ABSTRACT

Objective

The aim of this study was to explore the nature, potential usefulness and meaning of complaints lodged by patients and their relatives.

Design

A retrospective, descriptive design was used.

Setting

The study was based on a sample of formal patient complaints made through a patient complaint reporting system for publicly funded healthcare services in Sweden.

Participants

A systematic random sample of 170 patient complaints was yielded from a total of 5,689 patient complaints made in a Swedish county in 2015.

Main outcome measure

Themes emerging from patient complaints analysed using a qualitative thematic method.

Results

The patient complaints reported patients' or their relatives' experiences of disadvantages and problems faced when seeking healthcare services. The meanings of the complaints reflected six themes regarding access to healthcare services, continuity and follow-up, incidents and patient harm, communication, attitudes and approaches, and healthcare options pursued against the patient's wishes.

Conclusions

The patient complaints analysed in this study clearly indicate a number of specific areas that commonly give rise to dissatisfaction; however, the key findings point to the significance of patients' exposure and vulnerability. The findings suggest that communication needs to be improved overall and that patient vulnerability could be successfully reduced with a strong

interpersonal focus. Prerequisites for meeting patients' needs include accounting for patients' preferences and views both at the individual and organisational levels.

Keywords: patient complaints, healthcare, dissatisfaction, qualitative approach, experiences

INTRODUCTION

Complaints registered by patients are considered important for indicating problems and obtaining feedback on healthcare services [1]. Despite the great importance of the quality of care and patient safety, some patients suffer harm from medical care [2, 3]. In previous research, patient safety reporting systems were used to study healthcare quality [3, 4]. However, few studies have focused on problems reported directly by patients. Understanding the issues and details of patient complaints may provide directions for healthcare improvements.

Background

The debate on patient safety and the quality of healthcare services has mainly represented a narrow clinical perspective, neglecting the patients' perspective. Establishing a broader framework for addressing patient safety will rely on understanding patients' experiences [5, 6, 7]. Quality and improvement needs have also been reported to motivate patients' complaints. Patients often draw attention to previous mistakes and preventing such mistakes or incidents from being repeated [8, 9]. In European countries and the United States, for example, evidence suggests that patients' complaints provide valuable information about the source of medical errors, which is crucial for improving patient safety [7, 8, 10].

Patient complaints about healthcare services have reportedly increased [11]. Such complaints are a growing concern for healthcare organisations worldwide and are a key mechanism for identifying problems experienced by patients [12]. Patients' main concerns are the quality and safety of healthcare services [13]. Other areas commonly reported are medical care and long waits [10, 14]. Further, communication and attitude problems, including unprofessional attitudes, have been associated with the quality of care and patient safety [14]. Experiences of insufficient or inadequate information, in addition to unsatisfactory communication or failings in respect and empathic staff responses are common [15, 16].

Patient complaints may also underline the hospital management's handling of complaints and the outcomes offered [11].

Patient complaints can assist in identifying problems and risks related to healthcare services. A greater commitment to addressing complaints can give insights into aspects of healthcare that traditional quality and safety reporting systems fail to capture [4]. One advantage of dealing with patient complaints is facilitating healthcare providers' preparedness to effectively manage and improve patient care [4, 17]. Patient risk and safety might be discussed in relation to medical errors or failures. Reason [18] divided failures into two types: active failure, such as unsafe actions taken by clinicians caring for patients (i.e. individuals), and latent failure, such as inevitable 'resistant pathogens' or factors arising from a stressful work environment, under-staffing and inexperience (i.e. the organisation). Active failure often occurs due to insufficiency in latent conditions in the healthcare organisation [18, 19].

Although some key service delivery areas have been prevalent in previous research on patient complaints, there remains a pressing need to obtain in-depth knowledge of the impact and issues of patient-reported problems. Therefore, the aim of this study was to explore the nature, potential use and meaning of complaints lodged by patients and their relatives.

METHOD

Research design

A retrospective study with a descriptive design was conducted to explore patient complaints made to a patients' advisory committee (PAC) in Sweden. The data were analysed using qualitative thematic analysis [20].

