



Patient narratives of surgical site infection: implications for practice

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SUMMARY

Background: Exploring patients' experiences has been used widely within healthcare to improve clinical service delivery. To date there has been minimal patient input of this kind into aspects of surgical site infection (SSI), such as surveillance or prevention interventions.

Aim: To obtain information from patients' experiences of SSIs to improve clinical practice.

Methods: Narrative interviews with 17 patients with SSIs (four deep, 12 organ space and one superficial) from three hospitals in England were conducted followed by thematic content analysis.

Results: Patients lacked overall awareness, concern and understanding of SSIs. Seven patients did not know that they had SSIs and, judging from patients' accounts, staff may have contributed to the lack of awareness by not informing patients of SSIs or downplaying their existence. The use of primary care resources was considerable and six of the patients were absent from work for two to four months.

Conclusions: SSIs have a low profile among patients which, if it were raised, could increase compliance with preventive interventions. This study confirms the appropriateness of using patient self-assessment post-discharge surveillance questionnaires to identify SSI symptoms, and highlights the need to identify total costings including to primary care, patients and the economy.

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Introduction

To date, surgical site infection (SSI) prevention practices and policy have been underpinned predominantly by laboratory studies, clinical trials and epidemiological studies. Qualitative, patient narrative research has not been used within this field, though it has been used widely in other areas of healthcare to improve service delivery.¹ Exploring patients' experiences can provide new insights and is especially relevant

to SSI as patients play an active role in managing surgical sites. Patients are responsible for reducing personal risk factors for acquiring an SSI, such as washing before surgery or smoking cessation, and are also responsible for caring for their wounds postoperatively and assisting with post-discharge surveillance (PDS).

Consequently, the purpose of this study was to elicit narratives from patients with SSIs to obtain information which will inform development of practice, guidelines or policy.

Methods

This qualitative study using narrative-based patient interviews was conducted in three hospitals in England. Approval

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was granted from the local National Health Service ethics committee.

Over a period of five months in 2011–2012, 60 patients, identified through the hospitals' surgical site surveillance programmes as having had an SSI during the previous six months, met the study's inclusion criteria, and were invited to participate in the study.

The surveillance programmes included all patients having colorectal, cardiac, orthopaedic joint surgery, or caesarean sections. SSIs were identified through direct patient contact by surveillance staff using the recommended SSI checklist.² SSI definitions and classifications were taken from the Surgical Site Infection Surveillance Service (SSISS) protocol.²

Participants were included if they were:

- identified as having an SSI (all classifications);
- an inpatient or discharged;
- able to provide informed consent;
- aged >18 years.

After written consent had been obtained, interviews were conducted by a researcher in the patient's own home, the hospital or the university. All interviews were carried out by the same interviewer. The interviews lasted around 1 h and were audiotape-recorded.

Narrative interviews were used to obtain participants' experiences of having an SSI. These are predominately used to elicit data on significant events. Being unstructured, they allow participants to focus on issues which are important to them rather than being led by the researcher.³ Participants were given an initial trigger question, 'Tell me what happened with your wound', to start the discussion and were then probed if necessary to provide more detail.

The first three interviews acted as pilot interviews with the research team reviewing the transcripts and confirming the interview technique before the remaining interviews took place. Data were transcribed and analysed after each interview and participants were recruited until data saturation was reached and no new themes emerged, yielding a sample size consistent with that of other exploratory interview research in healthcare.⁴

Thematic content data analysis was carried out independently by three researchers.⁵ Transcriptions were entered on to the first column of an Excel spreadsheet. Blocks of text were then paraphrased into short summaries which were entered into a second column. The short summaries were then further reduced into keywords or phrases in a third column. The decision-making process was made explicit through this process.⁶ There were no major discrepancies among the researchers and minor discrepancies were discussed and resolved. Remaining team members reviewed the spreadsheets and confirmed the generation of the themes. The themes identified and presented in this paper were supported unequivocally by the researchers.

Results

Of the 60 patients who met the study criteria and were invited to take part, 17 agreed to be interviewed (Table I). Sixteen patients had been discharged from acute care and one patient was still a hospital inpatient.

