

Patients' expectations and experiences of being involved in their own care in the emergency department: A qualitative interview study

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Abstract

Aims and objectives: To investigate patients' experiences of being involved in their care in the emergency department (ED).

Background: Previous research shows that when patients experience involvement during care visits, this increased their trust in the care, gave a sense of control and promoted their autonomy.

Design: A qualitative descriptive design with semi-structured interviews, using the "Consolidated criteria for reporting qualitative research" (COREQ) checklist.

Methods: Using convenience sampling, semi-structured interviews were conducted with 16 patients in the ED.

Results: The study identified four categories: attention and inattention; communication and understanding; varying levels of participation; and inefficient and inaccessible care. The results show that patients expected to be treated with respect and to be involved in an open dialogue about their care. Patients' experiences of participation were related to their sense of control.

Conclusions: Based on the results of the study, the authors found that factors such as dialogue, information, attention and participation affected the patients' involvement during the ED visit. Experiences of involvement and control were linked to patients' experiences of care and of patients as individuals.

Relevance to clinical practice: Healthcare providers' awareness of the importance of paying attention to the patient as an individual, and of the need for simple, continuous communication could facilitate patient involvement in own care.

KEYWORDS

communication, emergency department, involvement, participation, patient, patient experience

What does this paper contribute to the wider global clinical community?

It highlights that patients' involvement in their own care varies depending on their health status as a patient, and the opportunity offered by healthcare providers.

It demonstrates that attention, simple and continual communication, and understanding are necessary for the patients to experience involvement in their care. It provides guidance on how future care for patients in the ED should be provided to promote patient involvement in own emergency care.

1 | INTRODUCTION

Participation and involvement are key concepts in health care and were regulated in the Health Care Act (1982) and the Patient Act (2014) to promote patient independence, participation and self-determination, and to oblige the healthcare providers to facilitate patient participation in own care. Despite that, 78% of emergency department (ED) patients experience participation in their own care (Sweden's County Council & Regions in collaboration, 2017). A Swedish report found that patients in Sweden score low on accessibility, information and patient participation (Lennartsson & Westling, 2016). One reason for this lack of participation among patients could be because they feel it is a struggle to get involved (Frank et al., 2009).

1.1 | Background

Acute onset disease occurs suddenly, is uncontrollable and unpredictable and can lead to feelings of helplessness, fear and insecurity. Together with an acute health problem, the environment in the ED is stressful and anxiety-provoking (Bongale & Young, 2013). Swedish EDs are characterised by quick, short and routine meetings with patients (Andersson et al., 2012), and this time-pressured and demanding environment can make it challenging to provide patients with information about their care (Blackburn et al., 2019). A report shows that the number of visits to Swedish EDs has increased steadily at about 3% per year, and in 2017, there were 2.5 million visits (The National Board of Health & Welfare, 2017).

To meet the ever-increasing challenge of visits to the ED, the patients are triaged to identify and prioritise those with most urgent conditions first (Stanfield, 2015). From a patient perspective, this can be experienced as mechanical and impersonal (Andersson et al., 2012). In order to become more efficient, caregivers are increasingly distanced from patients; this has resulted in patients being excluded from important discussions about their state of health and being left alone with the range of treatment options that are available to them (Barry & Edgman-Levitan, 2012). Short meetings and quick assessments are perceived as obstacles to creating the deeper relationship necessary between healthcare providers and the patient to provide safe care and opportunities for participation (Andersson et al., 2012).

Studies show that patient participation is affected by the healthcare professionals' skills, knowledge and attitudes to patient participation and the care environment (Hwang et al., 2019; Vaismoradi et al., 2015). Current reviews and analyses have identified a few factors that can affect patient participation: the patient's situation; patient's knowledge about care and own state of health; and healthcare provider and patient willingness to include the patient in active participation (Angel et al., 2015; Tobiano et al., 2015). A study by Ringdal et al., (2017) shows that patients do not want a passive role in own care but want to take an active role and to be informed about their condition. By including the patient in own care, the care becomes patient-centred. This concept positions the patient as a partner of the healthcare team and he/she is viewed as an expert on themselves as a person. Patient-centred care means that healthcare providers take the patient's perspective and integrate the patient into the care process with a focus on the patients' experiences and preferences (Spatz & Spertus, 2012). Contributory factors to patient-centred care include healthcare provider flexibility, open and respectful contact with patients, and facilitation of partnerships. Even more important are treating the patient as an individual, providing adequate information and managing their health problems, as these factors promote patient self-care (Lateef, 2011). By supporting each patient, showing an interest in the patient's situation, engaging in dialogue and seeing the patient as an individual, healthcare providers can increase patient involvement (Tobiano et al., 2015).