Setting

A systematic random sample of patient complaints filed with a PAC in a Swedish county in 2015 was chosen. The primary task of PACs is to assist with problems arising from healthcare services. In Sweden, patients have the right to make complaints regarding healthcare services,

and PACs for each county and municipality receive such complaints. PACs are legislative, and they are an independent and impartial body without any authority to make judgements or punishments regarding healthcare. They review reports about concerns regarding publicly financed healthcare services. These reports are documented in the reporting system by an administrator, and in some cases the reports are supplemented with a written mail about a patient's or a relative's concern.

Sample and data collection

After obtaining permissions and approvals for the research, data were collected in 2016 and shared from the patient complaint reporting system. A systematic random sample of 170 complaints was derived from a total sample of 5,689 patient complaints registered in 2015 (see Figure 1 for a flow chart, inclusion criteria and sample selection). The patient complaints analysed in this study contained detailed narratives written by a patient or a relative. Most of the complaints were approximately one A4 page, but ranged from three lines to six pages in length.

Data analysis

A qualitative thematic analysis was performed [20]. The objective was to identify and describe patterns of meanings within the content of the complaints. The first step of the analysis was to carefully read the complaints repeatedly to get an overall sense of what was predominant in, and characteristic of, the data. Then the reading became more systematically with attention on identifying meanings in the data and understanding patterns in the text. Meaning units were marked (the data were divided into fractions based on different meanings) and patterns of meanings were identified, condensed and arranged in initial themes. The authors attempted to delve deeper into the data, reflecting on the complaint details, to allow new insights to emerge. From this process, themes and subthemes were elaborated through a reflective process. The emerging themes were reviewed and further refined and discussed

among the researchers. The analysis involved an iterative movement between the whole data and the emerging themes, going back and forth between original data and reflection. Finally, the analysis yielded 6 themes and 14 subthemes that were used to organise and describe the findings.

Ethical considerations

This study was approved by the regional ethics committee in Gothenburg (DNo. 951-15). The data were provided anonymously by the patient complaints reporting system; none of the names or other personal information of patients, relatives, nurses or other persons in the complaints were obtained.

RESULTS

The patient complaints described experiences of patients' and/or relatives' dissatisfaction with healthcare services. These reports commonly described experiences of significant incidents, disadvantages and problems with an impact on the patient's health, medical or nursing care, or patient safety. There were experiences of problems with access to healthcare services, problems regarding the quality of healthcare, and communication. Overall, the complaints can be viewed from two perspectives: individual failings among healthcare professionals in terms of fulfilling their responsibilities or deficiencies in their delivery of healthcare services, and problems at the organisational level, comprising problems in, or resulting from, structural conditions. The meanings of the complaints are further described in six themes, with related subthemes, displayed in Table 1. The subthemes are illustrated with examples and extracts from the patient complaints, shown in Table 2.

Access to healthcare services

The complaints described problems regarding access and availability of different healthcare services. These complaints were characterised as *not getting in contact with healthcare*

services, not getting access to healthcare and needing 'to fight' and *feelings of abandonment when access to healthcare, treatment or aids was lacking*.

Problems getting in contact with healthcare services concerned experiences of not being able to get in touch with healthcare services by telephone or online. This was troublesome when one could not contact the appropriate provider or department, as direct contact was a prerequisite for access to healthcare. Other problems were long wait times or missing information regarding whom to contact, and problems owing to the complexity of the telephone system.

Not getting access to healthcare, personal struggle and a need 'to fight' were exhibited in reports describing experiences of needing to fight for help or having to overcome significant difficulties to obtain healthcare. Reasons such as deficiencies in resources, staffing and the number of occupied hospital beds were described. For instance, when patients had to leave the hospital without undergoing their operation as scheduled.

Feelings of abandonment when lacking access to care, treatment or aids included experiences of certain healthcare services was ceasing. For example, patients described the impact of physiotherapy being withdrawn.

Continuity and follow-up

Problems regarding continuity of healthcare and follow-up were described. Complaints included concerns regarding *deficiencies in continuity or problems with follow-up visits or check-ups.*

Patients and/or relatives complained about lacking continuity in contact with physicians. Repeatedly consulting a new physician was a concern, as it negatively influenced patient's healthcare and treatment.

