The tip of an iceberg? A cross sectional study of the general publics' experiences of reporting healthcare complaints

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The tip of an iceberg? A cross-sectional study of the general publics' experiences of reporting healthcare complaints.

Abstract

Introduction: Learning from patient complaints is important for the development of healthcare. However, there are indications that complaints of adverse events in healthcare are underreported.

Aims: To investigate the hypothesis that complaints are underreported and to identify barriers to filing complaints of adverse events related to encounters with healthcare personnel.

Methods: A questionnaire was sent to a random sample of 1,500 individuals in the County of Stockholm, asking whether or not they had filed complaints of adverse events. Respondents were also asked whether they had had reasons for doing so but abstained, and if so their reasons for not complaining. We also asked about participants' general experience of and trust in healthcare.

Results: The response rate was 62.1%. Official complaints have been filed by 23 respondents (2.7% CI: 1.7-3.7), while 159 (18.5% CI: 15.9-21.1) stated that they have had legitimate reasons to file a complaint but had abstained. The degree of underreporting was greater among patients with a general negative experience of healthcare 37.3% CI: 31.9-42.7) compared to those with a general positive experience (4.8% CI: 2.4-7.2). Respondents with a general negative experience also had lower trust in healthcare. The reasons given for abstaining were, among others, 'I did not have the strength', 'I did not know where to turn', and 'It makes no difference anyway'.

Conclusion: We found a considerable discrepancy between the actual complaint rate and the number of respondents stating that they have had reasons to complain but have abstained. This indicates that in official reports of complaints we only see 'the tip of an iceberg'.

Introduction

Whereas healthcare by and large is doing its best to improve and promote health, adverse events occur. Fortunately such incidents are rather unusual. In Stockholm, the capital of Sweden, there are each year around 15 million healthcare visits, but only about 8,500 registered complaints, including all internal incident reports as well as complaints from patients. However, the number of complaints is steadily increasing [1, 2].

Patients file their reports with the National Board of Health and Welfare (Socialstyrelsen) or with a Patients' Advisory Committee (Patientnämnd). The latter authority also administers complaints about patients' experiences of negative healthcare encounters, i.e., complaints concerning how the patient is received by healthcare employees. The main types of complaints addressed to Patients' Advisory Committees concern medical maltreatment (42%), availability (12%), encounters (12%), and monetary issues (7%) [2], but the complaints often reveal combinations of reasons for complaining. As an example, a snapshot review showed that around thirty per cent of the complaints registered as concerning maltreatment also brought up negative encounters [3].

The general aim of authorities' administration of complaints is to improve patient safety and efficiency in healthcare. The patients' motives for filing a complaint might, however, differ; they may also concern a wish for an explanation, someone to be accountable for what happened, financial compensation, or receiving an apology [4-6].

We have found no systematic reviews of barriers to complaints regarding negative healthcare encounters focusing on patients. It is, however, well reported that complaints from patients as well as hospital staff regarding adverse events tend to be widely underreported [7-10]. In this paper, based on a questionnaire survey, we test the hypothesis that patients' tendency to file complaints in relation to the number of incidents perceived to be worthy of a complaint is underreported, disclosing only the tip of an iceberg. We also investigate whether trust in and experiences of healthcare are related.

Material and methods

A questionnaire concerning experience of healthcare, negative encounters, trust, and complaints to the Patients' Advisory Committee was distributed to a randomly selected study population (n=1500; 50% women and 50% men, aged 18-99 years) registered by the Swedish National Tax Board as living in the County of Stockholm in April, 2008. The questionnaire included seven questions with fixed response alternatives and space for comments. In addition, it contained two open-ended questions regarding the respondents' personal

experiences of negative healthcare encounters, as patients and as relatives. The focus of the present analysis is on the questions regarding respondents' general experience of Swedish healthcare, their trust in healthcare, whether they have filed a formal complaint with the Patients' Advisory Committee, whether they have had reason to file a complaint but have refrained from doing so, and if so why, and how they perceive their personal experience of encounters with personnel in the healthcare system.

Response options for the question regarding respondents' general experience of Swedish healthcare were 'mainly positive', 'mainly negative', 'both positive and negative', and 'no experience'. Since there were no significant differences between those who had a mainly negative general experience and those who had a both positive and negative general experience, we have merged these into one group in the analysis ('negative general experience'). For estimation of the respondents' degree of trust in healthcare, they were given four response alternatives ranging from 'very high' to 'very low' (in the analysis the responses were dichotomised into 'high trust' and 'low trust'). Response options regarding having filed or having had reason to file a complaint were 'yes' and 'no'. As a follow-up question we asked for the underlying reasons for not filing a complaint when having had reasons to do so. The reasons were classified in units based on their main content. Finally, response options to the question about personal experiences of encounters with healthcare personnel were 'very positive', 'fairly positive', 'rather negative', and 'very negative'. In the analysis they were dichotomised into positive and negative experiences of such encounters.

The results were analysed using Epi-Calc2000 and presented as odds ratios (OR) and proportions with 95% confidence intervals (CI). When testing the iceberg hypothesis, we used the Chi-2 test; significance level 0.05 was chosen.