The empowerment of patients through patient-centred care and shared decision-making are international key goals of healthcare systems (Miao et al., 2019). The concept of participation comes from the Latin *participare* – “to participate” (Cahill, 1998) and is often described as “participating” and “cooperating” (Cahill, 1996). According to Castro et al., (2016), the term patient participation can be defined as “a patient's rights and opportunities to influence and engage in the decision-making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional's expert knowledge.” According to Sahlsten et al., (2008), the degree of participation depends on several factors, such as the patient's attitude, willingness, previous hospital experience, level of medical knowledge, physical ability and ability to make rational decisions. However, encouragement from the healthcare providers, information, clear communication and spending time with the patient may also affect the patient's willingness to participate. Blackburn et al., (2019) list communication and information as essential for improving patient satisfaction with

care and empowering patients in own care. Being treated by several different healthcare providers working in the multidisciplinary environment of the ED can be confusing for patients. The healthcare providers should therefore ensure that patients understand the reason for the treatment, what is expected of them, and give them the opportunity to ask questions if something is not clear. Communication, education and information need to be shared with the patient to increase understanding of their situation and level of self-reliance. These aspects are also perceived to increase patient safety, because patients participate in their own care (Lateef, 2011). Talking about patients over their heads and using medical jargon has been shown to decrease patient understanding and hinder patient participation (Oxelmark et al., 2018).

Though the growing use of the concept of patient-centred care, it not always corresponds to the description in the literature. The healthcare organisations have a complex task to transform care to be more patient-centred (Fix et al., 2018). Institute of Medicine (IoM, 2001) presented Crossing the Quality Chasm: A New Health System for the 21st Century, one of the most influential frameworks for quality assessment, that has been implemented by Agency for Healthcare Research and Quality (AHRQ, 2021) as the Six Domains of Health Care Quality. According to AHRQ, the healthcare system should be safe, effective, patient-centred, timely, efficient and equitable. To offer the patients the health care that they need and understand, knowledge and understanding of patients' expectations are required to be involved in the highest quality of care. This knowledge gap can be filled by investigating patients' expectations and experiences of being involved in their own care, and by understanding the factors that are important for making patients more active and which promote participation in own care.

2 | AIM

The study aim was to investigate patients' expectations and experiences of being involved in their own care in the ED.

3 | METHODS

3.1 | Design

The study was conducted at the ED of a county hospital in southern Sweden in 2018. To realise the purpose of the study, a qualitative descriptive design with semi-structured interviews was chosen (Schreier, 2012). "Consolidated criteria for reporting qualitative research" (COREQ) (Tong et al., 2007) have been adhered to in the reporting of this study, see Supplementary File 1.

3.2 | Participants and data collection

The study was conducted in spring 2018 with patients at the ED in a county hospital in southern Sweden; convenience sampling was used. The inclusion criteria were participants should be 18 years

or older and speak the Swedish language. There were no exclusion criteria. Patients who met the inclusion criteria received letters with information on the study on arrival at the ED. The letter contained information on the study and voluntary participation. The patients who received this letter were called by telephone a maximum of 2 times the following week to give them more detailed information. If the patient chose to participate, a time and place for the interview was agreed on. Of the total 30 patients who were selected for participation and received an information letter, 16 patients chose to participate; 2 were not interested and 12 did not respond to the telephone call. The age range of the participants was 23–66 years, and the sample included ten men and six women.

Two patients who wanted face-to-face interviews chose to be interviewed at home. The remaining 14 interviews were conducted by telephone. Previous studies show that this method is as reliable as interviewing face-to-face (Novick, 2008). The interview questions focused on the purpose of the study, for example "What does it mean for you to be involved in your own care at the ED?" and "How do you experience being involved in your own care during the visit to the ED?". After a pilot interview, two questions were re-worded before the interviews continued. The author chose to include the pilot interview in the study, as it maintained good quality and responded to the purpose of the study. The interviews lasted between 7–28 minutes. The interviews were recorded and transcribed verbatim. No new data emerged after 14 interviews; therefore, data collection was completed after 16 interviews.

3.3 | Data analysis

The study's first author is a specialist nurse in emergency care and has 7 years' experience with care in the ED setting. Work experience and daily contact with patients give the author an understanding of the environment and problems that are present in the ED. The author did not have a care relationship with any of the study participants. The interviews, transcription and data analysis were carried out by the first author in consultation with the co-authors. To ensure that the first author's prior understanding did not affect the result, manifest content analysis was chosen as the analysis method for interpreting the visible and obvious aspects of the text (Graneheim & Lundman, 2004). The transcribed interviews were repeatedly read through to familiarise researchers with the content and to get an overview of the full picture. The text was re-read with the purpose of highlighting meaning units. If necessary, these meaning units were abbreviated to condensed sentences without altering the content. The condensed sentences were then encoded to describe events. The codes were read repeatedly to determine the corresponding content. Codes with corresponding content were compiled in subcategories. These were adjusted as needed. When 9 subcategories were created, these were compiled with the matching content, resulting in 4 categories. Individual quotes from the text were added under each subcategory to substantiate the meaning (Graneheim & Lundman, 2004).

