Struggling for access to appropriate healthcare services: A qualitative content analysis of patient complaints

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Struggling for access to appropriate healthcare services: A qualitative content analysis of patient complaints

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Abstract

Aim: This study aimed to describe circumstances concerning access for patients and relatives to take part in patient health and safety in a hospital setting.

Design: This study used a qualitative descriptive design and was conducted at a Swedish university hospital.

Method: The 79 complaints reported by patients and relatives included in this study were registered between January 2017 and June 2019. These complaints were classified as concerning access to healthcare services. Data were analysed using qualitative content analysis.

Results: The overarching theme, *struggling for access as a human being in the healthcare system*, encompassed three themes describing patients' and relatives' needs. The three themes were (1) *navigating through the healthcare organization*, (2) *making sense of self and what is going on* and (3) *being acknowledged as having needs*.

Conclusion: Patients and relatives continuously participate in various ways in healthcare to promote health and prevent patient harm. Our findings contribute important knowledge about the meaning of access from a broad healthcare system perspective. Access was restricted in terms of appropriateness in how patients' needs were met. This restriction of access risked the deterioration of patient health and safety.

Impact: Patients and relatives play an active part in patient health and safety, although their attempts are sometimes hindered. Restrictions in the appropriateness of access prevented patients and relatives from taking part in patient health and safety, which appeared to mean that they had to adapt and expend effort to the point that it negatively affected their health and everyday life. These findings concern all patients, relatives and healthcare professionals in hospital-associated settings.

Patient or Public Contribution: No patient or public contribution.

KEYWORDS
access, hospital care, nursing, patient complaints, patient participation, patient safety, quality, relatives

1 | INTRODUCTION

Healthcare systems that experience high numbers of adverse events have increasingly acknowledged patients' part in ensuring patient safety. The World Health Organization (WHO; 2021) stresses that achieving safe healthcare requires informed and involved patients who are treated as full partners in their own care. Patient participation is more commonly associated with shared decision-making (Eldh, 2018), although, from a patient perspective, the concept can include the patient's involvement in any life situation (Eldh et al., 2010). A fundamental component of patient participation is interaction between patients and healthcare professionals (Cahill, 1996). Previous research shows that healthcare professionals are positive towards patients participating in their health and safety situations (O'Dowd et al., 2018). However, research also finds that healthcare professionals did not always acknowledge patients' and relatives' attempts to take part (Hor et al., 2013). The fact that a patient had access to healthcare services does not mean the healthcare provided was perceived as appropriate (Levesque et al., 2013). To influence patients' safety actions, patients and relatives need access to healthcare professionals who understand and attend to patients' concerns and needs at the point in time when they are called for (Gyberg et al., 2021). In this qualitative study, we understood access as a precondition for patient participation. To bring forth the patient and relative perspectives, we made use of an electronic report system for patient complaints in a Swedish university hospital. Written complaints classified as regarding access through the hospital's classification system could this way be included. In this way, the meaning of access, or lack of access, to healthcare services was explored through patients' and relatives' spontaneous descriptions of encounters within hospital-associated settings.

2 | BACKGROUND

2.1 | Patient participation

The literature suggests patient participation is a concept that was initially understood and described from a healthcare professional perspective and commonly associated with shared decision-making in healthcare planning (Eldh, 2010). However, further attributes of this concept have been identified, such as shared information and knowledge between patients and healthcare professionals (Cahill, 1996; Sahlsten et al., 2007; Thompson, 2007), some degree of power surrendered to the patient (Cahill, 1996) and the actual activities in which a patient participates (Cahill, 1996). Central to patient participation is the existence of a relationship (Cahill, 1996). By adding patients' perceptions to the concept of participation, Eldh et al. (2010) identified attributes involving patients' attitudes and actions in relation to healthcare professionals, the healthcare system and their own health and disease. Those authors suggested that the definition by the International Classification of Functioning, Disability and Health that states 'participation is involvement in a

life situation' (WHO, 2001, p. 127), would be more inclusive given its patient perspective on patient participation (Eldh et al., 2010). In this definition, which we also used for this study, patient participation involves opportunities for patients to take action, such as preventing illness or practicing self-care in any situation (Eldh, 2018).

Sahlsten et al. (2007) stated that in nursing, patient participation 'means that patients should have the opportunity to participate in their own care, adjusted to ability and the current situation' (p. 632). Cahill (1996) called these opportunities antecedents; that is, events that must occur before patient participation can happen. For example, patients need to have access to the reasoning process to participate in inferences regarding different solutions to problems raised (Thompson, 2007). Furthermore, patients will not be able to participate without access to appropriate and comprehensible information and knowledge (Cahill, 1996). To further capture perspectives on opportunities for patients and relatives to participate in patients' healthcare and safety throughout healthcare services, we used the concept of access, which also contributed to a system perspective.