Of the sample of 1,500, 1,484 were eligible; altogether 992 participants (62.1%) returned a completed questionnaire (58% were women and 42% men). The median age was 49 years.

The study was approved by the Regional Research Ethics Committee, Dnr 2008/439-31.

Results

Our analysis shows that 23 persons [2.7% (CI: 1.7-3.7)] have turned to the Patients' Advisory Committee with complaints about the quality of their encounters, while 159 [18.5% (CI: 15.9-21.1)] stated that they had had legitimate reasons to file a complaint but had chosen to not go through with them (Chi-2=114, df=1). There was a strong association between type of general

experience of healthcare and inclination to file a complaint [OR: 7 (CI: 4.7-10.3)]; see Table 1. We found no significant sex or age-related differences where complaints were concerned.

A majority of the respondents, 60.3% (CI: 56.2-64.4), stated that they had a mainly positive general experience of healthcare, 34% (CI: 29-39.6) had a negative general experience, and 5.5% (CI: 0-11.8) had no experience of healthcare. Of the respondents with a positive general experience of healthcare, 99.5% (CI: 99-100) stated that their personal encounters with healthcare personnel had been positive. Of those who had a negative general experience, 19.5% (15.1-23.9) reported personal experiences of negative encounters. Comparing the two groups, we found a strong correlation [OR: 44.2 (CI: 13.7-142.3)].

We also found a strong correlation between a general negative experience and low trust in healthcare on the one hand and a general positive experience and high trust on the other [OR: 21 (CI: 11.1-40.3). Of those who had reasons to file a complaint but did not do so, one-third reported that they had low trust in healthcare. This can be compared to those who had no reason for filing a complaint; nine out of ten had high trust in healthcare; see Table 2.

Respondents stating that they had had reason to file a complaint regarding negative encounters with healthcare personnel but abstained were asked to comment why they abstained. Input was received from 140 respondents. The most common responses were ‘I did not have the strength’, ‘I did not know where to turn’, and ‘It makes no difference anyway’. Other reasons stated were, for example, that it was too difficult and that the respondent was afraid of the consequences; see Table 3.

Discussion

Comparing the number of respondents who have filed a complaint with the number who have not but who think they had legitimate reasons to do so, we found a significant difference, indicating that the complaints filed shows only the tip of an iceberg. The ratio between complaints filed and non-reported events that, according to the respondents, would qualify for a formal complaint was approximately 1:7 in the survey population. Among those with a general negative experience of healthcare, it was approximately 1:8.

In the total study sample, almost all participants had had experience of healthcare – only fifty participants had not. We found a strong correlation between a positive/negative general experience of healthcare and personal experiences of positive/negative encounters with healthcare personnel. These findings might indicate that the respondents do not clearly distinguish between medical maltreatment and negative encounters, or that these experiences interact; they are both important for the impression and assessment of healthcare services.

Other studies have indicated that negative encounters might become a threat to patient safety because they affect communication and patient behaviour [11-13]. Earlier studies have also indicated that patients who have been received in a hostile, rude, or otherwise negative manner are more predisposed to go through with malpractice claims [6, 14]. Our study shows that a larger percentage of those with a negative general experience of healthcare file complaints, compared to those with a positive general experience.

The encounter's effect on trust

Not surprisingly, those with a negative general experience of healthcare who had filed a complaint or had had reasons for doing so reported lower trust in healthcare at the time of the survey, compared to those with a positive general experience who had not filed a complaint and had had no reason for doing so. A large proportion of the latter group had high trust in healthcare. Trust seems to be important for several reasons, for example for concordance and ultimately for patient safety [13,15]. If trust in healthcare is jeopardised by negative encounters, it seems important also to examine more carefully the bottom of the iceberg, i.e. to study those who do not file complaints.

Reasons for not complaining

Many of the most frequent reasons for not filing complaints have in common that the respondents felt that the obstacles were too great or that it required more strength than they could muster. Quite a few express the belief that reporting adverse events is futile, implying distrust regarding either the ability or the willingness of healthcare to actually take notice of and learn from the complaints. Furthermore, some respondents chose not to complain due to fear of reprimands, such as receiving worse care or having their treatment withdrawn – an alarming result that also implies a considerable lack of trust among the respondents.

These responses identify the main barriers to receiving input via formal complaints. The obstacles prevent learning about adverse events and are therefore liable to have negative effects on the development of healthcare services and prevention of future adverse events. The responses also indicate that if the healthcare system wants this kind of input, it needs to offer patients more support. Better provision of information seems to be part of the solution, since some respondents were not even aware that they could file a formal complaint or did not know how to do it, but one can also conclude from the responses that discontented patients might need more hands-on active support in getting their complaints filed.

Validity

There was no limit in time regarding which events respondents might consider and refer to. This means that our results cannot be compared with official reports presenting annual complaint rates. For this reason we have not focused on comparisons with earlier research but on relative associations within the present data and the manifest reasons for not filing complaints.

Conclusions

The present study indicates that healthcare complaints filed regarding encounters reveal only the tip of an iceberg. Complaints seem to be considerably under-reported, especially among those with a negative general experience of healthcare. The commonest barriers to complaints are that patients do not find the strength to make them, do not know where to turn, or do not find it worthwhile since they do not believe it will make any difference. Since negative encounters seem to influence trust in healthcare, we suggest that those who do not file complaints should also be studied more carefully.