3.4 | Trustworthiness

To assess quality in qualitative research, the concepts of reliability, credibility and transferability according to Graneheim and Lundman (2004) were used. To achieve reliability in qualitative research, it was important to have a thorough description of the phenomenon and the research process. The research process was described in as much detail as possible to enable reproduction of the study theoretically and to achieve equivalent results. A selection of quotes was used in the results to further confirm the study's reliability. Credibility in the study was achieved by including participants with varying age and gender, who made observations from various perspectives. This made it possible to share the participants' wide experiences and obtain a richer variation in responses. The most suitable meaning units were selected to determine the meaning of the text and to achieve credibility. The study was also conducted in accordance with the research regulations at the University of Borås and in consultations during supervision, which increases reliability. Transferability could be achieved through the use and application of the study results in other healthcare environments or populations. Convenience sampling was chosen as the basis for the selection, with 10 information letters a day distributed over 3 consecutive days, to obtain as wide a spread as possible, but without active selection of candidates for the study. The results of the study can provide an insight into patients' experiences and expectations of involvement in other healthcare environments that are also characterised by low patient involvement (Graneheim & Lundman, 2004).

4 | ETHICAL CONSIDERATION

The Act concerning the Ethical Review of Research Involving Humans (SFS 2003:460) states that studies conducted as part of university education at advanced level, in this case at Master's level, require no application or permission from the Ethics Assessment Board. The manager of the ED was informed and approved the study. The study was carried out in consultation with and after approval by the supervisor from the University of Borås. In agreement with the Swedish Research Council (2002), the four basic ethical principles of humanistic research—the information requirement, the consent requirement, the confidentiality requirement and the utility requirement—were used to protect the participants in the study. The participants in the study received detailed written and verbal information about the purpose of the study, as well as information about confidentiality and the opportunity to stop their participation at any time. All participants gave written consent to participate in the study.

5 | RESULTS

Four categories with 9 subcategories were identified in the study, see Table 1.

TABLE 1 Overview of the study categories.

Category	Subcategory
Attention and inattention	To be respected
	To get attention
	To be forgotten
Communication and understanding	To have an open dialogue
	To be simply informed
Varying levels of participation	To influence their one care
	To have a sense of control or lack of control
	To ask for more resources
Inefficient and inaccessible care	To stand up for oneself

5.1 | Attention and inattention

Patients stated that meetings with healthcare providers could be “mechanical” and impersonal, especially in the high-stress environment of the ED. Nevertheless, healthcare providers were experienced at handling stress and most patients were satisfied with the attention they had received in direct contact with them. However, patients' experience of attention was adversely affected when healthcare providers appeared to be irritated with patients or colleagues, were loud or showed nonchalance.

5.2 | To be respected

Patients wanted to be treated with respect, kindness and understanding and as individuals. The majority stated that this expectation of respect had been realised, and the healthcare providers had been nice and showed interest in the patient's situation. Thus, the patients were satisfied with the response they received; however, they sometimes experienced difficulties in getting the attention of healthcare providers or other staff at the ED.

'I want to be respected like all other people, treated with respect... I hope that the staff are nice, maybe not happy but understanding...'

(Participant 16)

5.3 | To get attention

Patients felt that they received attention when they had the opportunity to tell healthcare professionals about their condition and symptoms, and when they received follow-up questions related to what they had previously communicated. The follow-up questions were seen as proof that what was said was also heard and accepted by healthcare providers. However, it was pointed out that just direct contact itself with healthcare providers meant the patients experienced being heard and seen. Receiving attention from healthcare

providers was important for the patients, and the majority were satisfied with the attention they received. When healthcare providers assigned time for the patient, despite stress and high workload, patients experienced this positively. Other factors that were valued highly were receiving explanations about symptoms, and the ability to ask questions and not be hurried.

'I've had a previous injury in my hand that I asked them to check on, and when I returned after a couple of hours in X-ray, I'd forgotten that I'd asked for it, but the doctor still remembered and answered it anyway, even though I had forgotten, so I was heard, received feedback and was remembered, better than myself in that case' (Participant 9).

Patients stated that they felt noticed when their concerns were taken seriously. Patients had positive experiences of healthcare providers when they read the patient's history of illness, tried to understand the patient's situation, and sat down with the patient and calmly explained the course of treatment and what might be expected. Patients also appreciated it when their needs were attended to by healthcare providers, which they experienced as being perceived as individuals and not as a group.

'It wasn't at all that you are treated like a package or on a conveyor belt, really not. I definitely think I've been looked at and seen, I really felt it'

(Participant 12)

5.4 | To be forgotten

The feelings of being neglected, overridden and not trusted were also raised. Patients expected that healthcare providers should listen to their experiences. They reported not getting attention, despite several attempts to explain their needs, feeling exposed lying in their beds in the corridor and calling for help without being noticed. Huge workloads and long waiting times were factors that led to the experience that healthcare providers were very busy and difficult to contact. Because they were afraid of being in the way or of directly disturbing the healthcare providers in their work, the patients felt forced to accept it. Patients expressed that they sometimes felt abandoned when they were left for several hours in the waiting room or in an examination room without supervision and anxious about their own health.

'I was in an emergency room /.../ for six hours without anybody coming in to ask how I was doing, but they had an ECG on me so they were sure that they might not need to, but I would have thought that someone once in six hours might have come in to see me and ask how things were'

(Participant 10).

It was difficult for patients to describe how they felt involved in their care. Insufficient medical knowledge and lack of knowledge about what the patient was able to affect resulted in the feeling of not being involved in their own care. Even the patient's legal right to involvement in health care was not well known by all patients. Patients experienced that they were unable to influence their own care, and it was the healthcare providers who decided the care. An attempt to influence the healthcare providers' decision could be difficult, sometimes almost impossible, which led to the feeling of powerlessness. Patients wanted the opportunity to make a decision.