Another subject of the complaints was *problems with follow-up visits or check-ups.* The complaints described shortcomings of routines and patients not being called for check-ups or examinations or delays in healthcare services.

Incidents and patient harm

The complaints also reported experiences of incidents and patient harm. Some patients described *severe diagnoses being missed or misjudged* and *patient harm arising from mistakes and incidents*.

Overlooking or misjudging severe diagnoses was reported, for instance, by patients being treated by a GP, who were later found to have advanced cancer. Such complaints of misjudgements and misdiagnoses involved life-threatening illnesses turning out to be something else or serious conditions being missed.

Patient harm from mistakes and incidents included, for example, postoperative wound infections and neurological injuries with ongoing symptoms several years after surgical procedures. Other incidents involved treatment and care inflicting harm on inpatients.

Communication

Communication problems were commonly described and seem to be a major characteristic of the analysed complaints. Patients were *lacking information about healthcare,* or situations arose that were a problem, often relating to *insufficient coordination.*

The complaints concerned situations where patients or relatives *lacked information on healthcare*. There were reports of communication problems concerning information and advice. In numerous situations, information regarding health, diseases, examinations or treatment plan was vague or inadequate. Sometimes, patients reported difficulties in asking questions and problems in pathways to receiving more information

Communication problems were also reported to result in *insufficient coordination* of healthcare. Ineffective communication caused flaws in cooperation between different

healthcare organisations, between units or in specific patient situations. Problems with coordination and communication between units resulted in patients suffering from gaps in care, not getting the help they needed.

Attitudes and approaches

Healthcare professionals' attitudes and approaches were a common source of the complaints, reported as experiences of patients *being ignored* or *being treated with disrespect*.

Healthcare professionals' attitudes were described as making patients feel *ignored* or being met with nonchalance. Patients reported, for example, not being seen or taken seriously, or feeling mistrusted or insulted. In different ways, the complaints illustrated experiences of healthcare professionals not appearing to pay attention to the patients' needs.

There were also reports of patients or relatives *being treated with disrespect*, making them feel offended or humiliated. Patients or relatives described being disrespected in various ways and feeling rushed or dismissed by healthcare professionals.

Healthcare options pursued against the patient's wishes

A small number of complaints involved going against the patient's wishes. These were examples of *healthcare without respect for the patient's views* or healthcare where the patient was *overlooked by healthcare professionals*.

Most of these complaints were related to *healthcare delivered without respect for the patient's views*. There were reports on agreements not being followed through or patients being coerced to agree to aspects of healthcare that contradicted their needs and wishes.

There were also complaints about *patients being overlooked by healthcare professionals*, for example, when confidentiality and anonymity were not maintained. Patients with psychiatric illnesses seem to be a particularly vulnerable group, as complaints regarding decisions being taken against their wishes or without their participation were common.

DISCUSSION

The patient complaints in this study reported problems regarding access to healthcare services, contact within healthcare services and pathways to obtaining the necessary healthcare. Problems regarding the quality of healthcare and patient safety were also reported, with some patients suffering effects from mistakes and incidents. Overall, communication problems were observed more or less in almost every patient complaint. Finally, a small number of complaints reported healthcare options being pursued against the patient's wishes; however, these reports are remarkable and particularly noteworthy.

The analysed complaints emphasise patients' vulnerability, as evinced in the recurring issue of patient exposure and vulnerability. Vulnerability occurred in encounters with healthcare professionals, where such vulnerability could increase or decrease [21]. Patients are generally vulnerable due to a lack of power and for instance, fear, worry and pain. Vulnerability is related to one's bodily state and can be enhanced by injury or illness. This context provides an important background for understanding that 'getting the fit right' for each patient requires that the healthcare be in tune with such complexity. In other words, patients may be on a spectrum where, they sometimes require autonomy and a high degree of personal agency; sometimes need support for decisions; and sometimes must be passive and dependent on the professional, needing decisions to be made for them, with each case depending on the degree of vulnerability and exposure. Moreover, this complexity concerning vulnerability can be understood within the view of patients' dignity. Delmar [22] highlights the complexity of dignity in healthcare. Thus, nurses and healthcare professionals upholding dignity in care are obliged to balance patients' expectations and values, sometimes allow patients to have a voice in relation to treatment and care and at other times support them and meet them in vulnerability. Patients want to be taken seriously, receive respect and preserve their dignity as the masters of their own lives, but it is important to acknowledge the

vulnerability and exposure of the patient in healthcare. Thus, achieving the right balance may mediate the issues that lead to complaints.

