.

Patient Contribution: A member check was performed with the help of one of the participants who read the findings to confirm familiarity.

1 | INTRODUCTION

Patient participation in patient safety has been suggested as a key to improving patient safety through a contribution of unique perspectives and knowledge (World Health Organization [WHO], 2021). Patient participation can be understood as the involvement of patients in a life situation (WHO, 2001). In the hospital setting, the existence of opportunities for patients to act to ensure their own safety is essential, and subsequently often involves the existence of a relationship between patients and healthcare professionals (Cahill, 1996; Eldh, A. (Ed.)., 2018). The avoidance of adverse events requires that patients be able to communicate any concerns about their safety at the point of care (Scott et al., 2019) or to provide feedback retrospectively, for example, by filing a complaint (Reader et al., 2014). Therefore, communication and trusting relationships between patients and healthcare professionals are essential (Abiétar et al., 2023; Eggins & Slade, 2016). Although patients are reportedly willing (Ringdal et al., 2017) and do act as participants in patient safety issues (Hor et al., 2013), research simultaneously presents multiple factors that limit patients' opportunities, abilities and willingness to participate in their own safety. Many patients who experience adverse events believe that the events could have been prevented had healthcare professionals listened to the patients' concerns (Ericsson et al., 2019). Furthermore, ignorance of patients' attempts to participate has been shown to compromise patient safety, resulting in unnecessary patient suffering and prolonged hospitalization (Hor et al., 2013). Given the crucial role of open and trusting communication between patients and healthcare professionals in promoting patient safety and the potential for increased risks of harm when communication or trust is lacking, it is essential to gain clear understanding of the challenges faced by patients during their hospitalization.

The role of the patient in the domain of patient safety is influenced by a multitude of factors. To begin with, the level of safety perceived by patients is influenced by factors, such as age, gender, type of healthcare setting and previous experience with adverse events. For example, higher levels of safety have been reported by younger compared to older participants, and by participants who had not experienced errors compared to those who had (Sahlström et al., 2014). In turn, patients' intentions to communicate their concerns were greater after experiencing errors and when interpreting a potential error as more serious (Davis et al., 2012). Other

> **What does this paper contribute to the wider global community?**
>
> - This paper contributes knowledge that patients have safety concerns and that identifying patient safety risks is a process that begins the moment patients come into contact with the hospital.
> - Patients resolve many of the identified risks themselves, often without healthcare professionals noticing.
> - When patients are no longer able to resolve their own safety concerns, healthcare professionals must recognize this and take appropriate action with or on behalf of the patient.

factors that contribute to patient participation in patient safety are knowledge sharing (Ringdal et al., 2017), the role of healthcare professionals in cultivating patients' already existing motivation (Tobiano et al., 2015), and respecting patients as experts (Oxelmark et al., 2018).

Similarly, as patients' experiences of adverse events positively affect their intentions to speak up, a systematic review has demonstrated that healthcare professionals' self-confidence in communicating errors is not only derived from experience but also from knowledge and training in interpersonal communication (Wawersik et al., 2023). However, social acceptance of a behaviour also plays a significant role in patients' intentions to communicate with healthcare professionals about their concerns (Davis et al., 2012). One vignette study showed that healthcare professionals' attitudes towards patient involvement in error prevention were circumstantial and that some patient behaviours were deemed more acceptable than others to healthcare professionals (Schwappach et al., 2013). By comparing two hypothetical error scenarios, the authors found that healthcare professionals expressed more favourable attitudes toward patient involvement in medical error reporting than in hand hygiene issues. Patients' discourses on patient safety may differ from discourses within the health care system and thus risk being overlooked (Abiétar et al., 2023). When relying on multiple actors to meet a variety of individual needs in the hospital setting, patients often encounter a lack of opportunities to participate in and influence their own safety, potentially leading to adverse events that

could otherwise have been avoided (Gyberg et al., 2023; Hågensen et al., 2018). It is essential to understand how interactions between patients and healthcare professionals affect patients' opportunities to protect themselves from harm. This understanding is crucial for the identification of potential areas for improvement and the maintenance of patient safety.

1.1 | Patient safety and risk

The Swedish Patient Safety Act (SFS 2010:659) defines an adverse event as 'suffering physical or mental injury or illness and death that could have been avoided if appropriate measures had been taken during the patient's contact with the healthcare system'. An adverse event is caused by medical management rather than disease (Leape et al., 1991). For this study, we consider patient safety to be somewhat flexible in all situations and that patients are essential resources in patient safety work and adapt to different conditions to protect their safety (Hollnagel et al., 2015). Thus, we also recognize that patient safety is an ongoing action by patients and healthcare professionals, not least in their interactions with one another, as proposed by Hor et al. (2013).

The concept of risk is understood in a variety of ways, offering insight into the mechanisms by which risks can be perceived in healthcare settings. Its meaning has changed over time, but today refers largely to danger (Douglas, 1992). Douglas (1992) suggests that estimates of probability and credibility are already 'primed with culturally learned assumptions and weightings' (p. 58). Thus, the perception of patient safety risks can be seen as being influenced and regulated by social groups or social organizations in which the patient is integrated to varying degrees. Risk can also be understood in contrast to trust, which, as we understand it, can influence the sense of risk when entering an expert system, such as a hospital. Giddens (1991) suggests that 'the future is constantly drawn into the present by the reflexive organization of knowledge environments' (p. 3). This constant reflexive application of factors, such as risk knowledge, for example, both constructs and provides ways of calculating risk (Giddens, 1990). Consequently, a patient's trust in the healthcare system's capability to estimate risks can contribute to a sense of security and a reduction in perceived risk. This perspective of expert systems cannot simply be ignored. Although the nature of institutions is closely related to the underlying mechanisms of trust in expert systems, access to personal encounters is particularly important for both healthcare professionals and patients (Giddens, 1990).