2.2 | Access: A precondition for participation

We defined access as involving 'the opportunity to reach and obtain appropriate healthcare services in situations of perceived need for care' (Levesque et al., 2013, p. 4). Access can therefore be considered to represent a result of the interface between the characteristics of the patient and the characteristics of the healthcare system (Penchansky & Thomas, 1981). Although access is a concept traditionally used when referring to entry to or use of healthcare services (Penchansky & Thomas, 1981), it also includes the way access to healthcare is being provided, that is, its appropriateness (Levesque et al., 2013). Therefore, we considered the healthcare system as a social system, where the interface or point of access is built on social relationships embedded in professional expertise and value-bases, and supported by technological and material solutions (Giddens, 1990). For example, the appropriateness of these opportunities can help to clarify how patients and their relatives motivate themselves to engage in activities (Levesque et al., 2013), such as the process of reasoning together with healthcare professionals, which allows inferences for different solutions to problems raised (Thompson, 2007). Through the lens of patients' and their relatives' experiences of encounters with healthcare professionals, factors such as the *fit* between their needs and measures taken by healthcare professionals, timeliness, treatment choices and technical and personal quality of care can be explored.

2.3 | Access and patient participation in patient safety

Patient safety can be described as 'a framework of organized activities that creates cultures, processes, behaviours, technologies and environment in healthcare that consistently and sustainably lower

risks, reduce the occurrence of avoidable harm, make error less likely and reduce the impact of harm when it does occur' (WHO, 2021, p. V). The WHO (2021) proposed engaging families and relatives in patient safety as a strategy to strengthen this framework of organized activities. This engagement is also considered one of the most powerful ways to improve patient safety. In the context of the prevention of patient harm, previous research confirmed the meaning of patient participation as including the importance of being invited to understand their own health condition, co-deciding directions in care, and engaging in error prevention (Ringdal et al., 2017). Research has shown that patients and relatives are willing to and do participate in several ways. For example, patients act by showing their identification bracelet if the healthcare professional forgets, reminding healthcare professionals to wash their hands (Ringdal et al., 2017) or taking preventive measures such as re-positioning themselves in bed to avoid pressure injuries (McInnes et al., 2014). Similarly, relatives participate in several ways, such as through their unique knowledge about patients' medication and taking an active role in negotiating how medications are managed (Manias, 2015). Previously experiencing an error contributed to a greater intention to ask healthcare professionals about safety measures, especially those perceived to be most beneficial (Davis et al., 2012). Normative beliefs have also been shown to play an important role in terms of patients' need to feel it is socially acceptable to ask about problems at hand (Davis et al., 2012). It has therefore been suggested that important ingredients for patients' participation in patient safety actions include healthcare professionals' encouragement, support and education regarding safety risks and management (Davis et al., 2012; McInnes et al., 2014). However, patients' and relatives' participation in patient safety has proven to be situational and faced with many challenges.

Patient participation appears to depend on a fluctuating awareness of patient safety and risk management among both patients and healthcare professionals (Davis et al., 2012; Manias, 2015). Missed opportunities can be explained by unfavourable environmental preconditions (McInnes et al., 2014) or healthcare professionals being too procedural or task-orientated (Manias, 2015). Mutual acknowledgement and collaborative relationships in which patients' ability and motivation are identified have been suggested to improve patient participation in safety actions (McInnes et al., 2014). However, power imbalances in patient-provider relationships may limit access for patients and relatives to participate in healthcare. Lack of acknowledgement of patients' and relatives' perspectives on a patient's health and healthcare measures, along with healthcare professionals' prevailing definition of truth may be explained by the discursive power of healthcare professionals as the experts (Hågensen et al., 2018). This expert discourse, which was empowered by impersonal instruments and pervaded trust in the work procedures of the system, risked overshadowing the meaning of social relationships and excluding patients from taking part participating in patient health and safety (Gyberg et al., 2021). Overall, perceiving barriers and a lack of access disempowers patients and their relatives and puts them in a passive position.

To our knowledge, few studies in this area have focused on patients' and relatives' perceptions of access and its appropriateness from a broader perspective, including any healthcare professional or situation that patients and relatives may encounter in a hospital-associated setting. Most research on access has been presented in terms of healthcare service availability rather than its appropriateness when entering the hospital. Thus, valuable knowledge is needed regarding how patients and relatives perceive circumstances concerning access to take part in patient health and safety in hospital settings. Moreover, most research about patient participation presented context-specific findings, or addressed specific procedures, interventions, or places. We assumed that adopting a broader healthcare system perspective would expand the knowledge base on circumstances that hinder or enable access to healthcare services, of which reciprocal relations are a crucial part of patient health and safety.

3 | THE STUDY

3.1 | Aim

The aim of this study was to describe circumstances concerning access for patients and relatives to take part in patient health and safety in hospital settings.

The research questions were:

- What type of desired access was described?
- How was access or lack of access described?
- How did patients and relatives describe the impact of access/lack of access?