The attitudes and approaches of healthcare professionals are of utmost importance and seem to colour the depths and details of complaints. In the present study, shortcomings in attitude and insensitive communication were reported; they were found to decrease patient satisfaction with care and sometimes even risked patient safety or added to the patient's suffering. Communication failure has been linked to problems such as patient safety and poor patient experiences [23, 24]. Important steps towards effective communication are healthcare professionals' attention on how information is understood by patients [25]. The approach to communication and tone with patients are imperative for the quality of healthcare. This is against the backdrop of the long-standing policy of patient-led care. The model of patient-centred care emphasises patients' experiences, values, needs and preferences in the planning, coordination and delivery of care [26]. Strategies like patient-centred care can give patients more choices and a voice in their own healthcare [27]. In patient-centred care, the relationship between the patient and healthcare professionals is central. There are benefits to more patient-centred care, and positive patient outcomes have been demonstrated, for example, in terms of increased patient satisfaction [26]. However, our findings suggest that more is needed beyond present attempts to apply patient-centred care. The results highlighting the significance of attitudes and approaches reveal a situation that remains professionally focused and not patient-focused. To gain a more patient-centred healthcare, changes in professional's attitudes and approaches are needed. To decrease patient´s vulnerability, healthcare professionals should act ethically and be directed towards patient´s experiences and needs [21]. A future challenge in healthcare is continuity of professionals, influencing the cooperation between teams and between different healthcare organisations. Teamwork and communication also influence the safety culture in healthcare organisations [24], similar to this study findings. In

addition to patient safety, continuity of staff is associated with higher patient satisfaction [28]. Issues regarding the sustainability of teams and continuity of professionals require further investigation.

Patients' concerns can provide important insights into healthcare, and patients may be the first to detect flaws in healthcare safety or quality [5]. The complaints seem to be what Reason [18] labels active and latent failures. Healthcare organisations must focus on preventing both types of failures and on fostering a safety culture. Patient complaints can be used to identify areas in need of urgent improvement. However, there is currently no evidence available that shows whether patient feedback contributed to improved outcomes [29]. Still, we argue that more work using patient complaints can be a resource to enhance healthcare services' preparedness to meet patients' needs. Acknowledging patients' complaints also provides an opportunity to respond to dissatisfied patients and thereby legitimise their complaints [30]. In addition, feedback to professionals may be important to improve the understanding of the impact on a patient that led to the complaint.

The generalisability of the findings of this study is limited, as data were collected from a systematic random sample in one county of Sweden. Given the limited evidence from qualitative studies exploring patient complaints in depth, this study is a novel addition to the evidence of needed healthcare improvements based on patients' views. One possibility for future research could be to learn from patients past experiences what goes right in healthcare in order to improve the quality of care.

Conclusion

The results suggest that patient complaints can give valuable insights to help increase the quality of healthcare. In addition to the range of issues giving rise to complaints, the findings point to recurring exposure and vulnerability of patients in healthcare encounters, which add to the difficulties encountered and seem to suggest that healthcare professionals do not always

‘get the fit right’ with regard to the situation and can fail to communicate effectively in terms of their tone. Consequently, the attitudes and approaches of healthcare professionals are critical. Strategies for a more patient-centred perspective can be beneficial, but our findings show that there are gaps in the centring of patients. Although the impact of patient-centred care has been researched for several years, guidelines on how to implement and sustain such care are lacking. Developing more patient-centred care may improve patient–provider communication and increase patient satisfaction with healthcare, both in medical consultation and nursing care. Yet our findings demonstrate that patient vulnerability and meeting patients’ needs are complex issues that involve more than simply ‘giving more choice’. Further research is needed into how such healthcare can be put into clinical practice with policies and guidelines regarding the quality of healthcare that can do justice to patients’ preferences and views in a way that is also sensitive to the dynamic and changing context of care.