Article summary

Article focus

- To test the hypothesis that patients' complaints about adverse events related to negative encounters in healthcare are underreported.
- To study barriers to filing complaints.
- To investigate whether trust in and experiences of healthcare are related.

Key messages

- Patient complaints about negative encounters are underreported, disclosing only the tip of an iceberg.
- The main barriers to complaints are that patients do not find the strength to make them, do not know where to turn, or do not find it worthwhile since they do not believe it will make any difference.
- Negative encounters seem to have a negative impact on the exposed patients' trust in healthcare.

Strengths and limitations of this study

The study reveals the barriers to complaining in a clear way which enables healthcare personnel to work actively to provide a more supportive environment for the patients in case of adverse events. The study sample was small and there was no time-limit regarding events respondents might consider and refer to. This means that our results cannot be compared to official complaint rates nor generalised to a broader population.

Funding statement

This work was supported by Stockholm County Council.

Competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: all authors had financial support from Stockholm County Counsil for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work.

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Contribution statement

Maja Wessel is the main author of the present paper and took leading part in its conception and design, statistical analysis, interpretation of the results and writing of the paper.

Niels Lynöe contributed with the original idea for the present study, took part in its conception and design, participated in the statistical analysis, and contributed substantially to the interpretation of the results and revision of the manuscript.

Niklas Juth contributed to the conception and design of the study, and has critically revised the manuscript.

Gert Helgesson contributed substantially to the conception and design of the study and to the interpretation of the results. He has taken a leading role in writing the paper.

Data sharing statement

There is no additional data available

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Table 1. The table shows the participants' tendency to complain in relation to different general experiences of healthcare. The results are presented as proportions with a 95% confidence interval. Those who had no experiences of healthcare (n=50) are excluded from the presentation.

General experience of healthcare:	Filed a complaint % (CI)	Had reasons to complain but abstained % (CI)
Positive (n=553)	1.5% (0.5-2.5)	7.8% (5.6-10)
Negative (n=314)	4.8% (2.4-7.2)	37.3% (31.9-42.7)
All (n=867)	2.7% (1.7-3.7)	18.5% (15.9-21.1)

Table 2. The table displays the proportions (with a 95% confidence interval) of the respondents who had high trust in healthcare in relation to whether they *had filed a complaint* to the Patients' Advisory Board, whether *they had had reasons for filing a complaint*, and their *general experience* of healthcare. Those who had no experiences of healthcare (n=50) are excluded from the presentation.

	High trust
Never complained (n=843)	87% (84.7-89.3)
Actually complained (n=23)	60.9% (41-80.8)
No reasons for complaining (n=703)	90.9% (88.8-93)
Reasons for complaining but abstained (n=163)	66.7% (59.5-73.9)
Positive experiences of healthcare (n=551)	97.6% (96.3-98.9)
Negative experiences of healthcare (n=312)	66.3% (61.1-71.5)

Table 3. Reasons for not filing official complaints to the Patients' Advisory Committee. Number of respondents=159.

Motive	Number (n) of responses
I did not have the strength	n=39
I did not know where to turn	n=18
It makes no difference anyway	n=17
I had other priorities	n=14
It was too difficult	n=13
I did not have time to do it	n=8
I was afraid of the consequences	n=8
The damage was already done	n=5
I did not know/think I had that option	n=4
I complained directly at the hospital	n=4
I do not like to complain	n=3
I did not complain out of consideration for the accused person	n=3
I did not complain due to collegial relations	n=2
I did not want to relive the trauma	n=1
I was not the closest relative	n=1
No reason stated	n=19

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Aims: To investigate the hypothesis that complaints are underreported and to identify barriers to filing complaints of adverse events related to encounters with healthcare personnel.

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We have found no systematic reviews of barriers to complaints regarding negative healthcare encounters focusing on patients. It is, however, well reported that complaints from patients as well as hospital staff regarding adverse events tend to be widely underreported [7-10]. One may wonder whether the same is true for negative encounters. In this paper, based on a questionnaire survey, we test the hypothesis that patients' tendency to file complaints regarding negative encounters in relation to the number of incidents perceived to be worthy of a complaint is underreported, disclosing only the tip of an iceberg. We also investigate whether trust in and experiences of healthcare are related.

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addition, it contained two open-ended questions regarding the respondents' personal experiences of negative healthcare encounters, as patients and as relatives. The focus of the present analysis is on the questions regarding respondents' general experience of Swedish healthcare, their trust in healthcare, whether they have filed a formal complaint with the Patients' Advisory Committee, whether they have had reason to file a complaint but have refrained from doing so, and if so why, and how they perceive their personal experience of encounters with personnel in the healthcare system.

Response options for the question regarding respondents' general experience of Swedish healthcare were 'mainly positive', 'mainly negative', 'both positive and negative' (i.e., a mixed experience not clearly pointing in any direction), and 'no experience'. Since there were no significant differences between those who had a mainly negative general experience and those who had a both positive and negative general experience, we have merged these into one group in the analysis ('negative general experience'). For estimation of the respondents' degree of trust in healthcare, they were given four response alternatives ranging from 'very high' to 'very low' (in the analysis the responses were dichotomised into 'high trust' and 'low trust'). Response options regarding having filed or having had reason to file a complaint were 'yes' and 'no'.