This study focuses on how patients understand and act on risks and potential adverse events in the hospital setting. A social construction perspective was chosen to illuminate social processes and the meaning behind actions. We address the whole process, from the identification of risks to the decision to file a complaint after experiencing an adverse event. This approach could contribute important knowledge about how patients construct meaning about their safety and how this affects their safety actions, including non-actions. This kind of knowledge could support both patients and healthcare professionals in promoting and creating opportunities for patient participation in patient safety.

2 | AIM

The aim of this study is to explore how patients with hospital experience construct patient safety, from the identification of a patient safety risk to the decision to file a complaint.

2.1 | Research queries

- How do patients understand and act on risks and potential adverse events in the hospital setting?
- How do patients make a decision to file a complaint, and what does that decision mean to them?

3 | METHODS

3.1 | Study design

The research design of this study is qualitative and exploratory. To understand social processes and human behaviour in specific situations, principles of the method of constructivist grounded theory, according to Charmaz (2014), was used. With this method, the tacit meaning behind a behaviour is of interest as a way to gain knowledge about how social interactions influence people's construction of meaning and, consequently, their actions (Charmaz, 2014; Morse, 2009).

3.1.1 | Sample and setting

This study was conducted in a large Swedish city. Twelve Swedish-speaking patients who had experienced adult somatic health care in three hospitals within a public university hospital system agreed to participate. The data were purposively collected to obtain as much diversity as possible with regard to gender, age, type of hospital setting, Table 1 and where the participants were in the safety response process (i.e. from identifying a risk to filing a complaint). Eight women and four men with an age range of 38–107 years (mean = 70) were interviewed. Seven lived alone, and five lived with a partner. In the year prior to the interview, the participants had experienced a total of 42 hospital admissions. Although the interviews focused predominantly on the most recent hospitalization, participants sometimes referred to earlier hospitalizations when relating or comparing different experiences. In terms of the hospitalization that was the focus of this study, nine participants had experienced healthcare in a medical setting, two in a surgical setting, and one in an orthopaedic setting. The time and place of each interview was determined

by the participant's preference. Four of the interviews took place in the participants' homes, and eight took place in public settings, either in hospitals or universities. Of the eight participants recruited in the hospital, five were interviewed during their hospital stays and three were interviewed 5–15 days after discharge. Participants who were recruited after discharge, following a complaint, were interviewed 42–871 days after discharge. One patient contacted us and asked to participate in the study after hearing about it. That patient's interview was conducted 166 days after discharge. All participants met the inclusion criteria, (i.e. they spoke and understood Swedish, were 18 years of age or older, and had hospital experience with adult somatic care in hospital settings).

3.2 | Data collection

Two strategies were used to recruit participants to capture the experience of the entire process, from the identification of a patient safety risk to the decision to file a complaint: (1) during ongoing care at the hospital, and (2) through the Patient Advisory Committee, Figure 1. In the hospital, the patient was identified by the researcher. The initiation of the study in the spirit of Glaser and Strauss (1967), with no purpose other than that the participant needed to have experience with hospital care, guided the recruitment of participants.

TABLE 1 Characteristics of the participants.

Characteristics of participant	n = 12
Age, range	38–107
Male (median)	70 (69)
Female, n (%)	8 (66)
Motherland	
Sweden, n (%)	11 (92)
Other, n (%)	1 (8)
Experience of hospital care	
Medicine setting, n (%)	9 (75)
Surgery setting, n (%)	2 (17)
Orthopaedic setting, n (%)	1 (8)

This initial sampling meant that the researcher did not know whether the patients had identified risks or experienced harm when they asked to participate. Later, patients were intentionally screened for the presence of identified risks and/or adverse events in their medical records. Thus, participants' narratives could be influenced by experiences of both unsafe care that had resulted in harm and safer care where potential risks could have been identified. This difference is known to influence how patients perceive risk and their propensity to act (Davis et al., 2012).

The attending nurse informed each patient of the study and asked if the researcher [AG] could contact the patient. If the answer was affirmative, the patient was given information about the study by the researcher and then asked to participate. Participants recruited through the Patient Advisory Committee were identified by a workgroup that confirmed receipt of incoming patient complaints by mail on a daily basis. This confirmation mail included information about the study and contact information. When the researchers were contacted, they provided verbal information about the study and asked the former patients to participate.

Prior to the interviews, all participants received verbal and written information and were given time to ask questions. All participants gave verbal and written consent to participate in the study. The recorded interviews lasted from 35 to 130 min (mean = 59).