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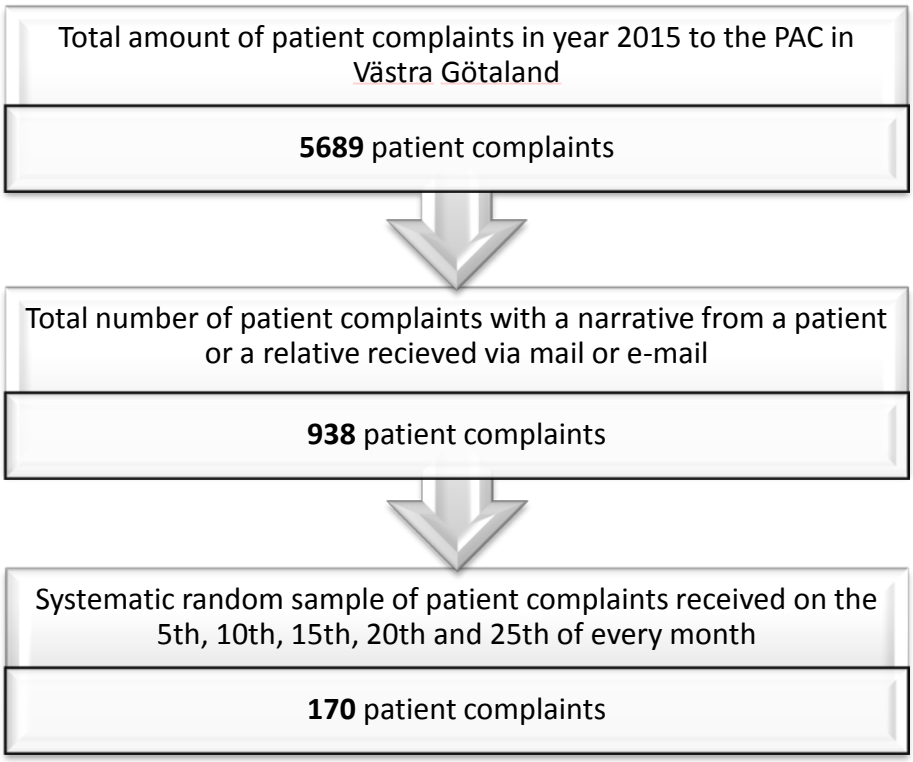

Figure 1. Flow chart and sample selection of patient complaints.

Table 1. Themes and related subthemes describing the content of the patient complaint.

THEMES	**Access to healthcare services**	**Continuity and follow-up**	**Incidents and patient harm**	**Communication**	**Attitudes and approaches**	**Healthcare options pursued against the patient's wishes**
SUBTHEMES	*Not getting in contact with healthcare services* *Not getting access to healthcare, personal struggle and a need 'to fight'* *Feelings of abandonment when delivery of healthcare services ceases*	*Concerns regarding deficiencies in continuity* *Problems with follow-up visits or check-ups*	*Severe diagnoses being missed or misjudged* *Patient harm from mistakes and incidents*	*Lacking information on healthcare* *Insufficient coordination*	*Being ignored* *Being treated with disrespect*	*Healthcare without respect for the patient's views* *Being overlooked by healthcare professionals*

Table 2. Subthemes illustrated with extracts from patient complaints.