As a follow-up question we asked for the underlying reasons for not filing a complaint when having had reasons to do so. The responses were subjected to qualitative content analysis [11]. The reasons presented in the responses were first identified and classified into basic (first-level) themes based on their main content. Thereafter the basic themes were condensed into a smaller set of second-level themes, where related basic themes were grouped together. Further analysis into third-level themes was conducted but was considered not to add anything of value.

Finally, response options to the question about personal experiences of encounters with healthcare personnel were 'very positive', 'fairly positive', 'fairly negative', and 'very negative'. In the analysis they were dichotomised into positive and negative experiences of such encounters.

The results were analysed using Epi-Calc2000 and presented as odds ratios (OR) and proportions with 95% confidence intervals (CI). When testing the iceberg hypothesis, we used the Chi-2 test, with the significance level 0.05.

Of the sample of 1,500, 16 questionnaires were returned due to death or unknown address; altogether 992 participants (62.1%) returned a completed questionnaire (58% were women and 42% men). The median age was 49 years.

The study was approved by the Regional Research Ethics Committee in Stockholm, Dnr. 2008/439-31.

Results

Our analysis shows that 23 persons [2.7% (CI: 1.7-3.7)] have turned to the Patients' Advisory Committee with complaints about the quality of their encounters, while 159 [18.5% (CI: 15.9-21.1)] stated that they had had legitimate reasons to file a complaint but had chosen to not go through with them ($p<<0.001$). There was an association between type of general experience of healthcare and inclination to file a complaint [OR: 7 (CI: 4.7-10.3)]; see Table 1. We found no significant sex or age-related differences where complaints were concerned.

A majority of the respondents, 60.3% (CI: 56.2-64.4), stated that they had a mainly positive general experience of healthcare, 34% (CI: 29-39.6) had a negative general experience, and 5.5% (CI: 0-11.8) had no experience of healthcare. Of the respondents with a positive general experience of healthcare, 99.5% (CI: 99-100) stated that their personal encounters with healthcare personnel had been positive. Of those who had a negative general experience, 19.5% (CI:15.1-23.9) reported personal experiences of negative encounters. Comparing the two groups, we found a rather strong correlation [OR: 44.2 (CI: 13.7-142.3)].

We also found a strong correlation between a general negative experience and low trust in healthcare on the one hand and a general positive experience and high trust on the other [OR: 21 (CI: 11.1-40.3). Of those who had reasons to file a complaint but did not do so, one-third reported that they had low trust in healthcare. This can be compared to those who had no reason for filing a complaint; nine out of ten had high trust in healthcare ($p<<0.001$); Table 2.

Respondents stating that they had had reason to file a complaint regarding negative encounters with healthcare personnel but abstained were asked to comment why they abstained. Input was received from 140 respondents. 17 distinct first-level themes were identified, and from these five second-level themes emerged: 'weakness', 'futility', 'lack of knowledge', 'mercifulness', and 'other action taken'. The most common responses (first-level themes) were 'I did not have the strength', 'I did not know where to turn', and 'It makes no difference anyway'. Other reasons stated were, for example, that it was too difficult and that the respondent was afraid of the consequences; see Table 3.

Discussion

Comparing the number of respondents who have filed a complaint with the number who have not but who think they had legitimate reasons to do so, we found a significant difference,

indicating that the complaints filed show only the tip of an iceberg. The ratio between filed complaints and non-reported complaints that, according to the respondents, would qualify for a formal complaint was approximately 1:7 in the survey population. Among those with a general negative experience of healthcare, it was approximately 1:8.

In the total study sample, almost all participants had had experience of healthcare – only fifty participants had not. We found a strong correlation between a positive/negative general experience of healthcare and personal experiences of positive/negative encounters with healthcare personnel. These findings might indicate that the respondents do not clearly distinguish between medical maltreatment and negative encounters, or that these experiences interact; they are both important for the impression and assessment of healthcare services.

Other studies have indicated that negative encounters might become a threat to patient safety since they affect communication and patient behaviour [12-14]. Earlier studies have also indicated that patients who have been received in a hostile, rude, or otherwise negative manner are more predisposed to go through with malpractice claims [6, 15]. Our study shows that a larger percentage of those with a negative general experience of healthcare file complaints, compared to those with a positive general experience.

The encounter's effect on trust

Not surprisingly, those with a negative general experience of healthcare who had filed a complaint or had had reasons for doing so reported lower trust in healthcare at the time of the survey, compared to those with a positive general experience who had not filed a complaint and had had no reason for doing so. A large proportion of the latter group had high trust in healthcare. Trust seems to be important for several reasons, for example for concordance and ultimately for patient safety [14,16]. If trust in healthcare is jeopardised by negative encounters, it seems important also to examine more carefully the bottom of the iceberg, i.e. to study those who do not file complaints.