All participants were approached in a face-to-face setting, without any other individuals present, and the interviews began with open-ended questions. For participants who were currently receiving ongoing care and who had not necessarily identified risks or experienced harm, the interviews began with the question, 'Tell me about your hospital stay'. For participants who had identified risks and/or experienced adverse events, the interview began with the question, 'Tell me about what happened, starting from the beginning'. Some participants' stories spun out, and only a few clarifying questions were asked. However, most of the time, once participants had shared as much as they could, more open-ended and focused questions followed, such as 'Tell me more about…' or 'What did you feel/think when…' or 'What did you do when…'. The interviews focused on how participants acted, felt, and thought in situations in which they identified a patient safety risk, experienced harm, or decided to file a complaint. Because theoretical terms can be abstract
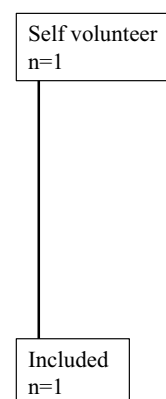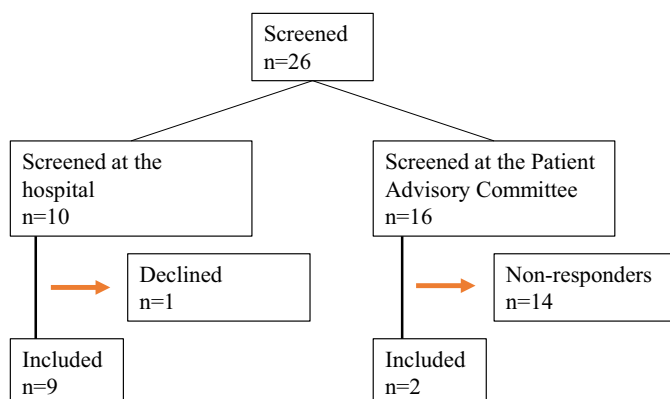

FIGURE 1 Recruitment flow chart. [Colour figure can be viewed at wileyonlinelibrary.com]

and unfamiliar, and because there are different ways of understanding and defining situations of unsafe care (Hågensen et al., 2018), the interviews used words that are more commonly used in everyday life. For example, participants were asked about their perceptions of various things in situations in which they felt safe or unsafe.

3.3 | Data analysis

The qualitative coding in constructivist grounded theory focuses on what is happening in the text (Charmaz, 2014). Furthermore, this is a theory-generating method that also offers different techniques, several of which have been used; therefore, the researcher is active in the construction of codes from the beginning by being open to exploring the theoretical possibilities of the data. In the initial coding for this study, the text was analysed sentence by sentence and incident by incident as a technique to stay as close to the data as possible. As new interviews were conducted, the new incidents were compared to those already coded. After the first five interviews, when the recruitment of participants was paused, the coding became more focused. Trends in the initial coding were reviewed, and decisions were made about which codes to categorize based on common analytical grounds and which codes made the most analytical sense. At this point, several categories had been constructed, and attempts had been made to put titles to the categories. Analytical ideas that had been developed could then be tested. Thus, data collection was

initiated again, and the inductive phase became a phase of abductive logic. This continued until the categories reached their theoretical saturation point, which we defined as a point at which the content was not enriched through the inclusion of additional data.

While the analysis continued in parallel with the interviews, the coding process with initial coding and focused coding was not linear. Memo writing was used as a technique to analyse ideas that emerged during the analysis process (Charmaz, 2014). Table 2 shows an example of initial and focused codes that, together, construct categories and ultimately the core category, *Navigating the path of least suffering*. The core category was ultimately constructed through the iterative process, with the objective of organizing the fundamental ideas of the categories. For example, what characterized the navigation in the first three categories was the way in which the participants tried to understand their situation and to find ways to avoid harm while at the same time preventing their actions from causing other kinds of suffering. The navigation in the last category illustrates how participants who were harmed tried to understand whether the event was normal and how they tried to get help, while at the same time dealing with the suffering and the consequences of not being believed.

3.4 | Rigour

Qualitative techniques were used to establish rigour. First, the researchers' subjectivity was understood to be fundamentally

TABLE 2 The coding process exemplified by the first category: Defining the boundary between one's own capacity and that of the hospital.

Extracts from the interviews	Initial coding	Sub-categories	Category
When it starts, I can't delay going to the bathroom. Even if they respond the moment I call for attention, I have to get up, and they have to get a chair, you know. So I really can't say it doesn't work because it's me who doesn't work. *I met a doctor who, I guess, did not have a lot of experience, but he was very nice and accommodating. Uh, and very often when I asked about something, he would say, 'I don't know anything about that, but I'll find out and get back to you'.*	To assess one's own care needs and the ability of health care professionals to meet those needs. To evaluate ways to satisfy one's need for information.	Making sense of hospital care	*Defining the boundary between one's own capacity and that of the hospital*
No, I think they didn't have any real team play, like 'you do this on this station and you do that on that station'. Instead, everybody did what they felt like doing (…) Eventually, it turned into chaos for them in there. I could hear them talking to each other in the corridor: 'Yes, but you were supposed to take this' and 'You were supposed to do that'. *Finally, I was admitted to a ward, which was fine, although a bit chaotic, because I did not primarily belong there. But then I was transferred to another ward, which was terrible because no one cared about the patients. They didn't do anything. (…) They always hindered me. Because I wanted to sit up and get up, but they said, 'No, no, no, no, it's not possible'. I was there for a few days, and then I was transferred to a third ward, where most of them were pleasant.*	To become uncertain about health professionals' ability to organize. Noticing variations in the healthcare professionals' capacity to accommodate individual needs.	Identifying anomalies in daily care	

intertwined with the research process (Olmos-Vega et al., 2022). All of the researchers had extensive experience in clinical practice, either as physicians or as nurses, and all were also strategically involved in patient safety issues. These characteristics were seen as both a risk and an asset to the credibility of the quality of the research. Personal reflexivity was used to discuss and test different ways of constructing the interview guide at an early stage.