4 | METHOD

4.1 | Design

This study was based on written patient complaints registered in a hospital's electronic report system for adverse events. With a qualitative descriptive design (Sandelowski, 2000), circumstances concerning access as reported in its natural setting was captured (LoBiondo-Wood & Haber, 2022). We used qualitative content analysis and inductively constructed themes relevant to the research objectives through interpretation of data from the purposefully included patient complaints (Graneheim et al., 2017).

4.2 | Setting and context of patient complaints

This study was conducted in an urban university hospital located in a large city in Sweden. The hospital is a public facility with a catchment area that includes both the city and nearby municipalities. The hospital has 17,000 staff and provides healthcare for 350,000

patients annually. At the study hospital, complaints from patients and their relatives are registered in an electronic report system for adverse events. Patients and their relatives can either complain directly to the hospital or to impartial external actors at the Patient Advisory Committee or Health and Social Care Inspectorate. Either the patients/relatives themselves write down what happened, or a healthcare representative summarizes patients' or relatives' descriptions of their experiences. At the end of 2016, the study hospital implemented a classification system based on the Swedish Patient Act (SFS, 2014). Healthcare actors who have a role in managing complaints classify each event according to this classification system. One of these 10 classifications is *access* to healthcare services.

4.3 | Sample and data collection

The sample used for this study was drawn from complaints registered from January 2017 to June 2019. In that period, 3787 complaints related to adult somatic healthcare (i.e., medical care concerning physical healthcare needs) were registered at the study hospital. Of these, 94 complaints were classified as events involving access to healthcare. Fifteen complaints had incorrectly been registered as a complaint and were excluded from the sample. This left 79 complaints for inclusion in this analysis that were based on patients' and relatives' experiences from specialties within adult somatic healthcare at the study hospital.

The included complaints were written by patients or their relatives themselves ($n=26$) or by healthcare professionals/representatives on behalf of patients and relatives ($n=53$), as illustrated in Figure 1. The 79 written complaints contained 22,588 words (range 14–1225 words), with a mean of 290 words and median of 134 words. Eleven complaints were registered anonymously, and the patients' age and gender could not be identified. Excluding these anonymous complaints, the mean age of the patients was 56 years (range 19–91 years) and 45% complaints concerned women.

4.4 | Data analysis

Qualitative content analysis was used to guide the data analysis. This is a method for subjective interpretation of content in text through a systematic classification process of coding and identifying themes and patterns and is considered appropriate when describing a phenomenon for which literature is limited (Graneheim et al., 2017).

The text of each complaint was initially read thoroughly several times to gain an overall understanding of the content. The subsequent de-contextualization of the text focused on identification of meaning units, which often contained a set of sentences or a paragraph with the same central meaning. Because the patient complaint narratives varied in length and depth and given the nature of the research questions, both manifest and latent content analysis were performed (Graneheim et al., 2017). Text written by healthcare professionals was generally more condensed and presented a summary of patients' and relatives' experiences. Analysis of the manifest content helped in answering the question about the kind of access that was referred to in the complaint. The latent content analysis focused on the underlying meaning and contributed to an extended interpretive level (Graneheim et al., 2017). Where possible, meaning units were condensed into shorter blocks of text that preserved the core content. These condensed units were coded and recoded as the analysis progressed and new data were added to build the researchers' understanding of the research questions. Data were then coded. In the coding process, codes were compared with other codes, with a focus on similarities within and differences between codes. Through re-contextualization, similar codes were recognized and grouped into categories. The coding and categorization process is exemplified in Table 1. Patterns of underlying meaning across several categories were grouped into themes and an overall 'red thread' became the main overarching theme. Comparative reading continued throughout the analysis process as categories and themes took form. This meant that categories were compared with categories, themes with themes, codes with categories and so on.
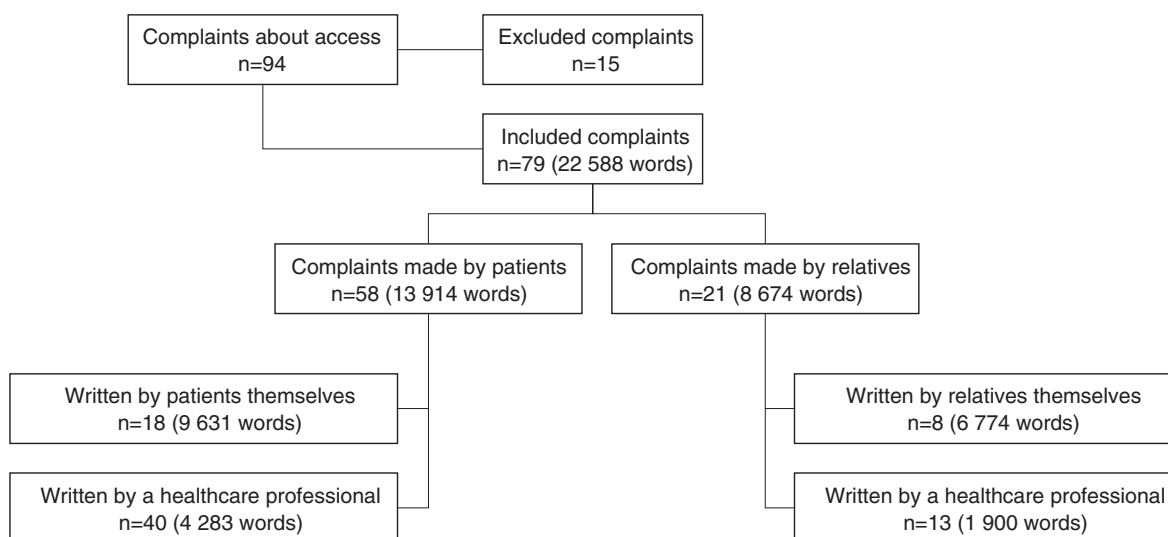