Reasons for not complaining

Weakness, perceived futility, and lack of knowledge about how to complain (or even that there was such an option) were second-level themes that covered most of the reported reasons for not having filed a formal complaint. Many of the most frequent reasons have in common that the respondents felt that the obstacles were too great or that it required more strength than they could muster. Quite a few express the belief that reporting adverse events is futile, implying distrust regarding either the ability or the willingness of healthcare to actually take

notice of and learn from the complaints. Furthermore, some respondents chose not to complain due to fear of reprimands, such as receiving worse care or having their treatment withdrawn – an alarming result that also implies a considerable lack of trust among some of the respondents.

Improvements of the reporting system

These responses identify the main barriers to receiving input via formal complaints. The obstacles prevent learning about complaints and are therefore liable to have negative effects on the development of healthcare services and prevention of future adverse events. The responses also indicate that if the healthcare system wants this kind of input, it needs to offer patients more support. Better provision of information seems to be part of the solution, since some respondents were not even aware that they could file a formal complaint or did not know how to do it. One can also conclude from the responses that discontented patients might need more hands-on active support in getting their complaints filed.

Validity

There was no limit in time regarding which events respondents might consider and refer to. This means that our results cannot be compared with official reports presenting annual complaint rates. For this reason we have not focused on comparisons with earlier research but on relative associations within the present data and the manifest reasons for not filing complaints.

Conclusions

The present Swedish study indicates that healthcare complaints filed regarding encounters reveal only the tip of an iceberg. Complaints seem to be considerably under-reported, especially among those with a negative general experience of healthcare. In order to develop and improve the quality of healthcare encounters, and services, by assuring critical feedback, it is important that healthcare providers offer more information and support to patients who want to make complaints. Since differences in healthcare systems and ways to handle complaints might affect the tendency to file complaints, and the difficulty to do so, it is not clear to what extent these findings are generalizable to other countries. Further research is needed.

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Competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: The study was partly funded by Stockholm County Council. SCC had no influence over the study. Apart from this, we have had no financial relationships with any organisation that might have an interest in the submitted work in the previous 3 years, and no other relationships or activities that could appear to have influenced the submitted work.

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Contribution statement

Maja Wessel is the main author of the present paper and took a leading part in its conception and design, statistical analysis, interpretation of the results, and writing of the paper.

Niels Lynöe contributed with the original idea for the present study, took part in its conception and design, participated in the statistical analysis, and contributed substantially to the interpretation of the results and revision of the manuscript.

Niklas Juth contributed to the conception and design of the study, and has critically revised the manuscript.

Gert Helgesson contributed substantially to the conception and design of the study and to the interpretation of the results. He has taken a leading role in writing the paper.

Data sharing statement

There is no additional data available

Table 1. The table shows the participants' tendency to complain in relation to different general experiences of healthcare. The results are presented as proportions with a 95% confidence interval. Those who had no experiences of healthcare (n=50) are excluded from the presentation. The internal drop-out rate for responding to the combinations of these questions was 75 or 7.6%.

General experience of healthcare:	Filed a complaint % (CI)	Had reasons to complain but abstained % (CI)
Positive (n=553)	1.5% (0.5-2.5)	7.8% (5.6-10)
Negative (n=314)	4.8% (2.4-7.2)	37.3% (31.9-42.7)
All (n=867)	2.7% (1.7-3.7)	18.5% (15.9-21.1)
Missing: (n=5)		

Table 2. The table displays the proportions (with a 95% confidence interval) of the respondents who had high trust in healthcare in relation to whether they *had filed a complaint* to the Patients' Advisory Board, whether *they had had reasons for filing a complaint*, and their *general experience* of healthcare. Those who had no experiences of healthcare (n=50) are excluded from the presentation. The internal drop-out rate for responding to the combinations of these questions ranged between 76 and 79; on average 7.8%.

	High trust
Never complained (n=843)	87% (84.7-89.3)
Actually complained (n=23)	60.9% (41-80.8)
Missing (n=6)	
No reasons for complaining (n=703)	90.9% (88.8-93)
Reasons for complaining but abstained (n=163)	66.7% (59.5-73.9)
Missing (n=6)	
Positive experiences of healthcare (n=551)	97.6% (96.3-98.9)
Negative experiences of healthcare (n=312)	66.3% (61.1-71.5)
Missing (n=9)	

Table 3. Reasons for not filing official complaints to the Patients' Advisory Committee. Number of respondents=159.

first-level themes	second-level themes
I did not have the strength (n=39) I was afraid of the consequences (n=8) I do not like to complain (n=3) I did not want to relive the trauma (n=1) I was not the closest relative (n=1)	Weakness
It makes no difference anyway (n=17) I had other priorities (n=14) It was too difficult (n=13) I did not have time to do it (n=8) The damage was already done (n=5)	Futility
I did not know where to turn (n=18) I did not know/think I had that option (n=4)	Lack of knowledge
I did not complain out of consideration for the accused person (n=3) I did not complain due to collegial relations (n=2)	Mercifulness
I complained directly at the hospital (n=4)	Other action taken
No reason stated (n=19)	