All interviews were conducted by the same researcher [AG], who, after each interview, reflected on the choice of words and the reactions of both parties. These reflections were further discussed by the research team. Before the interviews ended, the researcher summarized what had been said and asked the participants if their responses had been understood correctly. All four researchers were involved in the analysis, although each had a different role. The first author [AG] analysed all the interviews. The last author [KU] contributed extensive experience in qualitative analysis by co- and counter-analysing parts of the data at different stages of the analysis process. By constantly comparing the data and testing the ideas that emerged, the categories were grounded in the data. For confirmation, the second [TB] and third [HW] authors, who are senior researchers with extensive experience in qualitative methods, read the interviews and reviewed the constructed categories. Finally, one of the participants also contributed to trustworthiness by reviewing the categories for the purpose of assessing recognizability. This study was also subjected to a review during a mini seminar earlier in the research process, with an earlier draft of this text. In this way, several external researchers contributed by challenging the methodological choices and adding perspectives. This study was guided by the checklist *Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist* (Data S1) according to Tong et al. (2007).

3.5 | Ethical considerations

The study was conducted in accordance with the ethical principles of the Declaration of Helsinki (World Medical Association, 2013). The original study plan was ethically approved by the Regional Ethical Review Authority, Sweden (ref. 447-15), but it had to be updated during the study period. The updated amendments were approved by the Swedish Ethical Review Board (ref. 2019-03405 and ref. 2022-069838). All names associated with the citations are fictitious.

4 | FINDINGS

The core category, *Navigating the path of least suffering*, encompassed the process from identifying patient safety risks to the decision to file a complaint. Analysis of the interviews revealed that the participants identified patient safety risks by interpreting the meaning of healthcare capacity in relation to their own capacity. This is illustrated in the first category, *Defining the boundary between one's own capacity and that of the hospital*. The second category, *Acting to minimize the impact on one's safety*, illustrates

how participants used these interpretations to take action, either by taking preventive measures themselves or by trying to activate healthcare professionals to take safety measures. The third category, *Finding oneself in the hands of healthcare professionals*, shows how participants ultimately either avoided an adverse event or came to suffer from it. Finally, the fourth category reveals the importance of *exploring the boundaries between normality and the abnormality of the situation* to verify whether their adverse experience could be rightly considered as something real and whether it could have been avoided. Seeking closure through recognition was essential. The four constructed categories and eight sub-categories are presented in Figure 2.

4.1 | Defining the boundary between one's own capacity and that of the hospital

The meaning-making of patient safety risks seemed to be constructed at the interface between the understanding of one's own capacities (e.g. past experiences; knowledge of one's own medical condition; physical, mental, spiritual, psychological and economic limitations; and thus one's perceived need for care) and the hospital's capacities (i.e. observations of how health care is organized; environmental resources and conditions; the behaviour of healthcare professionals; and thus their access to these resources). This process began the moment the participants entered the hospital, and sometimes before.

4.1.1 | Making sense of hospital care

By default, the hospital was seen as a safe place in which to seek medical care in times of suffering and uncertainty. Upon entering the hospital, the participants began, more or less intuitively, to make sense of their new situation within the hospital. This meant trying to understand how healthcare was organized in terms of work routines, such as what would happen when and where, and who had information about what. The capacity of the hospital was assessed by observing the behaviour of the healthcare professionals, evaluating the material conditions, and assessing the communication paths. In this way, a point of intersection was identified between the hospital's capacity and the participants' limitations, capabilities, and needs.

> Stefan: *When it starts, I can't delay going to the bathroom. Even if they respond the moment I call for attention, I have to get up, and they have to get a chair, you know. So I really can't say that it* (hospital care) *doesn't work, because it's me who doesn't work.*