FIGURE 1 Features of the included complaints ($n=79$).

TABLE 1 Illustration of the analysis process.

Meaning units	Condensed meaning units	Codes	Categories	Themes	Main theme
The answer I received is that one does not access the cardiologist if one is not registered to a cardiologist and that I need a referral from primary care to come in contact (with the doctor). I also receive information about that. Even though I am registered at the pacemaker clinic, I must have a referral from primary care since the pacemaker clinic only has registered nurses working there. After talking to 1177 (national healthcare counselling) I feel enormously helpless and confused and realizing that I will not get anywhere with my errand. (1)	They can only access a cardiologist through a referral from primary care, even though the patient is registered at a pacemaker clinic at the hospital. Not finding a doctor that can help provokes confusion and a feeling of being helpless.	Helpless when trying to find ways through healthcare	Entrance to healthcare	Navigating through the healthcare system	Struggling for access as a human being in the system of healthcare
An assistant nurse enters the waiting room at 1.50am (after 6h of waiting) and recommends the patient to seek care in primary care instead. When deciding to seek care in the primary care, he asks the healthcare team to discharge him. He is leaving at his own risk, says the registered nurse. Seeking care at the emergency center in primary care the day after, he is once again referred to the emergency department at the hospital (35)	The assistant nurse recommends the patient to seek primary care while the registered nurse advises against. After seeking the primary care, the patient must return to the ED again.	Difficulties finding proper level of care	Proper level of care		
During follow-ups, not even the nurse could interpret the abbreviations without looking it up. No explanations offered why the blood samples turn out the way they are. Have had meetings with different doctors each time and some I have not even understood what they are saying (…) I do not know if there are any injuries since nobody takes it seriously when I ask. All I know is that my daily life is affected since I am exhausted and feeling crummy. (13)	Not even the nurse can interpret the abbreviations. Information is not offered nor comprehensible. Concerns not being taken seriously. Daily life affected by being tired and feeling crummy.	Hidden health condition causes	Health condition orientation	Making sense of self and what is going on	
The relatives of a critically ill patient wish to talk to the patient's doctor about continued plans and care activities. (…) I perceive that the doctor reluctantly agrees to talk with them before she leaves. The relatives are being notified and therefore sit down and wait for the doctor from 1.30pm to 4.30pm. They become more and more frustrated. At four thirty, another doctor says that the doctor I spoke to left for the day. (11)	Relatives of a critically ill patient wait for hours to talk about forthcoming care plans with the patient's doctor, who does not show up as agreed.	Excluded from healthcare planning	Direction orientation of care		

4.5 | Qualitative rigour

Qualitative rigour refers to additional approaches and procedures performed to establish authentic and trustworthy meanings from the research findings (LoBiondo-Wood & Haber, 2022). This study was based on patients' and relatives' spontaneous descriptions of their healthcare experiences. The use of naturally occurring material with no interaction from the authors before the analysis began added to the trustworthiness of this study by avoiding issues such as interviewer bias (Elo et al., 2014). Moreover, we included all complaints in the reporting system for adverse events that had been registered as concerning access to healthcare. This limited any interference from the researchers' preconceptions about access during data collection. The researchers repeatedly returned to the data to ensure that their interpretations were true to the data (Elo et al., 2014). As an interpretation check, members of the research team were given different roles. The initial analysis was mainly conducted by the first author. The fourth author then reanalyzed parts of the data, while the second and third authors, who had not been involved in the initial analysis, read the patient complaints thoroughly and controlled whether the interpretations of the constructed categories and themes were rooted in the data.

Another difficulty that researchers face is establishing the degree of interpretation and the abstraction level of categories and themes (Elo et al., 2014). Therefore, reflexive group discussions among the research team were held with support from the two-dimensional model developed by Graneheim et al. (2017). This ensured that issues such as category abstraction levels that were too high could be identified and corrected. The data were quantified in the reporting phase, as shown in Table 2. The number of incidences was presented to enhance the transparency of the data and clarify the magnitude of the individual phenomenon (Bengtsson, 2016). We assumed that this may add to the emphasis on the perspectives of access that patients and relatives encounter in healthcare

professionals in different parts of the hospital, e.g., in-hospital or out-patient care. Taken together, the complaints covered activities in different parts of the hospital. Finally, we deliberately chose citations covering as many perspectives and circumstances of access as possible and tried to include a variety of people who contributed to making complaints, as suggested in literature (Elo et al., 2014).