Appendix: Questions asked in the survey

1. What is your general experience of Swedish healthcare as a *patient*?

□ Mainly positive □ Mainly negative □ Both positive and negative

□ I have no experience of Swedish healthcare as a patient

2. What is your general experience of Swedish healthcare as a *relative or guardian of a patient*?

□ Mainly positive □ Mainly negative □ Both positive and negative

□ I have no experience of Swedish healthcare as a relative or guardian of a patient

3. How would you describe your degree of trust in Swedish healthcare?

□ Very high □ Fairly high □ Fairly low □ Very low

4. What is your experience of encounters in Swedish healthcare in general?

□ Very good □ Fairly good □ Fairly bad □ Very bad

5. Is your trust in healthcare affected by the quality of encounters?

□ No □ To a little extent □ To some extent □ To a great extent

6. Have you ever filed a formal complaint regarding a healthcare encounter at the Patients' Advisory Board (PaN)?

□ Yes □ No

7. Have you had reason to complain to PaN but refrained from doing so?

□ Yes □ No

If yes, what was your reason for not complaining?

(8) Do you have experience of negative encounters as a *patient*?

□ Yes □ No

If yes, please provide a description of the event(s)

(9) Do you have experience of negative encounters as a *relative or guardian of a patient?*

□ Yes □ No

If yes, please provide a description of the event(s)

The tip of an iceberg? A cross-sectional study of the general publics' experiences of reporting healthcare complaints.

Abstract

Introduction: Learning from patient complaints is important for the development of healthcare. However, there are indications that complaints of adverse events in healthcare are underreported.

Aims: To investigate the hypothesis that complaints are underreported and to identify barriers to filing complaints of adverse events related to encounters with healthcare personnel.

Methods: A questionnaire was sent to a random sample of 1,500 individuals in the County of Stockholm, asking whether or not they had filed complaints of adverse events. Respondents were also asked whether they had had reasons for doing so but abstained, and if so their reasons for not complaining. We also asked about participants' general experience of and trust in healthcare.

Results: The response rate was 62.1%. Official complaints have been filed by 23 respondents (2.7% CI: 1.7-3.7), while 159 (18.5% CI: 15.9-21.1) stated that they have had legitimate reasons to file a complaint but had abstained ($p<0.001$). The degree of underreporting was greater among patients with a general negative experience of healthcare 37.3% CI: 31.9-42.7) compared to those with a general positive experience (4.8% CI: 2.4-7.2). ~~Respondents with a general negative experience also had lower trust in healthcare.~~ The reasons given for abstaining were, among others, 'I did not have the strength', 'I did not know where to turn', and 'It makes no difference anyway'. Respondents with a general negative experience also had lower trust in healthcare.

Conclusion: We found a considerable discrepancy between the actual complaint rate and the number of respondents stating that they have had reasons to complain but have abstained. This indicates that in official reports of complaints we only see 'the tip of an iceberg'.

Introduction

Whereas healthcare by and large is doing its best to improve and promote health, adverse events and complaints occur. Fortunately such incidents are rather unusual. In Stockholm, the capital of Sweden, there are each year around 15 million healthcare visits, but only about 8,500 registered complaints, including all internal incident reports as well as complaints from patients. However, the number of complaints is steadily increasing [1, 2].

Patients file their reports with the National Board of Health and Welfare (Socialstyrelsen) or with a Patients' Advisory Committee (Patientnämnd). The latter authority also administers complaints about patients' experiences of negative healthcare encounters, i.e., complaints concerning how the patient is received by healthcare employees. The main types of complaints addressed to Patients' Advisory Committees concern medical maltreatment (42%), availability (12%), encounters (12%), and monetary issues (7%) [2], but the complaints often reveal combinations of reasons for complaining. As an example, a snapshot review showed that around thirty per cent of the complaints registered as concerning maltreatment also brought up negative encounters [3].

The general aim of authorities' administration of complaints is to improve patient safety and efficiency in healthcare. The patients' motives for filing a complaint might, however, differ; they may also concern a wish for an explanation, someone to be accountable for what happened, financial compensation, or receiving an apology [4-6].

We have found no systematic reviews of barriers to complaints regarding negative healthcare encounters focusing on patients. It is, however, well reported that complaints from patients as well as hospital staff regarding adverse events tend to be widely underreported [7-10]. One may wonder whether the same is true for negative encounters. In this paper, based on a questionnaire survey, we test the hypothesis that patients' tendency to file complaints regarding negative encounters in relation to the number of incidents perceived to be worthy of a complaint is underreported, disclosing only the tip of an iceberg. We also investigate whether trust in and experiences of healthcare are related.

Material and methods

A questionnaire concerning experience of healthcare, negative encounters, trust, and complaints to the Patients' Advisory Committee was distributed to a randomly selected study population (n=1500; 50% women and 50% men, aged 18-99 years) registered by the Swedish National Tax Board as living in the County of Stockholm in April, 2008. The questionnaire

included seven questions with fixed response alternatives and space for comments. In addition, it contained two open-ended questions regarding the respondents' personal experiences of negative healthcare encounters, as patients and as relatives. The focus of the present analysis is on the questions regarding respondents' general experience of Swedish healthcare, their trust in healthcare, whether they have filed a formal complaint with the Patients' Advisory Committee, whether they have had reason to file a complaint but have refrained from doing so, and if so why, and how they perceive their personal experience of encounters with personnel in the healthcare system.