5.5 | Communication and understanding

It was made clear that communication between healthcare providers and patients could be improved. The expectation was that healthcare providers should be more obvious about what they do. By using medical language or Latin, the patient was prevented from understanding. Mutual communication with the healthcare providers and more simple information about health care were expected. Straightforward and simple information about what was expected to happen at the different moments in care was considered to increase the patients' own experiences of involvement.

5.6 | To have an open dialogue

Patients expressed that they felt that the dialogue with healthcare professionals was usually unidirectional. Thus, patients wanted to have an open dialogue about their care. Patients' experienced that a dialogue increases openness with the opportunity to ask questions or receive feedback on the proposed examination or treatment. During consultation with the physician, patients' experiences of open dialogue mostly increased, because physicians allowed more opportunities for dialogue than other healthcare providers and the meetings could provide more detailed information. The majority clearly stated that, although their expectation for dialogue was not realised, they had respect for the healthcare providers' competence.

'He took his time, asked me and gave me the opportunity to ask, and had some comments and a calming message from a medical perspective'

(Participant 8)

5.7 | To be simply informed

The patients expected simple information about what was to be done, and why they had to wait. A lack of waiting information was experienced by several patients. The patients accepted the waiting time but would have liked information about the expected waiting time. None of the patients required exact time indications

and understood that it was impossible for healthcare providers to provide this, but expected the healthcare providers to inform them whether the expected waiting time was minutes or hours. By expressing a preference to get a time perspective, patients wanted to manage their waiting time, such as going to the cafeteria or toilet without fear of missing the healthcare providers. Little information was considered better than no information at all, so even though the expected waiting time could be longer, patients wanted some information.

'You do not have control over whether you can get away... you do not know how long you can sit in a room, you do not know how long to wait, so you never know how long things will take. Whether I'm going to sit in that room for 5 minutes, half an hour, or hours'

(Participant 5).

Patients had the impression that treatment was already decided by the physician when they came to the patient, and no choices were given. Some patients said they understand that they have options regarding examinations and treatments offered during the visit, but they also felt an unwillingness or fear of influencing the medical assessment because they thought they might risk not receiving the care they needed. For example, if the patient could choose freely, then she/he could deselect important blood samples or substitute them with other insignificant parameters. The information that the patients received during their visit was usually good, but the waiting time to get the information was usually felt to be too long. Patients thought it would be valuable to get general information about what was happening in the ED in the moment, especially during long waiting times, or when there were several accidents and an extremely high number of patients. That information could create space for more understanding of the waiting time and make patients and relatives better accept the situation. Another expectation was to receive more frequent and continual information.

'It costs nothing to say "there is an extremely high number of people here and we have only one doctor"... even if patients did not ask, they could just say "there's an extremely high number of people, it will take a while just so you know, but of course we will do our best". Fine! Then you know it will take a while, you don't sit there thinking, where the hell are they... they can't have so much to do...'

(Participant 5).

5.8 | Varying levels of participation

The importance of the patient's ability to affect their own care at the ED was highlighted. The feelings of vulnerability, anxiety and fear

could be experienced intensely on arrival at the hospital; even so, a sense of participation could strengthen the patient's role. However, participation was experienced as varying depending on their state of health. In addition, the level of control varied among patients depending on their general condition and how much it affected the patient at the visit to the ED.

5.9 | To influence one's own care

Patients experienced an opportunity to influence their own care when they were able to describe the cause or symptoms of their condition to healthcare providers. The ability to decide on treatments was important for the patients. Some expected to be given a choice of treatments and examinations, while others did not experience the need to be involved in the decisions. The most important issue for patients was to know what was actually being done and what was the best option. Patients experienced that the healthcare providers sometimes refrained from expressing their thoughts, and the expectation was that they should share the assessments and thoughts they had about the patient and the situation. Although the patients did not always understand all the investigations they had, they felt more involved in their care if they were given the opportunity to ask questions.

'Last time I was there, the blood tests were taken. I have no idea what kind of sample it was. I would feel involved if I actually got to know what the samples they took were for, and then I would have the opportunity to ask questions'

(Participant 15).

Some patients expressed that they felt it was almost wrong to give the patient choices in critical healthcare issues, because the more choices the patient makes decreases the number of choices available to healthcare providers. Receiving adequate care to address the symptoms was perceived to be more important than the ability to control their own care; however, patients wanted the opportunity to discuss less crucial issues. In situations where the patient and the physician did not agree on treatment, the patients hoped that the physician could motivate and argue for their choice. The patients' expectation was that it could lead to an understanding of the position of physicians, who, in the patient's opinion, were the decision-makers and regulated the care strategy, and the patient would only consent to it or refrain.