Through these observations, the participants described how they identified the healthcare personnel to approach, when to approach them, and what to ask for and what not to ask for.
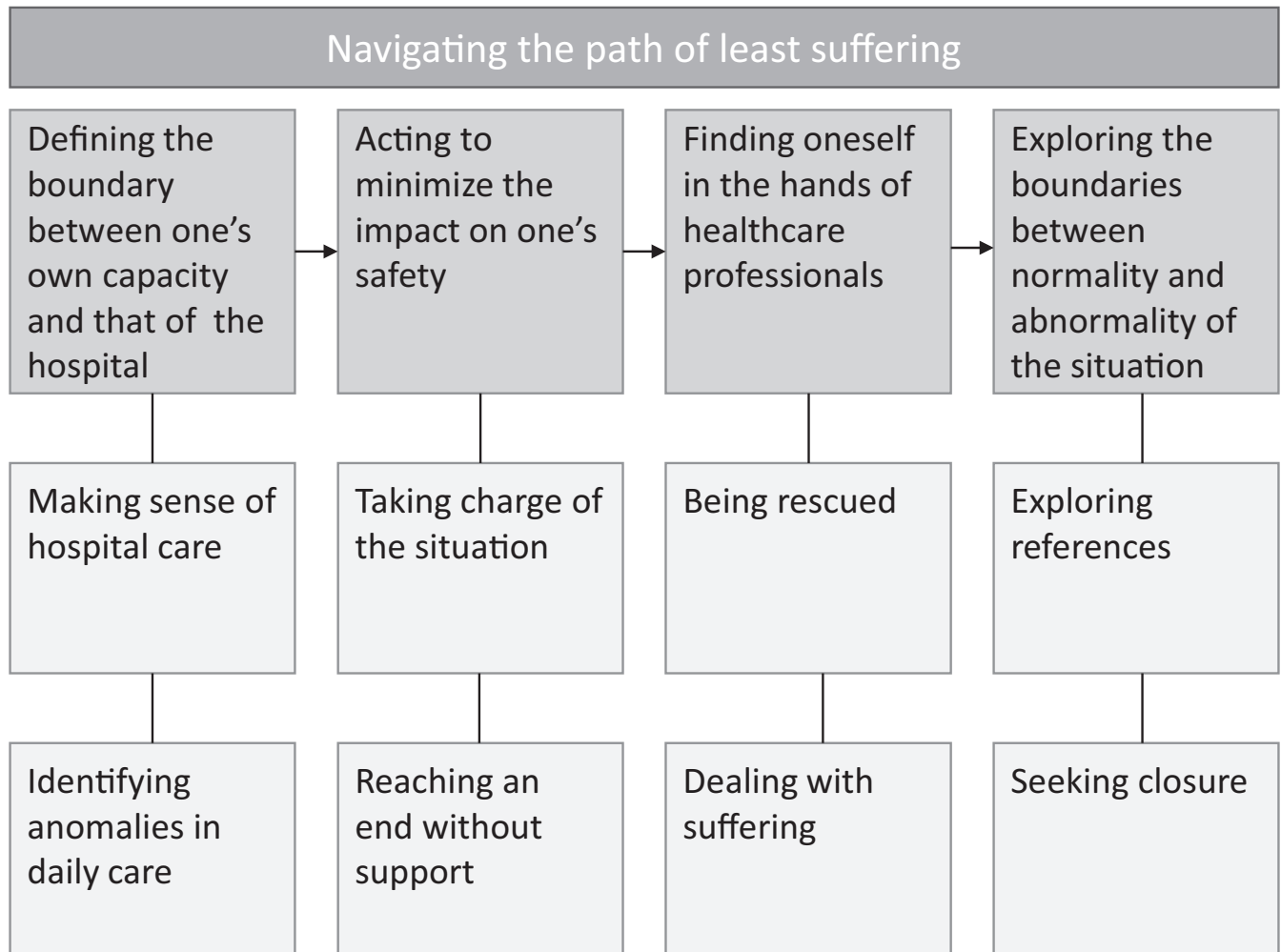
FIGURE 2 Categories and sub-categories of the process extending from the identification of patient safety risks to the filing of a complaint.

Identifying anomalies in daily care

In making sense of hospital care, participants identified deviations from common rules as well as idiosyncrasies and uncertainties. The interface between these identified anomalies and the participants' own capacity acted as a trigger for reflection on their own safety and well-being and how to maintain it. For example, the realization that medications were being changed without consultation with the patient was perceived as a risk, both in the hospital and after discharge. Deviations in medication administration were also observed.

> Nora: *They never came with my sleeping pills. I waited and waited. I think it was midnight, but by then half the night had passed. Medicine has to be distributed properly, morning, noon, and evening so that it gets to the right place.*

Other anomalies included the identification of individual healthcare professionals with derogatory behaviours. These personnel were seen as potential threats to the participants' safety and well-being, as the participants knew that conflicts could easily arise if they approached those professionals with specific care needs. Some participants had previously experienced dangerous situations in hospital settings, while others experienced these types of situations for the first time during their hospitalizations. For example, one participant overheard another patient behaving aggressively toward healthcare professionals, which caused the participant to empathize with being in the same situation as the healthcare professionals and what that would be like. Consequently, this caused the participant to worry about not being able to sleep safely.

4.2 | Acting to minimize the impact on one's safety

The participants' interpretations and assessments of the interface between their capacity and that of the hospital in terms of how, when, to what, and to whom they had access determined their perceived risks and, consequently, their actions. However, adverse events and potentially serious risks were sometimes not given much attention, even by the participants themselves. For example, one participant mentioned in passing that a bed broke down while she

was lying in it, and another did not consider a fall accident to be that serious, even though she had bruises all over her face when she recalled the event. On occasion, the participant's view of risk matched that of the healthcare professional, and other times it did not. This could be the difference between a safe participant and one who suffers an adverse event.

4.2.1 | Taking charge of the situation

The participants took preventive action as soon as the situation required it. By that time, they had often weighed the pros and cons of different actions. One strategy was to take control of the situation when the healthcare professional had not recognized the risk. In these situations, the participants gave step-by-step instructions on how they preferred to be mobilized, for example. Another strategy was to take the initiative to resolve a situation with available resources. One patient was immobilized and was unable to reposition himself in bed without assistance. The patient noticed a handle hanging out of reach above his head. He used a control device to raise the bed to its maximum height and was then able to use the handle to assist with the required repositioning manoeuvre. However, a healthcare professional who entered the room at the same time was alarmed by the bed's height and wondered what the patient was doing.

Another way for participants to protect themselves from harm was to refuse potentially harmful offers from healthcare professionals. For example, a patient with cirrhosis of the liver caused by alcohol consumption was offered a low-alcohol beer for dinner. The patient, who had long since stopped drinking, regarded this offer as poisoning and was horrified at the possible consequences. Other examples included a patient who was offered medications that had obvious negative side effects that were harmful given the patient's current state of health.

> Filip: *I had to be careful because I understood that they* (the healthcare professionals) *didn't have all the information about me either.*

Not trusting the nurse's competence, the patient avoided further discussion of alternative medications to relieve his pain.