The following themes were generated from the data:

- patients were not concerned about SSIS prior to surgery;
- patients failed to recognize when they developed an SSIS;
- staff downplayed the existence of SSIS;

Table I
Demographic and other details of the 17 participants

Participant	Sex	Age range (years)	Surgical category	SSI classification	Hospital length of stay (admission + readmission)	No. of district nurse visits in primary care	Time off work (at the time of interview)
1	M	60–69	Orthopaedic	Organ space	3 days + 5 weeks	None	Retired
2	M	60–69	Cardiac	Organ space	3 weeks + 3 weeks	15	Retired
3	F	30–39	Caesarean section	Uterine	1 week	None	Maternity leave
4	M	60–69	Colorectal	Organ space	8 weeks	2	Retired
5	F	30–39	Caesarean section	Uterine	3 days	None	Maternity leave
6	M	80–89	Colorectal	Deep	4 weeks	32	Retired
7	M	50–59	Colorectal	Organ space	4 weeks	16 (ongoing)	2 months (ongoing)
8	F	40–49	Cardiac	Organ space	3 weeks + 1 week	None	4 months (ongoing)
9	F	60–69	Orthopaedic	Superficial	4 days	None	Retired
10	M	70–79	Colorectal	Deep	6 weeks	38	2 months (ongoing)
11	M	40–49	Cardiac	Organ space	5 days + readmission	8	2.5 months (ongoing)
12	F	60–69	Colorectal	Organ space	2 weeks + 2 weeks	25	4 months (ongoing)
13	F	60–69	Colorectal	Deep	5 days	20	Retired
14	M	50–59	Colorectal	Organ space	2 weeks	None	Retired
15	F	80–89	Orthopaedic	Organ space	4 days + 3 months	Inpatient	Retired
16	F	60–69	Orthopaedic	Organ space	1 week + 2 weeks	None	2.5 months (ongoing)
17	M	60–69	Colorectal	Deep	2 weeks	None	Retired

SSI, surgical site infection.

- patients assumed responsibility for SSIs;
- financial costs to primary care, the patient and the wider community

Patients and concern about SSIs

Almost all of the participants were not concerned about the possibility of developing a wound infection following their surgery:

The thought of an infection never even crossed my mind. (participant 4)

It never entered my head. (participant 2)

Only two participants were worried about developing SSIs. One participant had developed an SSI following previous surgery and the other participant was related to someone who had developed an SSI.

I did worry about it, especially having one the first time. I did worry what if I am going to get another one? I hoped I wouldn't but unfortunately I did. (participant 5)

Although the focus of the interviews was SSIs, patients frequently referred to meticillin-resistant *Staphylococcus aureus* (MRSA) in conversation. Both patients (and perhaps some staff) viewed SSIs differently from MRSA which they perceived as a more serious infection. Unlike SSIs, patients were concerned about acquiring MRSA when they came into hospital for their surgery.

I did mention to the surgeon, I did say, well how are things like the MRSA statistics at the moment? (participant 12)

It was just one of those things I think when you get an infection. It's not like MRSA or anything like that. (participant 3)

Failure to recognize SSIs

Not only were patients not concerned about developing SSIs, when they did develop SSIs they failed to recognize that they were SSIs or misdiagnosed their symptoms. Participants thought their infections were simple rashes (participant 9), allergic reactions to antiseptic washes (participant 5), part of the normal healing process (participants 6, 13, 16) and one participant thought he was having a heart attack (participant 1).

Seven patients were not aware that they had an infection at all and denied having SSIs:

I didn't realise I had an infection, when I got your letter [to take part in the study] I thought where is the infection? There may have been one, but [the hospital] never told me about it. (participant 10)

Well, I wasn't aware I got an infection. Do you call this an infection? I don't think it's an infection. (participant 6)

I have a big rash on my knee – they gave me some antibiotics and that cleared itself then there was some inflammation so she gave me more antibiotics. I don't know why I got the rash. [Interviewer – Did you have an infection?] No, just a rash. (participant 9)

This phenomenon of not recognizing SSIs first became apparent during the recruitment phase of the study, when a patient eligible for recruitment responded to the invitation saying he could not take part as he did not have an SSI. The hospital surveillance team confirmed that this patient did indeed have an SSI as diagnosed according to the Surgical Site Infection Surveillance Service criteria, resulting in surgical reopening of the wound and three cycles of antibiotics.²

An interesting perception held by three patients was that the SSI clinical symptoms they experienced and the courses of antibiotics were part of the normal healing process following surgery.

I was on an antibiotic drip but I just assumed that was normal after an operation. (participant 6)

They kept me on antibiotics as they do normally all the time I was in [the hospital]. (participant 13)

Staff and SSIs

Seven participants said hospital staff appeared to be reluctant to provide information about SSIs or minimized the seriousness of infections.