'If you want a specific type of treatment or examination as a patient, and the doctor suggests another, if we say so it's tricky to discuss what is important, hopefully the doctor can explain why he wants to do the treatment he wants to do, which may have to do with resources' (Participant 14)

5.10 | To have a sense of control or lack of control

The patient's sense of control increased when the patient was not seriously ill, and decreased the more affected the patient was by their illness. Some patients expressed that it could be dangerous or disastrous if the patient had control during the visit, because they have insufficient medical knowledge or lack of insight into available resources. However, communication between the healthcare providers and the patients was important as was sharing experiences and attitudes. The clearer and surer the staff were in their assessments or actions, the calmer the patients were, and they could still experience a sense of control in what was happening during the visit.

'... the doctor I met for the first time, a pretty young woman, said exactly what the doctor said when I was there the week after, but she felt insecure in some way. At the next visit, I had to meet a doctor who explained a little better, he had a little more confidence. I got it explained better and then I felt safe and could go home and feel safe in it'

(Participant 10).

Lack of control could also be demonstrated by the experience of not being heard or a lack of involvement in decisions regarding what was happening to them or around them at the ED. The lack of knowledge on medical issues could also give rise to a sense of lack of control, related to the difficulty of mentioning, or the ability to decide, on certain treatment. If the healthcare providers took time to get to know the patient, and to see and support their needs, this increased patient control in the situation. The experience of lack of control over waiting time was indicated by several patients.

'By getting a time perspective, it could be a way to feel that you have control, because when you lie in a room, you think, "dare I go out and pee or will the doctor come then". Then you feel that you do not control it either, because you are afraid that the doctor may come in and you are not there'

(Participant 15).

5.11 | Inefficient and inaccessible care

Health care in general was experienced as inaccessible. Primary care was considered to be difficult to access, but there was an awareness that at the ED there was always someone to talk to, despite the fact that the environment at the emergency room could be experienced as unwelcoming. At arrival at the ED, the patient's own picture of disease was the central point and the most important for the patient. The patients' experience was that they had to stand up for themselves and be seen and heard, so as not to be forgotten by the healthcare providers.

5.12 | To ask for more resources

The environment at the ED was experienced as being difficult and stressful, and more resources were needed. Patients' felt that more resources would support the healthcare providers' working environment and reduce waiting times for patients. The opinion was that the healthcare providers did a good job, despite lack of staff, which were in more demand at times of high patient inflow or accidents. There was also the concern that the heavy workload affected the healthcare providers' ability to prioritise efforts. Stress and negative attitudes among healthcare providers, as well as lack of structure and experienced chaos, as noted by patients, were experienced negatively. Patients' experience was that the healthcare providers would lose control of the situation on the ED if the workload was heavy. Many working procedures were experienced by patients as unclear, and they wanted them to be clarified and distributed to patients.

'I saw that others who came down with the X-ray patch went straight to some nurse who was passing by, which they really shouldn't have done. I understood that I should have queued again... but it was possible to get past the queue in that way and shorten my waiting time, so I did it, because there was a really long queue again'

(Participant 13).

The expectation was that the visit to the ED would go faster, and that patients who did not need investigative procedures, but only needed to fix a given condition, should not have to wait for several hours. At the same time, there was an understanding that finishing quickly was not always possible, depending on the time needed to wait for results or examinations. Sometimes the waiting time was experienced as being unreasonably long in relation to what was eventually done. The wait was experienced as less stressful when the environment around the waiting area was calmer. Problems like a lack of beds or chairs in the waiting area and patients sitting on the floor were noted. The fact that the coffee machine and vending machine were often broken and the chairs in the waiting room were hard and uncomfortable to sit on for several hours was also mentioned several times.

'Waiting times were 5 hours to sew three stitches, so I don't think it was so good, it could have been improved'

(Participant 6)

Patients made suggestions such as bringing in volunteers or extra staff who could be available at the ED to talk, calm and help the worried, alone, or helpless patients during their stay at the ED, while at the same time relieving the healthcare providers.

5.13 | To stand up for oneself

The patients experienced the feeling of being displaced and helpless. The fear was that if patients withheld their own feelings or were seen to be shy, they would be neglected. Patients expressed the need to stand up for themselves and to adopt a tough attitude in the harsh environment of the ED. To stand up for oneself was a way of being seen as an individual and not being forgotten in the crowd.

'You must be very determined, because if you are a little too quiet, you will not be visible in the harsh environment of the ED'

(Participant 10)

6 | DISCUSSION

Generally, most patients stated that they felt that they received attention in direct contact with healthcare providers. Opportunities to find time for the patient were highly valued, especially when there was a high workload in the ED, and when the healthcare providers seemed to be busy. By supporting and seeing a patient as an individual, a relationship could be developed between the patient and the healthcare providers, which was also reported by Tobiano et al., (2015). The reason could be that the patient experienced more attention from the healthcare providers. This feeling of attention in an emergency situation, or when the patient felt vulnerable, seemed to be a prerequisite for experiencing feelings of security. By being observant of the patient's needs and life situation, the patient was given the opportunity for involvement in their own care. Confirmation of the patient and their concern was also an important aspect of the experience of attention.

Negative factors such as the feeling of not being heard or trusted, and feeling ignored and abandoned by healthcare providers, affected patients' experiences of opportunities for involvement, which is also confirmed in a study by Forsgårde et al., (2016). Patients felt that healthcare providers should pay attention to the patient and his/her needs, from the time of arrival at the ED and throughout the whole visit. Patients want to be treated as individuals, which does not require additional time or special resources from the healthcare providers. It was enough to create interaction and integration with the patient to gain involvement, and to show a willingness to understand and respect the patient's feelings.