4.2.2 | Reaching an end without support

Participants described how they sometimes had to stop trying to resolve a problem to ensure or maintain their safety and well-being. The patients, being dependent on the actions of the healthcare professionals, persistently struggled with the need to get the professionals' attention as they feared being viewed as a 'difficult patient'. This persistent work (e.g. asking questions about procedures, medical results, planning, mediating between healthcare professionals, or confronting healthcare professionals when

medical examinations or planning were perceived as flawed) was described by Malin as 'everyone passing the ball, but no one taking it'. This led to the patients experiencing great frustration, exhaustion, doubt, and a feeling of being left out. When one participant woke up after anaesthesia, she was given verbal information about pain relief and how to care for the surgical wound. Aware of her current limited ability to think clearly and the lack of social support at home, she tried to make sure that she would be able to manage her situation after discharge:

> Jenny: '*You have to write this down. What you are telling me, I need it on paper'. And, uh, I didn't get that.* (...) *So I had to contact the hospital* (after discharge) *and spend extra time in the healthcare system because they didn't give me the information.*

As a result, this participant also had to manage her pain for several days before receiving appropriate medical treatment.

4.3 | Finding oneself in the hands of healthcare professionals

When the participants had the ability to act on their perceived risks, they appeared to protect themselves from a variety of adverse events, including fall accidents, ulcer injuries, adverse drug reactions, economic failure, and disease regression. However, when they were dependent on the responses of healthcare professionals, their safety became more vulnerable. Sometimes, the healthcare professionals acknowledged and responded to the patients, and at other times, the patients exhausted their own attempts to engage the healthcare professionals. As a result, the patients were left to deal with the suffering themselves.

4.3.1 | Being rescued

An adverse event could unfold quickly without anyone being prepared for it. In these cases, healthcare professionals acted quickly to help the patient. They also took precautions after the event to ensure that a similar event would not happen again, as in Marie's situation after she fell.

> Marie: *It may be that they* (the healthcare professionals) *notice that I am walking unsteadily, for example. Then they like to take me under their arm or walk behind me and reassure me:* 'Don't hesitate to ask for help, I'm always behind you'. *This makes me feel safer.*

In situations where the participants had identified risks and communicated them to healthcare professionals, the responses varied. However, when acknowledged, adverse events appeared to be avoided, and potential uncertainty was reduced, making the patient

feel safe. Overall, a high level of confidence was evident in the ability of healthcare professionals to ensure patient safety. The patients also had a high level of understanding of the healthcare professionals' work situation. For example, in situations where the healthcare personnel appeared to be overworked and stressed, the participants felt compassion and did not expect the professionals to be able to deal with their concerns.

4.3.2 | Dealing with suffering

Sometimes the participants' concerns were ignored or minimized because of differing perspectives on their problems. At these times, the participant's perspective was easily overridden by the healthcare professional's perspective. For example, if a participant was cold and asked for an extra blanket, a nurse might refuse because of his or her own perception of the temperature in the patient's room, for example. One patient, who was unable to mobilize herself, was left naked on the bed in an awkward position for more than an hour, despite her attempts to reach out for help.

> Wilma: *I had been sitting in the bed for a while when a man and two women came to help me lie down. I ended up a little diagonally in the bed with my feet pressed against the foot of the bed. I said, 'I can't lie down like this'. One of the girls just said, 'Yes, but the occupational therapist will come and help you later'. 'You have to help me NOW', I said. 'I can't lie like this'. 'No, no, no, he will come later', the women said, and they left. And the man didn't do anything wrong. He said, 'I'm sorry. I can't do anything without the help of others'. So he left, too. And I was left lying there with no blankets or anything.*

The participants sometimes consciously chose to endure pain, for example, rather than get into conflict with the healthcare professionals. One participant refers to two nurses who seemed agitated even before interacting with the patients. The participant was suffering from cancer pain and the doctor had prescribed painkillers, which the participant had been told to ask for if he needed them.

> Stefan: *Yes, it has both worked and not worked. What I do when it doesn't work is just hold on until the next shift comes. It can take a while. It hurts a lot. It can vary from very painful to less painful. So you are dependent on the staff in that sense. Now, knowing their temperament, I don't say, 'I'd like to have my painkillers', but I change my approach and say, 'Would it be possible? when you're not so busy?' and 'If you have the opportunity, could you give me these painkillers?' Then I won't make them angry.*

Rather, the participants suffered and hoped for better opportunities to come. This decision could also be the result of a loss of confidence in, for example, the competence of healthcare professionals or their willingness to listen to what the participants have to say.

4.4 | Exploring the boundaries between normality and abnormality of the situation

After experiencing an adverse event, the participants clearly often struggled with uncertainties about whether the event could be legitimized as something real and whether it could have been avoided. Resolving these uncertainties seemed to be a crucial step in reconciliation within themselves and, if possible, with the hospital. Finding closure was essential, and this process seemed to last as long as questions remained unanswered. This may have been the case for some of the participants who continued to suffer and think about what had really happened, even up to two and a half years after leaving the hospital.

4.4.1 | Exploring references

The healthcare professionals' responses to adverse events had an impact on the participants' well-being and subsequent actions. The acknowledgment of some adverse events by the healthcare professionals increased the participants' confidence and motivation. Occasionally, healthcare professionals took the initiative to file a complaint on behalf of the participant, even though the participant was unaware that this was an option. One participant expressed how this relieved tension. However, when she told her husband, his response was that filing a complaint was a bit much, and that the adverse event could not possibly have been that serious. Her husband's response disempowered the participant again. To help determine whether an event was normal or abnormal, some participants talked to other people in their social networks who had experience and knowledge of similar situations.