I wasn't told I had an infection until after I was discharged the second time I went in. (participant 3)

Nobody said to me you have got an infection, ever. (participant 10)

One participant who was a nurse said:

I asked the nurse what the result from the swab was. She looked at my notes and said it was a coliform bacillus. Later she came back and said the medical staff had told her to tell me that my wound was only colonized with coliform bacillus not infected with it. ... Doctors don't like admitting to infections. (participant 8)

Again, the comparison with MRSA was made, with staff stating that SSIs are less important.

When [the nurse] told me about the infection she said it's nothing to worry about, it's not MRSA. (participant 14)

One participant who developed an organ space infection four months after having a knee replacement told the interviewer she did not have an infection and said she had to be readmitted for further surgery because 'apparently the metal work deteriorated and they don't know why' (participant 15).

Some participants also reported that staff minimized the severity of the problem or had stressed the rarity of such adverse outcomes. One consultant told participant 1 that he was the first of his patients ever to develop SSI: 'You've broken my record, you're my first patient ever to get one of these'. When participant 4 asked his surgeon why he had acquired an SSI he was told:

Whether there's an element of human error or whether there's a body malfunction or whatever, it happens to 15–20% of the people having this surgery, and we have no control over it happening. (participant 4)

Assuming responsibility for SSIs

Adding to the evidence that patients are uninformed about SSI were their perceptions about what caused SSIs. Five patients believed it was their own fault either through an act of omission or because they were simply 'prone' (participant 4) to infections. For example, one participant thought her sternal wound infection developed as a result of sleeping on her back rather than on her side (participant 2). Another participant assumed her infection was a result of failing to wear 'maternity pants' (participant 5). Other participants quoted the following reasons:

I did kind of worry thinking maybe it's my fault. What have I done wrong? Was I not cleaning [the wound] enough? (participant 3)

It must be me because when I had a hysterectomy a few years before, I got peritonitis, so I think it's just me. (participant 16)

A further six participants said acquiring an SSI was down to chance or 'the luck of the draw' and in some cases explicitly discounted the possibility that it might have been the fault of the healthcare system.

Infection ... you either get it or you don't. I was just unlucky. (participant 11)

I suppose it's just bad luck really that that happened. (participant 12)

Only one patient thought that his SSI may have been caused by the hospital.

I don't know, probably dirty instruments in the theatre, I don't know, just uncleanliness. When you are in the hospital it's entirely their problem to stop you getting infections. You are in their hands, they should use whatever they need to use to stop germs. (participant 14)

Patients often drew a distinction between SSIs and MRSA, believing SSIs to be a different kind of problem from MRSA. Patients identified some of the causes of MRSA as being 'dirty hospitals' (participant 14), and a need for hand hygiene (participant 17). Although the patients attributed acquiring an SSI to luck, they held the hospital responsible for MRSA.

I would be very cross [if I contracted MRSA] because I felt it should be a preventable disease. (participant 12)

Patients blamed the hospital for MRSA infections as they believed that MRSA infections were caused by hospital negligence. By contrast, they did not blame the hospital for SSIs as they saw these as a different kind of problem which they thought was caused by chance. The implication is that if patients were aware that many SSIs are preventable they would hold hospitals responsible for these also.

If I had thought that [the SSI] happened because of a reason, somebody had slipped up somewhere, I would have kicked up. (participant 16)

Financial costs

During the interviews patients referred to the amount of time they spent in hospital, the visits from district nurses after

discharge, and those who were in employment talked about being off work (Table I). Six of the patients had been readmitted, and even though patients had been in hospital for a considerable time, they still required substantial treatment in primary care. Seven patients had between eight and 32 visits from a district nurse.

Regarding the financial impact of the SSI to the patient, there were mixed views. Nine participants had retired and felt that the additional costs to themselves were minimal and mainly incurred through travelling to the hospital and parking charges, though one participant who lived 15 miles from the hospital claimed the additional petrol consumption was 'costing a fortune' (participant 11). However, six employed participants felt the cost of the infection more acutely. At the time of the interviews, employed participants had been absent from work between two and four months and as yet none had returned to work.

Oh God, it's cost me an arm and a leg, I was self-employed earning £2000 a month. (participant 10)

My husband had to go back to work or we would have lost a week's wages which would have been a big chunk from the mortgage. (participant 5)

In addition to this, two participants stated that their partners had taken time off work to look after them.

My husband had quite a lot of time off work because of it, to look after me. (participant 8)

Whereas it is not possible to use these findings as a basis for identifying SSI costs to working patients or the wider economy, they give an indication that the impact could be considerable.