4.6 | Ethical considerations

All reported patient complaints were anonymized. Cited extracts were chosen in a way that ensured identification of any individual was not possible. All procedures in this study complied with the Declaration of Helsinki (World Medical Association, 2013), and the study was approved by the Regional Ethical Review Board in Gothenburg (Dnr 447-15, amendment Dnr 2019-03405, and amendment Dnr 2021-06565-02).

5 | FINDINGS

Three themes and nine categories were identified. These categories reoccurred in a variety of situations in the different parts of the hospital (Table 2). Overall, circumstances concerning access for patients and relatives to take part in patient health and safety were characterized by the need to: (1) come in contact with healthcare professionals able to attend to their specific needs (*navigating through the healthcare organization*), (2) know what to expect of the healthcare system and themselves (*making sense of self and what is going on*), and (3) encounter healthcare professionals who acknowledged and responded to their needs (*being acknowledged as having needs*). It appeared that patients and relatives had to adapt and expend effort to a point that it negatively affected their health and everyday life. Access to appropriate healthcare services appeared to be heavily

TABLE 2 Themes and categories of access associated with hospital care.

Themes	Categories	Pre-hospital care and triage	In-hospital care	Out-patient care	Total
Navigating through healthcare organization	Entrance to healthcare	—	—	6	6
	Proper level of care	15	—	3	18
	Ideal specialty	6	—	1	7
Total					31
Making sense of self and what is going on	Process transparency	8	5	6	19
	Health condition orientation	6	1	3	10
	Direction orientation of care	—	9	13	22
Total					51
Being acknowledged as having needs	Interpersonal needs	6	3	—	9
	Nursing needs	9	13	—	22
	Medical needs	21	7	3	31
Total					62
Total		71	36	34	144

based on mutual understanding and trust. This mutuality was easily disrupted when patients/relatives had to re-navigate through the healthcare system and encountered multiple actors with different roles and purposes. The main overarching theme that combined the themes and categories was identified as _struggling for access as a human being in the healthcare system._

5.1 | Navigating through the healthcare organization

Navigating through the healthcare organization was shown to be challenging for all parties involved. For patients and relatives, this navigation appeared to have high costs in terms of time, transportation and personal emotional investment through arguments with healthcare professionals when trying to legitimize their needs as valid.

5.1.1 | Entrance to healthcare

Patients' and relatives' navigation through the healthcare organization involved searching for a person who could help solve the problems at hand. Commonly, these patients and relatives already had a healthcare contact from previous in-hospital care or visits to the emergency department. However, when obstacles emerged, patients and relatives could not easily find ways to solve their problems despite existing healthcare plans, agreements, promises and arrangements. Problems described in the complaints involved failing health conditions, identification of risks concerning medicines, delayed medical certificates, referrals to examinations or doctor visits and problems concerning transportation or medical costs. Patients and relatives described not being able to reach a single person who could help them navigate to a proper contact was described as exhausting.

> It took me about 1.5 months from the time I discovered that something was wrong with me to the day when I got in contact with the right physician. (…) It felt like running around in a maze, and even though I tried to get help, it didn't feel like I got any. I was only bandied about. (Former hospital inpatient) (1).

Finding a way to the right person in the healthcare organization required hard work, including making phone calls, transportation between different places, and arguing with healthcare professionals in attempt to legitimize patients' needs as valid. At the same time, patients and relatives struggled with health issues, daily life and worries over their own or their relatives' health condition.

5.1.2 | Proper level of care

Navigation through the healthcare organization also involved finding a proper level of care, which concerned efforts to assess the severity and urgency of patients' conditions. Depending on the severity and urgency, decisions on how, where and when patients needed to receive medical attention were made. There was some discrepancy between patients'/relatives' and healthcare professionals' assessments, which created tensions and raised emotions. Many patient complaints contained descriptions of healthcare professionals rejecting the patient's presence at the emergency department. Most commonly, healthcare professionals assessed the patient's condition as less severe and urgent than the patient's own assessment. This discrepancy caused conflicts when patients were rejected or referred to primary care, especially in cases when patients had already been referred to the emergency department by other actors in the healthcare system, including actors at the hospital and in primary care.

> First, I had tried to get help through the orthopedics; they requested me to seek care at the ED (…) When I sought help the 16th of Jan for surgery wound infection after the knee surgery, I was rejected by her (the receptionist at the ED). I refused to leave the chair, my wife had to help me because I was too sick, had fever, was dizzy, had pain. The physician went through with a surgery the day after, CRP 300! (a protein in the bloodstream as a response to inflammation). (Patient receiving medical investigation for complications during hospital care) (50)

Contradicting recommendations resulted in patients being frustrated and confused. This sometimes resulted in unpleasant arguments with healthcare professionals and sometimes in patients leaving with conditions that later turned out to be worse than first expected.