Subtheme	Extracts from patients complaints
Not getting in contact with healthcare services	A patient not obtaining an appointment with the GP reported not having the medication needed: 'It's not the first time this has happened. Except that I must have my medication; it makes me feel anxious.' (82) Another patient described being anxious when in pain and not being able to speak to any nurses over the phone: 'It almost took an hour; I was in pain and was really anxious before I got to talk to a nurse.' (152)
Not getting access to healthcare services, personal struggle and a need 'to fight'	A patient with hearing and vision impairments reported not having an interpreter needed for communicating with healthcare services. Owing to this lack of support, the patient felt that they had been discriminated against and could not handle daily life: 'I feel I am discriminated against; I can't handle my daily life.' (9)
Feelings of abandonment when healthcare services cease	A patient with a physical disability described previously accessed services for training as vital for sustaining physical functions. The patient reported feeling abandoned and their health being threatened when they could no longer avail of those healthcare services: 'Do they want us to be worse? // Why destroy our lives?' (149)
Deficiencies in continuity	A patient reported a lack of continuity in contact with physicians. Repeatedly getting a new physician cause the patient to feel vulnerable and frustrated. The patient was concerned because this negatively influenced the care and treatment: 'During the time that I have been a patient at this clinic [two years], there has been no continuity at all of doctors. My sick leave has lapsed every time before I could get a new appointment with the GP. I have contacted them several times, and I constantly hear, "We do not have staff". Every time, except once, I have been consulted by new doctors.' (150)
Problems with follow-up visits or check-ups	A patient with a long-term illness, who required regular check-ups to test blood samples, described being overlooked when there were changes in the staffing at the local healthcare centre: 'I was overlooked, should have been checked up regularly for my blood samples. That is no patient safety at all.' (90)
Severe diagnoses being missed or misjudged	A relative described an experience of the patient with advanced cancer not getting chemotherapy for cancer as planned: 'I still wonder, why didn't they start the treatment? My dad asked them repeatedly when it would start; he trusted the doctors. // At one of his late consultations, the doctor admitted that they had planned for chemotherapy and that there had been plenty of time for chemotherapy, except they had made all these mistakes.' (2)

	A patient having a severe blood disorder, who was at risk of abnormal bleeding, reported that her test results had been unknown for several years: 'The test results from my blood sample were 54, while reference values were 165–387.' (15)
Patient harm from mistakes and incidents	A concerned relative reported that during hospitalisation, her elderly parent had fallen and hit her head so badly that she later died. The patient was treated with Warfarin, a blood thinning medication, and eventually died from injuries caused by the fall: 'If there had been a correct risk assessment in relation to my mother's impaired health, low blood pressure and medication, she would probably be alive today.' (131)
Lacking information on healthcare	A relative reported communication problems regarding information and advice: 'At a consultation with doctor x, she thought that I was awkward, being a relative asking too many questions all the time about my father and why he didn't get the treatment.' (2) A patient reported not getting information regarding test results or treatment plans when contacting healthcare services. No one could answer the patient's questions: 'The doctor told me to call his secretary and then he would call back immediately. Now three months have passed.' (123)
Insufficient coordination	A patient reported problems with getting the local primary healthcare centre to issue the medical certificate she needed for her sick leave: 'I need a medical certificate for my sick leave because of my back problems. Since I'd been at the specialist unit, my GP referred me to that specialist for the certificate, and the specialist referred me back to the GP.' (142)
Being ignored	A patient visiting a clinic for a skin lesion reported a situation where he felt ignored by a healthcare professional: 'She throws a very nonchalant glance at my lesion and says to me that it is a totally normal age-related change and nothing to bother her for. // With a harsh tone she says, "If we were to treat such changes, we would drown in such matters".' (57)
Being treated with disrespect	A close relative described being mistaken for a patient with dementia and being locked in a unit. At first, he was surprised and could not make sense of what was happening. When he realised that he had been taken to the wrong place, the staff refused to allow him to leave. Afterwards, the man was shocked that he had been mistaken for a patient with dementia and locked in the unit:

	‘I’ve never felt so disrespected in my life.’ (155)
Healthcare without respect for the patient’s views	A patient with a strong fear of childbirth together with the midwifery staff and the physician made a birth plan. She was guaranteed a caesarean section, should the childbirth become traumatic. The woman experienced this situation, and although she was in a panicked state, she reported feeling completely ignored and having to carry out a vaginal delivery. The woman and her partner were upset by this traumatic experience: ‘If I had had the caesarean section when I wanted to, the panic would have been avoided and I would have been able to participate in my son’s birth.’ (16)
Being overlooked by healthcare professionals	A patient with a mental health disorder reported that health professionals did not maintain secrecy. A physician called an authority without the patient’s consent: ‘I got furious, as he would not admit to wrongdoing.’ (80)