> Johanna: *And they* (researchers of an ongoing study involving her specific diagnosis) *had some guidelines for treatment, including how to do a test where the heart rate could not be more than 70% of the expected maximum heart rate. The physical therapist was aware of this, but the attending physician was not.*

In this way, the participant was able to understand the accuracy of a procedure while also verifying whether this specific knowledge could be expected from the physician by comparing the awareness of other healthcare professionals. The long experience of healthcare with recurring errors and adverse events could sometimes provide a sense of normality.

Jenny: *I am very used to them* (healthcare professionals) *not doing things well. So, you just have to get used to it.*

This appeared to create difficulties for the participants in sorting out what was what and why they were feeling mentally and physically unwell. The type of support they received from healthcare professionals and others in their social network and the extent and manner in which the adverse event had affected them seemed to determine what they did next.

4.4.2 | Seeking closure

Among the participants who experienced adverse events, some did not consider the adverse events to be problematic or did not pay much attention to them. Confidence that the healthcare professionals had done all they could to keep them safe reduced their sense of having been mistreated. Initially, patients may have been in a situation in which they were grateful to have survived their disease. However, when a patient's suffering was neglected, it was easily exacerbated with additional feelings of self-doubt, shame, anger, and grief. The neglect also undermined trust in the healthcare system and its ability to provide appropriate care in the event of a future need for hospitalization. Some participants had decided to file complaints with the hospital. There were several motivating forces to do so. First, the prolonged suffering caused significant problems in everyday life, as the participants found themselves in situations in which they had to repeatedly contact different actors in the healthcare system and explain their situations repeatedly. They also considered the risks for future patients in the same situations and how these risks could be avoided. Karl received an answer to the question of what the professionals would do to prevent his adverse event from happening again. However, the hospital's efforts to make improvements were dismissed as rather weak.

Karl: *They noted a reaction* (an allergic reaction during anesthesia) *and will keep an eye on it in the future to make sure no more patients are affected. What kind of suggestion is that? So it's a doctor in a ward in this hospital who…* (laughing) *I'm sorry.*

Another participant also received a response that was unsatisfactory.

Malin: *And the reply I got was 'Your errand has been closed'-end of message. Are they allowed to do this? When I submitted my complaint to the hospital, I also received the response: 'Thank you for your feedback. We have forwarded it to the attending physician'. But my concern is that the doctor is not getting back to me. Then, it needs to be escalated, right? So for me, it's like shouting into a void.*

Participants who did not receive a sincere or adequate response, if any, felt the need to file a complaint with an external authority. Their hope was that it would help bring power to the importance of the matter, and that, in the best case, they would receive help to put an end to the suffering and perhaps receive an apology.

5 | DISCUSSION

The analysis of this study showed that the construction of the meaning of patient safety began the moment the participants entered the hospital, if not before. The participants also took patient safety actions at the moment they were needed before an adverse event occurred. Through the use of their knowledge, experience, observations, judgements, and creativity, the participants prevented a multitude of potential adverse events. Sometimes, this was done in collaboration with healthcare professionals, and sometimes in the presence of the healthcare professionals with them seemingly unaware. After experiencing an adverse event, the participants' understanding of patient safety continued to develop. This development seemed to be a result of the driving force to seek closure. Thus, patients' perspectives and actions are a real asset in patient safety work beginning from the moment they enter the hospital.

This study confirms previous findings that patients are already active in patient safety (Hor et al., 2013; Ringdal et al., 2017). However, the behaviour of healthcare professionals is also known to influence patients' propensity to act and speak up about patient safety risks (Davis et al., 2012). Furthermore, healthcare professionals' propensity to engage patients in patient safety has been shown to be context dependent and depends on various factors (Manias, 2015; Schwappach et al., 2013; Sutton et al., 2019). Thus, tensions still arise in situations in which discrepancies occur between patients' and healthcare professionals' understanding of different situations.

Expert knowledge has been found to give healthcare professionals discursive power in defining and making decisions about patient safety interventions, and this can cause unnecessary suffering (Hågensen et al., 2018). This finding is in line with the findings of this study, which showed that the participants put a lot of effort into legitimizing their situation or suffering as something real and important to deal with. These findings can be compared to those of the study by Werner and Malterud (2003), which examined how women with chronic muscle pain and illness were shaped by normative expectations of disease during encounters with physicians. The women in the study worked hard to maintain their self-esteem and dignity while attempting to make their 'unexplained' symptoms credible and socially real (Werner & Malterud, 2003). Similarly, participants in our study worked hard to make 'unrecognized' risks and suffering credible to protect their safety while maintaining their trustworthiness and not being seen as 'difficult patients'.

Overall, our participants felt safe in the hospital. However, after the experience of constantly trying to explain their situation and not being taken seriously, they felt grateful and even lucky

when they met a healthcare professional who took them seriously and listened to them. This mix of 'good' and 'bad' encounters with a variety of healthcare actors in different parts of the hospital organization appeared to be somewhat random according to the analysis. This can be explained in several ways. First, institutions are well known to have already established and predefined decision processes that may exclude some options and favour others (Douglas, 1992). Furthermore, as mentioned above, expert discourse brings discursive power to healthcare professionals to define issues and make decisions in the hospital setting that leave out alternative versions from the patient's perspective about his or her safety (Hågensen et al., 2018). This risks undermining the trusting relationships that are key to patient participation in patient safety.