Communication and understanding were seen as complex and mutual processes. Patients experienced that thoughts and feelings were expressed between the patient and the healthcare providers, but that this process needed to be improved. Patients wanted not only information but a dialogue. Dialogue with the healthcare providers was stated to be an important factor for the experience of involvement in health care. Open dialogue could be seen as a tool for the patients facilitating an opportunity to influence their care. Ringdal et al., (2017) recognised as well that patients were not satisfied with a passive role in own care but wanted to be a part of

discussions and decision-making. Clear dialogue and information, where the patient had the opportunity to ask questions and participate in their care, could reduce anxiety, and decrease new visits to the ED. Patients' experiences of involvement in their own care decreases when they do not have enough information, and ongoing information, to handle their situation, which creates feelings of frustration and powerlessness. The importance of appropriate and timely information was also shown by Kynoch et al., (2019), because it can empower patients with knowledge and decrease the anxiety and stress associated with a hospital admission. Ongoing information and dialogue created the feeling of being involved, because control could be taken over the situation. Awareness of the importance of communication with the patient increases patient safety and patient involvement in their own care.

Swedish ED is a 24-hour environment where anyone in need of care can seek help, which may explain the ever-increasing workload (The National Board of Health & Welfare, 2017). Patients shared the view that healthcare providers were working hard to cope with the high workload in the ED, but there was a concern that the resources were insufficient, which could affect the patients. In cases of increased patient inflow, the workload for healthcare providers and waiting times for patients in the ED would also increase. Nevertheless, waiting times were usually considered to be unreasonably long in relation to the nature of the visit. It was not only the length of the wait that led to irritation and affected waiting, but also information on what was expected, the current environment, patient comfort and interaction with the staff, which is a phenomenon that is described in other studies (Spechbach et al., 2019; Xie & Or, 2017). It was believed that these factors contributed to the negative experience of waiting. Aspects of patient comfort, such as integrity, environment, cleanliness and access to food were important to patients and were also noted by Viotti et al. (2020). Lack of routines and supervision make patients feel abandoned. An impression shared by several patients was that they needed to stand up for themselves and make their presence known so as not to be forgotten. The tough attitude patients adopted could be seen as a response to the harsh environment of the ED, which was described as frustrating and worrying, but which could be avoided by presence and attention.

An ability to influence their own care during their visit to the ED was important for patients; however, their general state of health played a significant role in the degree of involvement experienced. Receiving the best possible health care, based on patients' needs, was seen to have the highest value. Patients were concerned that their ability to influence their care could lead to negative consequences for them, by attempting to influence a field unknown to them, a concern that is also demonstrated by Ting et al., (2016). This could be the reason why patients did not want choices or the ability to influence important decisions about their care. Another reason could be the fear of making the wrong decision. This could be counteracted by joint decision-making and providing the patient with information about their condition, which could influence decision-making for their care and treatment. Drach-Zahavy and Shilman

(2015) found in their study that patient participation depended on the approach of healthcare providers and patients.

There were divided opinions about the level to which healthcare providers tried to make the patient more involved. While some patients felt that healthcare providers were paying them attention, initiating good communication and providing the conditions for the patient to be part of the care, there were also those who felt that healthcare providers did not want to give them the opportunity to be involved in their own care and the patient was not invited to participate. Patients' lack of confidence that healthcare providers wish to include them in their care could be problematic. To promote good relationships between patients and healthcare providers, and to achieve confidence, clarity and presence are necessary. Attention to the patient and simple communication could be crucial for patients to experience involvement during their visit to the ED.

7 | CONCLUSION

Based on the results of the study, the authors found that factors such as dialogue, information, attention and participation affected patients' involvement during their ED visit. Experiences of involvement and control were linked to patients' experiences of care and as individuals. The results show that patients want to be treated as individuals. Patients wanted to be involved to the degree that they expected to participate. Regardless of how involved patients chose to be in their own care, they wanted continual information about what was happening. By giving the patient tools to be involved, the patient's independence was promoted.

This study is one of several that shows the need for improvement to increase the patient's participation in care, in this case in emergency care. Despite previous suggestions for improvement, further measures are needed to provide patients with the safe, effective, patient-centred and suitable health care to which they are entitled. Individual needs and preferences should be considered to make health care more patient-centred and to give the patients the possibility to be more involved in their care at the ED. Continued studies on staff experiences of promoting patients' participation may be of value to acquire a complete picture of patients' involvement in the ED, as well as to achieve a better understanding of the phenomenon and implement improvements.

8 | LIMITATIONS

The results of this study were based on 16 qualitative interviews. Convenience sampling was chosen to reduce the risk of bias that could have occurred if the author had selected participants strategically. However, the participants in the study were all relatively young and more strategic sampling could result in a wider age range of participants. Interviews conducted by phone may not be as in-depth

as face-to-face interviews, but because the study was part of a Master's thesis at advanced level, the scope of the study was limited due to time and resources. If the study is repeated, the participants would also be asked about the reason for seeking care as the authors are aware that the reason for seeking care could impact the experience of participation in own care. Exclusion criteria would also be included because it might influence sampling.