Response options for the question regarding respondents' general experience of Swedish healthcare were 'mainly positive', 'mainly negative', 'both positive and negative' (i.e., a mixed experience not clearly pointing in any direction), and 'no experience'. Since there were no significant differences between those who had a mainly negative general experience and those who had a both positive and negative general experience, we have merged these into one group in the analysis ('negative general experience'). For estimation of the respondents' degree of trust in healthcare, they were given four response alternatives ranging from 'very high' to 'very low' (in the analysis the responses were dichotomised into 'high trust' and 'low trust'). Response options regarding having filed or having had reason to file a complaint were 'yes' and 'no'.

As a follow-up question we asked for the underlying reasons for not filing a complaint when having had reasons to do so. The responses were subjected to qualitative content analysis [11]. The reasons presented in the responses were first identified and classified into basic (first-level) themes ~~classified in units~~ based on their main content. Thereafter the basic themes were condensed into a smaller set of second-level themes, where related basic themes were grouped together. Further analysis into third-level themes was conducted but was considered not to add anything of value.

Finally, response options to the question about personal experiences of encounters with healthcare personnel were 'very positive', 'fairly positive', '~~rather~~ fairly negative', and 'very negative'. In the analysis they were dichotomised into positive and negative experiences of such encounters.

The results were analysed using Epi-Calc2000 and presented as odds ratios (OR) and proportions with 95% confidence intervals (CI). When testing the iceberg hypothesis, we used the Chi-2 test, with~~,~~ the significance level 0.05~~ was chosen~~.

Of the sample of 1,500, 16 questionnaires were returned due to death or unknown address~~ the questionnaire was successfully sent to~~1,484~~ persons were eligible~~;~~-~~ altogether 992

participants (62.1%) returned a completed questionnaire (58% were women and 42% men). The median age was 49 years.

The study was approved by the Regional Research Ethics Committee, Dnr. 2008/439-31.

Results

Our analysis shows that 23 persons [2.7% (CI: 1.7-3.7)] have turned to the Patients' Advisory Committee with complaints about the quality of their encounters, while 159 [18.5% (CI: 15.9-21.1)] stated that they had had legitimate reasons to file a complaint but had chosen to not go through with them (p<<0.001~~Chi-2=114, df=1~~). There was an ~~strong~~ association between type of general experience of healthcare and inclination to file a complaint [OR: 7 (CI: 4.7-10.3)]; see Table 1. We found no significant sex or age-related differences where complaints were concerned.

A majority of the respondents, 60.3% (CI: 56.2-64.4), stated that they had a mainly positive general experience of healthcare, 34% (CI: 29-39.6) had a negative general experience, and 5.5% (CI: 0-11.8) had no experience of healthcare. Of the respondents with a positive general experience of healthcare, 99.5% (CI: 99-100) stated that their personal encounters with healthcare personnel had been positive. Of those who had a negative general experience, 19.5% (CI: 15.1-23.9) reported personal experiences of negative encounters. Comparing the two groups, we found a rather strong correlation [OR: 44.2 (CI: 13.7-142.3)].

We also found a strong correlation between a general negative experience and low trust in healthcare on the one hand and a general positive experience and high trust on the other [OR: 21 (CI: 11.1-40.3). Of those who had reasons to file a complaint but did not do so, one-third reported that they had low trust in healthcare. This can be compared to those who had no reason for filing a complaint; nine out of ten had high trust in healthcare (p<<0.001); ~~see~~ Table 2.

Respondents stating that they had had reason to file a complaint regarding negative encounters with healthcare personnel but abstained were asked to comment why they abstained. Input was received from 140 respondents. 17 distinct first-level themes were identified, and from these five second-level themes emerged: 'weakness', 'futility', 'lack of knowledge', 'mercifulness', and 'other action taken'. The most common responses (first-level themes) were 'I did not have the strength', 'I did not know where to turn', and 'It makes no difference anyway'. Other reasons stated were, for example, that it was too difficult and that the respondent was afraid of the consequences; see Table 3.

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Comparing the number of respondents who have filed a complaint with the number who have not but who think they had legitimate reasons to do so, we found a significant difference, indicating that the complaints filed show~~s~~ only the tip of an iceberg. The ratio between filed complaints ~~filed~~ and non-reported ~~events~~ complaints that, according to the respondents, would qualify for a formal complaint was approximately 1:7 in the survey population. Among those with a general negative experience of healthcare, it was approximately 1:8.

In the total study sample, almost all participants had had experience of healthcare – only fifty participants had not. We found a strong correlation between a positive/negative general experience of healthcare and personal experiences of positive/negative encounters with healthcare personnel. These findings might indicate that the respondents do not clearly distinguish between medical maltreatment and negative encounters, or that these experiences interact; they are both important for the impression and assessment of healthcare services.

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Not surprisingly, those with a negative general experience of healthcare who had filed a complaint or had had reasons for doing so reported lower trust in healthcare at the time of the survey, compared to those with a positive general experience who had not filed a complaint and had had no reason for doing so. A large proportion of the latter group had high trust in healthcare. Trust seems to be important for several reasons, for example for concordance and ultimately for patient safety [~~13~~14,~~15~~16]. If trust in healthcare is jeopardised by negative encounters, it seems important also to examine more carefully the bottom of the iceberg, i.e. to study those who do not file complaints.