Giddens (1990) suggests that although trust is essentially in the abstract system, the encounters between patients and healthcare professionals serve as important opportunities to establish trustworthiness. However, the access points to face-to-face encounters are also vulnerable in abstract systems. This is particularly evident in short, one-time encounters, in which healthcare professionals have little time to build trust and bring their expertise to the table, compared to repeated encounters between the same people. Healthcare professionals may be more easily judged as representatives of the system in brief meetings; therefore, they are required to exert more effort to build trust (Giddens, 1990). Overall, it may not be surprising that the perceived quality of encounters varies and appears rather random in the context of modern abstract systems. What is interesting in the context of the present study, however, is what this means for patients in terms of patient safety.

From the participants' point of view, their efforts to engage the healthcare professionals in their safety concerns were sometimes met, making the participants feel safe. On other occasions, their concerns were overlooked, leading in the worst case to adverse events. When concerns were not acknowledged, future efforts to approach the hospital or specific healthcare professionals could be understood as risk-taking. Thus, risk can be interpreted, like tossing dice, as 'the probability of an event occurring, combined with the magnitude of the losses or gains that would be entailed' (Douglas, 1992, p. 23). The gain may be estimated on the basis of trust in the abstract system and individual positive experiences, while the loss may be estimated in terms of safety based on previously experienced adverse events, including physical, mental, emotional, spiritual, and financial losses. This could explain why the participants expressed 'feeling lucky' when finally being taken seriously. This argument is supported by previous findings showing that patients may choose to leave the hospital or resist seeking medical care again if they experience a loss of safety or well-being in the hospital (Gyberg et al., 2023). This meaning construction of risk, which affects patient safety actions, can be an important consideration in future improvement work in patient safety. However, for a deeper and more nuanced understanding, further research is needed that addresses the patient's perspective of risk and how it affects patient participation in patient safety.

5.1 | Limitations

The in-depth interviews provided rich and relevant data, which are fundamental to the credibility of grounded theory studies (Charmaz, 2014). However, this study was limited by the relatively small scale of the design, as it was conducted in one country in a high-resource setting. The study group was also homogeneous, with all but one participant being of Swedish origin and the majority being women. As a study focusing on social processes, caution might be needed when attempting to extrapolate these findings across cultures (Douglas, 1992). Thus, an extension of this study design might strengthen transferability by including participants with experiences from a variety of hospital settings around the world. This broader arena of patient safety cultures could potentially provide a broader and richer knowledge of patients' abilities and capacities to construct patient safety in a variety of situations.

One strength of this study was that a whole process was explored, and participants were recruited from different parts of that process. A limitation that emerged during the project was the slow recruitment of participants who had filed complaints through the Patient Advisory Committee. The reason for this was that only 20% of the incoming complaints were reported by patients. The other 80% were reported by relatives. The workload of the Patient Advisory Committee working group assisting with the study was considered too high in relation to the small number of participants being recruited each month. As a result, recruitment was stopped before sufficient data had been collected. Consequently, the fourth category was not sufficiently explored, preventing the researchers from identifying the point at which saturation had been reached. Alternative and more efficient ways to identify and recruit participants with experience in the later part of the process are needed.

6 | CONCLUSION

Our findings show that participants, in their role as patients, began constructing the meaning of patient safety the moment they entered the hospital, and sometimes earlier. After the patients experienced an adverse event, their understanding of patient safety continued to evolve as they sought closure. Therefore, having healthcare professionals ignore the patient's understanding of patient safety risks and perceived adverse events contributed to both short- and long-term patient suffering. This, in turn, could lead to repeated contact with different parts of the healthcare system, which could potentially be risk taking for patients in terms of the likelihood of further loss of safety and well-being. It is evident from the research findings that many of the participants lacked sufficient support from the healthcare system when trying to make sense of their situation. Consequently, it can be suggested that future research could potentially benefit from including individuals from alternative settings, such as family members or patient organizations. Such research could further explore how various social interactions contribute to the construction of meaning and

the extent to which different factors facilitate patients' recovery after suffering from an adverse event. The findings of this study have clinical implications at both the individual and organizational levels. Knowing that patients' questions and concerns are well thought out and relevant to their perspectives on patient safety in their current situations may help motivate healthcare professionals to spend more time to truly understand patients' perspectives. This could make the difference between a safe patient and an adverse event. However, hospital environments need to have a structure that allows for the development of trusting relationships in which patients are empowered to be proactive. This could be done, for example, by making greater use of patient representatives at different levels of the healthcare system.

AUTHOR CONTRIBUTIONS

All authors have approved the final version and all meet at least one of the following criteria (recommended by the ICMJE; http://www.icmje.org/recommendations/): (1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; (2) drafting or revising the article critically for important intellectual content. Anna Gyberg contributed to the acquisition of data, to most of the data analysis, and to the drafting of the manuscript. All authors contributed to the interpretation and critical revision of important content. The final version was approved for publication by all authors, who also agreed to take responsibility for all aspects of the work. As study supervisor, Kerstin Ulin was responsible for critical revision and supervision.

ACKNOWLEDGEMENTS

FUNDING INFORMATION

CONFLICT OF INTEREST STATEMENT

No conflict of interest has been declared by the authors.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Gyberg, A., Brezicka, T., Wijk, H., & Ulin, K. (2024). From identifying patient safety risks to reporting patient complaints: A grounded theory study on patients' hospital experiences. *Journal of Clinical Nursing, 33*, 4421–4433. https://doi.org/10.1111/jocn.17355