5.1.3 | Ideal specialty

Finally, navigating through the healthcare organization involved finding the ideal specialty for the patient's health condition. This navigation started with patients seeking care at the emergency department at the hospital or another healthcare facility. Sometimes it took time for specific medical needs to be identified. This meant that patients who had ended up at the healthcare facility without identification of the ideal specialty had to travel elsewhere. This prolonged the time spent waiting for medical attention. The delayed medical assessment and patients' efforts throughout this process made them tired. Some patients felt so frustrated and tired that they chose to leave the hospital before being assessed by a physician.

5.2 | Making sense of self and what is going on

To engage, patients and relatives needed to know what to expect of themselves. Opportunities for engagement were created by patients/relatives gaining insight into what was going on, the

patient's health condition, and potential plans. Not having these insights meant that access to engagement appeared marginalized, and consequently presented a threat to patient healthcare and safety.

5.2.1 | Process transparency

To know one's place in a process and to know what was going on appeared to be crucial. Knowing that something was going to happen but not when and how triggered many questions for which patients and relatives needed answers to ensure they were prepared.

> In-hospital patient accepted for heart surgery experiences an ill-treated reception by the night shift staff. Ignorant treatment without answering the questions. (Healthcare professional reporting an inpatient's complaint) (17)

When they did not receive answers to questions, patients felt left out, ignored and frustrated. If they were not participating in their own healthcare, patients and relatives sometimes gave up, either by stopping engaging (i.e., becoming passive receivers of care) or by leaving hospital at the cost of their own suffering. However, once situations and procedures were explained and patients were involved, trust was reinforced and uncertainty relieved.

5.2.2 | Health condition orientation

Orientation to patients' health conditions also requires involvement in healthcare activities. However, access to information about patients' conditions was not automatically shared by healthcare professionals. Factors obstructing patients' access to information about their condition were described as incomprehensible written information, limited pathways through the organization, and meetings with healthcare professionals who lacked time, were unwilling to answer questions, or lacked insight about patients' conditions or care plans.

> A potential explanation or time for questions did not exist. I tried to ask some questions to the responsible physician, but was treated by a physician who leaned over and answered, "Yes, what do you want me to say about that…" I gave up. (A patient's relative trying to learn more about the inpatient who was in palliative care) (57)

Being given access to the results of examinations and assessments helped patients and their relatives move forward because they had insight about what would come next and therefore what they could expect of themselves as participating in their own care.

5.2.3 | Direction orientation of care

Despite clarity of the direction of care being expressed as needed, patients' and relatives' part in the decision-making process appeared to be marginalized. Healthcare professionals were described as not listening to the patients when they tried to address their situations and wishes, and sometimes not even acknowledging that the patients or relatives had important roles in the planning process.

> At Monday evening when finishing my job, I had 12 missed phone calls from my father and learned from my sister that dad had received information from responsible staff that he was going to be discharged the 3rd of April. Dad was very stressed and sad when I called him, he expressed great worry to go home because he didn't feel ready to finish rehabilitation and suffered from chest pain. (A hospital inpatient's relative) (76)

Decisions made by healthcare professionals were sometimes unexpected. Therefore, patients and relatives had to adjust and adapt to changes of plans at short notice. Similarly, broken agreements put patients and relatives in a difficult position of trying to renavigate through the healthcare organization, as noted in the first category *navigating through the healthcare organization*. Broken agreements involved returning phone calls, appointments for doctor visits, examinations, and drug treatment. This meant that patients and relatives had to spend a lot of time trying to find someone who could help them move forward and argue for their needs when talking to new actors regarding the matter, while experiencing deteriorating health and increased struggles in daily life.

5.3 | Being acknowledged as having needs

Regardless of whether patients' needs concerned attention to nursing needs, medical needs or merely reassurance from healthcare professionals, lack of acknowledgement and response to their needs risked counteracting a safe path forward. When they were not acknowledged, patients and relatives persisted in presenting their concerns. However, matters were sometimes taken into their own hands, potentially at the risk of their safety because they were not being acknowledged.

5.3.1 | Interpersonal needs

Patients described a need for healthcare professionals to check on them from time to time to make sure that they were all right, especially during prolonged waiting times and times of suffering. When feeling vulnerable, interpersonal encounters were desired to reduce uncertainty and worries. The need for someone to visit

patients appeared to occur at times when symptoms were perceived as threatening or incomprehensible.

> The patient suffers from episodes of VT (ventricular tachycardia) and experienced a rush in the heart during the night and became worried. Earlier night staff have come to check in on the patient during these episodes, but no one arrives this night, so the patient calls for attention. The staff arrive and confirm that they saw this at the monitoring screen, though they said that it was no danger why they did not check in on the patient. But if they had come it would have been more reassuring. (Healthcare representative report of an inpatient's experience) (17)

The need to be checked on related to healthcare professionals' reassurances that everything was under control and the need for someone to acknowledge suffering experienced.