8.1 | Relevance to clinical practice

This study shows that patients visiting the ED experienced a varied level of involvement in their own care and that this depended on the patient's state of health and opportunities provided by healthcare providers. In addition, this study shows that attention was given to patients, and that simple and continual communication with the patient to promote understanding is necessary for patients to experience involvement in their own care. The authors hope that this study can provide guidance to emergency departments on how care should be delivered to promote patients' involvement in their own care.

CONFLICT OF INTEREST

The authors report no conflict of interest.

AUTHOR CONTRIBUTIONS

The first author performed data collection and acted as the primary coder of data. Each author has made substantial contributions to the work and has approved the submitted version. All authors read and approved the final manuscript.

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REFERENCES

- Agency for Healthcare Research and Quality (AHRQ). Six domains of health care quality. Retrieved on 2021-02-01, from <http://www.ahrq.gov/talkingquality/measures/six-domains.html>
- Andersson, H., Jakobsson, E., Furåker, C., & Nilsson, K. (2012). The everyday work at a Swedish emergency department – The practitioners' perspective. *International Emergency Nursing*, 20(2), 58–68. <https://doi.org/10.1016/j.ienj.2011.06.007>
- Angel, S. & Frederiksen, K. N. (2015). Challenges in achieving patient participation: A review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies*, 52(9), 1525–1538. <https://doi-org.e.bibl.liu.se/10.1016/j.ijnurstu.2015.04.008>
- Barry, M. J. & Edgman-Levitan, S. (2012). Shared decision making—pinnacle of patient-centered care. *The New England Journal of Medicine*, 366(9), 780–781. <https://doi.org/10.1056/NEJMp1109283>
- Blackburn, J., Ousey, K., & Goodwin, E. (2019). Information and communication in the emergency department. *International Emergency Nursing*, 42, 30–35. <https://doi-org.e.bibl.liu.se/10.1016/j.ienj.2018.07.002>
- Bongale, S. & Young, I. (2013). Why people complain after attending emergency departments. *Emergency Nurse: The Journal of the RCN Accident and Emergency Nursing Association*, 21(6), 26–31. <https://doi-org.e.bibl.liu.se/10.7748/en2013.10.21.6.26.e1200>