Discussion

This study found that patients sometimes misdiagnosed SSI symptoms and failed to recognize SSIs. This has implications for PDS of SSIs. Inpatient SSI surveillance has been routine practice in the USA and Europe for the past decade and more recently PDS has begun to be implemented. Collecting post-discharge data is important as 13–80% of SSIs present after discharge.⁷

Post-discharge surveillance data can be collected at outpatient clinics or in primary care by surgeons, general practitioners, and surveillance teams or by patients themselves using self-assessment questionnaires. A self-assessment questionnaire is provided by SSISS in England.² This questionnaire lists SSI symptoms which are essential to diagnosing an SSI and patients are required to place a tick beside symptoms they are experiencing. This study confirms the value of this style of questioning as patients in this study showed that they were able to recognize SSI symptoms. However, questions that require patients to make a diagnosis would not be reliable as patients in this study demonstrated that they misdiagnosed SSI symptoms and failed to recognize SSIs. The self-assessment questionnaire produced by SSISS begins by asking patients if their wound healed without problems. This particular question may provide unreliable data as patients in this study were unsure what constituted normal wound healing.

The findings from this study raise concerns over patients who do not return self-assessment questionnaires. It is assumed that non-responders are unlikely to have SSIs.

However, this study questions such an assumption, finding that patients are unaware when they have SSIs. It is suggested that additional follow-up methods should be used to contact patients who do not return questionnaires, such as telephone calls.

Overall, participants in this study were poorly informed regarding SSIs; participants were unaware of SSIs, did not recognize SSIs, and did not know the causes of, or the risk factors for, SSI. This may have been a result of the low public profile of SSI. Evidence for this is can be seen when the participants' perceptions of SSI were compared with their perceptions of MRSA.

Although MRSA can often be the causative organism for an SSI, participants appeared to view SSIs and MRSA as two distinct, unrelated infections. By contrast with their poor awareness of SSIs, all participants had heard of MRSA, were concerned about contracting it and knew the importance of cleaning and hand washing. Participants also believed that MRSA was caused by hospital negligence though most participants had no idea what caused SSIs.

Unlike the term 'SSI', the term 'MRSA' has a high profile among the general public and within hospital wards, having been frequently in media headlines, and the focus of several national hand-washing campaigns.^{8,9} Hospital staff in this study may also have contributed to participants' low awareness of SSIs as they appeared reluctant to discuss SSIs with patients and downplayed their existence, telling patients that SSIs were nothing to worry about.

One positive outcome, documented in the literature, of MRSA's high public profile is the increased compliance among patients with interventions to prevent MRSA.⁹ Compliance with interventions was also demonstrated in this study with participants talking about using antiseptic washes to prevent MRSA infections. This is potentially encouraging for the prevention of SSIs. If the profile of SSIs were raised among the general public and among hospital staff, then patient compliance with interventions to prevent or reduce SSIs, such as smoking cessation or wound care, should increase.

A considerable limitation of most studies which identify the costs of SSIs is that they focus on the direct costs to the hospital only, often excluding indirect hospital costs, costs to primary care, costs to patients and costs to the wider economy which can be greater.¹⁰ One Spanish study found that the healthcare cost of an SSI accounted for only one-tenth of the overall costs which rose to US\$97,000 when patient costs and wider economy costs were included, and that additional length of stay only identified 35% of hospital costs.¹¹ It is not possible to transfer the total cost of an SSI from the Spanish study to other countries because of differences in, for example, healthcare systems, production costs, cost of living and working age limits. However, it is necessary to identify total SSI costs to raise the profile of SSIs. One economic study states that costs are the key component of a successful infection control programme.¹¹ A systematic review of economic studies of SSIs found no studies from the UK which quantified the direct, indirect and intangible costs of SSIs in hospitals, primary care, to patients and the economy.¹⁰

This study did not set out to collect quantifiable data on costs but it has highlighted the use of primary care resources which are often overlooked. For example, each participant in this study received an average of nine district nurse visits at a cost of £78 per 1 h visit.¹²

This study also hinted at the cost to patients and their families through loss of earnings and the cost to the economy through loss of production, with all six of the patients who were in employment prior to surgery having extra time off work due to wounds which failed to heal.

The three hospitals were large hospitals within one geographical area in England and patients in other areas may hold different views. Staff were not interviewed to corroborate the patients' recollections and only 17 of 60 invited to participate did so.

In conclusion, this study confirmed the value of patient self-assessment using PDS to identify SSI symptoms but showed that non-responders cannot be ignored as patients do not realize when they have SSIs. It has already been demonstrated that a high public profile results in increased compliance with interventions such as with MRSA, and this study shows that SSIs have a low profile among patients and possibly also staff. The study also highlighted the costs to primary care, patients and the economy.

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Conflict of interest statement

None declared.

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