5.3.2 | Nursing needs

Descriptions about nursing needs involved all types of support that patients needed to function, such as being able to communicate, mobilize, empty their bladder, eat, maintain hygiene, keep warm, rest or sleep. All complaints that involved nursing needs highlighted a lack of support. This lack of support hindered opportunities for self-care, safety measures and expressing further needs.

> The patient was told not to get out of the bed without calling for assistance. The patient calls for help, but no one is coming. According to the patient he is waiting for about 1 hour. He needs to pee so much that he goes up on his own. He falls and can no longer refrain from urinating. Lying on the floor for about 2h before he gets the staffs attention (…) The patient perceives the staff as very unpleasant. Felt scared and jumpy afterwards. (Registered nurse relating an inpatient's experience) (12)

Some patients did not dare to call for attention after being ill-treated, resulting in them waiting for the next shift to take over or taking unnecessary risks when performing activities. Overall, patients and relatives described various circumstances that prevented patients from accessing nursing care. Environmental disadvantages, organizational concerns, technical failures and negative attitudes among healthcare professionals were described as factors preventing access to attention for the described needs.

5.3.3 | Medical needs

The medical attention sub-category involved all patients who were about to be or were assessed by healthcare professionals, most often

a physician. Commonly, these descriptions concerned experiences where the patient's health condition was not acknowledged as significant. This involved different situations, such as being critically ill and not receiving medical attention for a long time, being referred to a waiting area without proper monitoring capacity, being ill-treated during assessment, not being assessed when finally seeing the physician or being brushed aside when pleading for medical attention.

> When I turned to go back, I heard one nurse say to another "I have already told them that they will have to wait." I heard she thought I was very annoying. I got angry and went back and said, "Now it is like this that my mother has gotten worse since I was here talking to you." She asked me if the weakened arm was at the same side as the leg which didn't carry my mother on the way to the bathroom. I said yes. Only then did something start to happen. At that time, we had been in the emergency room for 3.5h. (Daughter of a patient suffering from a stroke at the emergency department) (77)

Patients and relatives expressed that they did not feel that they were taken seriously or listened to when trying to explain how much they were suffering. Discrepancies were evident between patients' and healthcare professionals' assessments of patients' needs for further examinations or medication. Patients described how they were discharged without pain killers or without other solutions to relieve for their suffering. Consequently, patients and their relatives were worried, scared and frustrated when left to deal with symptoms on their own.

6 | DISCUSSION

As patient participation is central to improving patient safety (WHO, 2021), we approached circumstances concerning access for patients and relatives to take part in patient health and safety from a broad healthcare system perspective. Therefore, all possible encounters at the hospital and in all possible situations were considered. The findings showed that multiple encounters with different actors with diverse roles and purposes in the hospital restricted relations built on trust and thus the access in terms of its appropriateness, that is, in how patients' needs were approached. We believe that this phenomenon contributed to patients and relatives struggling to gain access to take part in patient health and safety throughout the healthcare system. The dehumanization theme in the analysis of the complaints was reflected by the failure to deliver care, such as keeping the patient warm, rested, clean, helping the patient to the toilet, being well nourished, feeling safe, comfortable, respected and being a part in care planning. This failure in delivering fundamental care has been criticized to constitute significant risks for the patients' recovery, safety, well-being and positive experience (Feo & Kitson, 2016). As most large-scale systems are dependent on a variety of specialties and expertise, responsibilities

need to be allocated across a variety of healthcare specialties to become more comprehensible. The anonymity of individuals acting in such a system therefore increases and makes it difficult to navigate the system, as 'one hand risks not knowing what the other does' (Wright, 1987). In other words, our findings can be understood from the view that the holistic perspective of fellow human beings and consequently opportunities for participation were potentially challenged by the complexity of modern healthcare systems. As indicated by our findings, this complexity may risk shifting the focus from patients' situations and needs to aspects such as whether the patient's situation and needs were of significance for a specific healthcare facility or a healthcare professional to deal with. Therefore, efforts to ensure patients have an active role such as sharing common goals and accountability, sharing knowledge and contributing resources, as described by Sahlsten et al. (2007), may be undermined by the healthcare system itself despite healthcare professionals' good intentions. A 'task-and-time' oriented care like this, was by Kitson (2018) suggested marginalizing the holistic oriented care as discussed in the light of Fundamentals of Care (FOC) framework. Except for building trustful relations with patients and relatives and assess fundamental physical, psychological and emotional care needs, the nurse must be contextually aware of prevailing healthcare system and culture at the hospital or at the ward (Kitson, 2018).