- Cahill, J. (1996). Patient participation: A concept analysis. *Journal of Advanced Nursing*, 24(3), 561–571. <https://doi.org/10.1046/j.1365-2648.1996.22517.x>
- Cahill, J. (1998). Patient participation – A review of the literature. *Journal of Clinical Nursing*, 7(2), 119–128. <https://doi.org/10.1046/j.1365-2702.1998.00132.x>
- Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*, 99(12), 1923–1939. <https://doi-org.e.bibl.liu.se/10.1016/j.pec.2016.07.026>
- Drach-Zahavy, A., & Shilman, O. (2015). Patients' participation during a nursing handover: The role of handover characteristics and patients' personal traits. *Journal of Advanced Nursing*, 71(1), 136–147. <https://doi.org/10.1111/jan.12477>
- Ethical Review in Human Related Research. (SFS 2003:460). Retrieved from http://www.riksdagen.se/sv/dokument-lagar/lagar/Svenskforfattningssamling/Lag-2003460-om-etikprovning_sfs-2003-460/
- Fix, G. M., VanDeusen Lukas, C., Bolton, R. E., Hill, J. N., Mueller, N., LaVela, S. L., & Bokhour, B. G. (2018). Patient-centred care is a way of doing things: How healthcare employees conceptualize patient-centred care. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 21(1), 300–307. <https://doi-org.e.bibl.liu.se/10.1111/hex.12615>
- Forsgårde, E. S., Attebring, M. F., & Elmqvist, C. (2016). Powerlessness: Dissatisfied patients' and relatives' experience of their emergency department visit. *International Emergency Nursing*, 25, 32–36. <https://doi.org/10.1016/j.ienj.2015.07.004>
- Frank, C., Asp, M., & Dahlberg, K. (2009). Patient participation in emergency care – A phenomenographic study based on patients' lived experience. *International Emergency Nursing*, 17(1), 15–22. <https://doi.org/10.1016/j.ienj.2008.09.003>
- Graneheim, U. H. & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to archive trustworthiness. *Nurse Education Today*, 24(2), 105–112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Health Care Act. (SFS 1982:763). Retrieved from https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso-och-sjukvardslag-1982763_sfs-1982-763
- Hwang, J. I., Kim, S. W., & Chin, H. J. (2019). Patient participation in patient safety and its relationships with nurses' patient-centered care competency, teamwork, and safety climate. *Asian Nursing Research*, 13(2), 130–136. <https://doi-org.e.bibl.liu.se/10.1016/j.anr.2019.03.001>
- Institute of Medicine (IoM). (2001). *Crossing the quality chasm: A new health system for the 21st century*. National Academy Press.
- Kynoch, K., Ramis, M. A., Crowe, L., Cabilan, C. J., & McArdle, A. (2019). Information needs and information seeking behaviors of patients and families in acute healthcare settings: A scoping review. *JBIR Database of Systematic Reviews and Implementation Reports*, 17(6), 1130–1153. <https://doi-org.e.bibl.liu.se/10.1112/JBISR-IR-2017-003914>
- Lateef, F. (2011). Patient expectations and the paradigm shift of care in emergency medicine. *Journal of Emergency Trauma Shock*, 4(2), 163–167. <https://doi.org/10.4103/0974-2700.82199>
- Lennartsson, F., & Westling, K. (2016). Vården ur befolkningens perspektiv – en jämförelse mellan Sverige och tio andra länder [the Commonwealth Fund's 2016 International Health Policy Survey of Adults in 11 Countries].
- Miao, M., Georgiou, A., Dahm, M. R., Li, J., & Thomas, J. (2019). Shared decision-making in emergency departments: Context sensitivity through divergent discourses. *Studies in Health Technology and Informatics*, 265, 128–133. <https://doi-org.e.bibl.liu.se/10.3233/SHT190151>
- Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *RINAH*, 31(4), 391–398.
- Oxelmark, L., Ulin, K., Chaboyer, W., Bucknall, T., & Ringdal, M. (2018). Registered Nurses' experiences of patient participation in hospital care: Supporting and hindering factors patient participation in care. *Scandinavian Journal of Caring Sciences*, 32(2), 612–621. <https://doi-org.e.bibl.liu.se/10.1111/scs.12486>
- Patient Act. (SFS 2014:821). Retrieved from https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientlag-2014821_sfs-2014-821
- Ringdal, M., Chaboyer, W., Ulin, K., Bucknall, T., & Oxelmark, L. (2017). Patient preferences for participation in patient care and safety activities in hospitals. *BMC Nursing*, 16, 69. <https://doi-org.e.bibl.liu.se/10.1186/s12912-017-0266-7>
- Sahlsten, M. J. M., Larsson, I. E., & Sjöström, B. (2008). An analysis of the concept of patient participation. *Nursing Forum*, 43(1), <https://doi.org/10.1111/j.1744-6198.2008.00090.x>
- Schreier, M. (2012). *Qualitative content analysis in practice*. Sage.
- Spatz, E. S. & Spertus, J. A. (2012). Shared decision making: A path toward improved patient-centered outcomes. *Circulation. Cardiovascular Quality and Outcomes*, 5(6), e75–e77. <https://doi.org/10.1161/CIRCOUTCOMES.112.969717>
- Spechbach, H., Rochat, J., Gaspoz, J. M., Lovis, C., & Ehrler, F. (2019). Patients' time perception in the waiting room of an ambulatory emergency unit: A cross-sectional study. *BMC Emergency Medicine*, 19(1), 41. <https://doi-org.e.bibl.liu.se/10.1186/s12873-019-0254-1>
- Stanfield, L. M. (2015). Clinical decision making in triage: An integrative review. *Journal of Emergency Nursing*, 41(5), 396–403. <https://doi-org.e.bibl.liu.se/10.1016/j.jen.2015.02.003>
- Sweden's County Council and Regions in Collaboration. (2017). National patient survey. Retrieved from <https://patientenkat.se/sv/resultat/Akutmottagningar/2017/>
- Swedish Research Council. (2002). *Ethical review of research involving humans*. Elanders Gotab. Retrieved from https://www.gu.se/digitalAssets/1268/1268494_forskningsetiska_principer_2002.pdf
- The National Board of Health and Welfare. (2017). Waiting times and patient flow in the emergency department. Retrieved from <https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachment/s/20493/2017-2-16.pdf>
- Ting, X., Yong, B., Yin, L., & Mi, T. (2016). Patient perception and the barriers to practicing patient-centered communication: A survey and in-depth interview of Chinese patients and physicians. *Patient Education and Counseling*, 99(3), 364–369. <https://doi-org.e.bibl.liu.se/10.1016/j.pec.2015.07.019>
- Tobiano, G., Marshall, A., Bucknall, T., & Chaboyer, W. (2015). Patient participation in nursing care on medical wards: An integrative review. *International Journal of Nursing Studies*, 52(6), 1107–1120. <https://doi.org/10.1016/j.ijnurstu.2015.02.010>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357.
- Vaismoradi, M., Jordan, S., & Kangasniemi, M. (2015). Patient participation in patient safety and nursing input - A systematic review. *Journal of Clinical Nursing*, 24(5–6), 627–639. <https://doi-org.e.bibl.liu.se/10.1111/jocn.12664>
- Viotti, S., Cortese, C. G., Garlasco, J., Rainero, E., Emelurumonye, I. N., Passi, S., Boraso, F., & Gianino, M. M. (2020). The buffering effect of humanity of care in the relationship between patient satisfaction and waiting time: A cross-sectional study in an emergency department. *International journal of environmental research and public health*, 17(8), 2939. <https://doi-org.e.bibl.liu.se/10.3390/ijerp17082939>
- Xie, Z. & Or, C. (2017). Associations between waiting times, service times, and patient satisfaction in an endocrinology outpatient department:

A time study and questionnaire survey. *Inquiry: a Journal of Medical Care Organization, Provision and Financing*, 54, 46958017739527. <https://doi-org.e.bibl.liu.se/10.1177/0046958017739527>

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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