Reasons for not complaining

Weakness, perceived futility, and lack of knowledge about how to complain (or even that there was such an option) were second-level themes that covered most of the reported reasons

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Conclusions

The present Swedish study indicates that healthcare complaints filed regarding encounters reveal only the tip of an iceberg. Complaints seem to be considerably under-reported, especially among those with a negative general experience of healthcare~~.~~. ~~The commonest barriers to complaints are that patients do not find the strength to make them, do not know where to turn, or do not find it worthwhile since they do not believe it will make any difference.~~ In order to develop and improve the quality of healthcare encounters, ~~as well~~

asand healthcare services, by assuring critical feedback, it is of great importanceimportant that healthcare providers offer more information and support to patients who wants to make complaints. Since negative differences in healthcare systems and ways to handle complaints might affect the tendency to file complaints, and the difficulty to do so, it is not clear to what extent these findings are generalizable to other countries. Further research is needed.encounters also seem to influence trust in healthcare, we suggest that those who do not file complaints should also be studied more carefully.

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Table 2. The table displays the proportions (with a 95% confidence interval) of the respondents who had high trust in healthcare in relation to whether they *had filed a complaint* to the Patients' Advisory Board, whether *they had had reasons for filing a complaint*, and their *general experience* of healthcare. Those who had no experiences of healthcare (n=50) are excluded from the presentation. The internal drop-out rate for responding to the combinations of these questions ranged between 76 and 79; on average 7.8%.

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Actually complained (n=23)	60.9% (41-80.8)
Missing (n=6)	
No reasons for complaining (n=703)	90.9% (88.8-93)
Reasons for complaining but abstained (n=163)	66.7% (59.5-73.9)
Missing (n=6)	
Positive experiences of healthcare (n=551)	97.6% (96.3-98.9)
Negative experiences of healthcare (n=312)	66.3% (61.1-71.5)
Missing (n=9)	

Table 3. Reasons for not filing official complaints to the Patients' Advisory Committee.

Number of respondents=159.

Comment [GH1]: First-level themes re-ordered and second-level themes added.

first-level themes	second-level themes
I did not have the strength (n=39) I was afraid of the consequences (n=8) I do not like to complain (n=3) I did not want to relive the trauma (n=1) I was not the closest relative (n=1)	Weakness
It makes no difference anyway (n=17) I had other priorities (n=14) It was too difficult (n=13) I did not have time to do it (n=8) The damage was already done (n=5)	Futility
I did not know where to turn (n=18) I did not know/think I had that option (n=4)	Lack of knowledge
I did not complain out of consideration for the accused person (n=3) I did not complain due to collegial relations (n=2)	Mercifulness
I complained directly at the hospital (n=4)	Other action taken
No reason stated (n=19)	

Appendix: Questions in the survey

Comment [GH2]: Added

1. What is your general experience of Swedish healthcare as a *patient*?

□ Mainly positive □ Mainly negative □ Both positive and negative

□ I have no experience of Swedish healthcare as a patient

2. What is your general experience of Swedish healthcare as a *relative or guardian of a patient*?

□ Mainly positive □ Mainly negative □ Both positive and negative

□ I have no experience of Swedish healthcare as a relative or guardian of a patient

3. How would you describe your degree of trust in Swedish healthcare?

□ Very high □ Fairly high □ Fairly low □ Very low

4. What is your experience of encounters in Swedish healthcare in general?

□ Very good □ Fairly good □ Fairly bad □ Very bad

5. Is your trust in healthcare affected by the quality of encounters?

□ No □ To a little extent □ To some extent □ To a great extent

6. Have you ever filed a formal complaint regarding a healthcare encounter at the Patients' Advisory Board (PaN)?

□ Yes □ No

7. Have you had reason to complain to PaN but refrained from doing so?

□ Yes □ No

If yes, what was your reason for not complaining?

(8) Do you have experience of negative encounters as a *patient*?

□ Yes □ No

If yes, please provide a description of the event(s)

(9) Do you have experience of negative encounters as a *relative or guardian of a patient?*

□ Yes □ No

If yes, please provide a description of the event(s)

Correction

Wessel M, Lynöe N, Juth N, *et al*. The tip of an iceberg? A cross-sectional study of the general publics' experiences of reporting healthcare complaints. *BMJ Open* 2012:**2**:e000489.

There are two misstatements in this article:

Page 1: Abstract (Results): "The degree of underreporting was greater among patients with a general negative experience of healthcare (37.3% CI: 31.9–42.7) compared with those with a general positive experience **(4.8% CI: 2.4–7.2).**"

The proportion **'4.8% CI: 2.4–7.2'** should be '**7.8% (5.6–10)'.**

Page 2: Material and methods: "Of the sample of 1500, 16 questionnaires were returned due to death or unknown address; altogether **992** participants (62.1%) returned a completed questionnaire…" The correct number of participants is 922.

BMJ Open 2013;**3**:e000489corr1. doi:10.1136/bmjopen-2011-000489corr1