The main theme, *struggling for access as a human being in the health-care system*, showed that this struggle negatively affected patients' health and everyday life while they were expending effort to legitimize their needs as important and urgent. Ignored or neglected attempts to engage provoked negative emotions, deteriorated patients' health and compounded the risk for patients' future safety, which was consistent with previous research (Hor et al., 2013). Except for the risks of anonymization in such a large-scale system, the struggle to be acknowledged as a human being may also be explained by the great atomistic approach on which the healthcare system is organized. This approach risks objectifying patients and counteracts a holistic approach, which is crucial for interpersonal encounters (Buber & Sällström, 2011). Furthermore, it has been argued that without any interactional connection, patients will continue to be construed as passive objects (Eggins & Slade, 2016). Eggins and Slade (2016) found that healthcare professionals' way of talking with or about patients determined whether a patient's agency was acknowledged. This resulted in either including patients as rationale and active co-contributors or excluding them as passive and sometimes problematic objects. Those authors further stressed that the exclusion of interactions with patients reinforced the traditional power of healthcare professionals, thereby counteracting patient participation and maintaining the patient's role as a passive observer.

Although our findings were based on complaints and therefore mainly shed light on negative events, most patients in the Swedish healthcare system are satisfied with their healthcare and do not suffer from adverse events. Moreover, a reciprocal relationship based on respect, trust, and equality, as suggested in the literature (Cahill, 1996; Eldh et al., 2010; Thompson, 2007), has been found to be desirable among healthcare professionals. O'Dowd et al. (2018) showed that interpersonal relationships and being able to help patients feel better gave healthcare professionals pleasure and boosted their work satisfaction. Overall, a focus on patients' emotional, psychosocial, and physical health conditions and needs and healthcare resources (physical and human) provides quality in healthcare. Therefore, it is crucial to give patients and relatives access to social interactions with healthcare professionals to promote patient participation. Greater emphasis on the meaning of relationships in the context of large-scale healthcare systems is needed to highlight opportunities for patient participation as an ongoing achievement of all parties involved.

6.1 | Limitations

In previous research, it has been found that complaints are multifaceted and involve interrelated matters, which presents a challenge when developing and using taxonomies to advance learning systems within healthcare (Harrison et al., 2016). In this study, the included complaints were classified by hospital administrative managers as matters mainly concerning access. We acknowledge that this classification process risked contributing to a loss of complaints relevant to this study, as well as the inclusion of complaints concerning other matters rather than solely access. As classified complaints often involve several inter-related issues (Harrison et al., 2016), multiple meaning was involved in the text, which is essential to consider in regard to trustworthiness, because interpretation was inevitable. In addition, two thirds of the patients' and relatives' complaints in this study had been summarized by healthcare professionals. Therefore, these written complaints were also influenced by the healthcare professionals' interpretations of the patients' and their relatives' narratives. Moreover, the patients and relatives who made complaints were not given the opportunity to reflect upon and discuss the phenomenon identified by the researchers. This means the words used in the reports may not correspond to the researchers' interpretation of their meaning (Bengtsson, 2016). The inclusion of follow-ups or expanded interviews with actors involved in specific situations could therefore be a reasonable approach in further studies. It is essential to note that the sample used for this study exclusively contained complaints about healthcare. Exploring how healthcare professionals, patients and relatives created opportunities for access to healthcare sources through an interview-based study may contribute additional important knowledge. This study was performed at one university hospital in Sweden with focus on somatic adult healthcare. The findings must therefore be interpreted in this context to assess transferability to other contexts.

7 | CONCLUSION

We found patients and relatives to be dependent on multiple actors to navigate through the healthcare organization, to make sense of

themselves and the situation and to fulfil diverse needs. This lack of access, that is, restrictions in terms of the appropriateness in how patients' needs were approached, risked patient safety and deterioration of patients' health conditions and negatively affected their daily living and social lives. Preconditions for healthcare professionals to create meaningful relationships with patients and relatives in hospital settings need to be addressed from a broader healthcare system perspective. The findings suggest that the 'task-and-time' mentality of the healthcare system outbalances the holistic care and consequently harm the patients. Kitson (2018) proposed that the framework of Fundamentals of Care helps predict risks for adverse events in healthcare systems that are lacking in the ability to build trustful relations or meet patients' needs in an appropriate and personalized way. Thus, further research might focus on the nurses' coordinating role in converting and integrating the patients' narratives into formats that align with multiple interests within the healthcare system and how holistic care is maintained throughout this process. Furthermore, patients' and relatives' dependency on multiple actors might be prevented by increasing the comprehensibility and transparency of hospital-associated settings. Complaints from patients and their relatives are a valuable and useful source for gaining the knowledge needed in the process of generating a healthcare system that is signified by high patient safety. Because this study only involved complaints, it would be valuable to further explore how healthcare professionals find ways in the complex healthcare system to create opportunities that enable interactions with patients/relatives to promote relationships based on trust and mutuality.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and 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 the article or revising it critically for important intellectual content. Thomas Brezicka and Anna Gyberg contributed to the data collection. Anna Gyberg contributed to the majority of the data analysis and drafting of the manuscript. All authors contributed with interpretations and critical revision of important content. The final version was approved to be published by all authors who also agreed to be accountable for all aspects of the work. As study supervisor, Kerstin Ulin was responsible for critical revision and supervision.

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CONFLICT OF INTEREST STATEMENT

No conflict of interest has been declared by the authors.

PEER REVIEW

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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