

# Patients' experiences of surgical site infection

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## Abstract

**T**he qualitative experience of having a surgical site infection (SSI) is often overlooked. The aim of this study was to present a description of how SSIs affect the lives of patients and their families. Seventeen former patients from three hospitals in England were interviewed to explore their experience of having an SSI. The interview data was transcribed and analysed into the following themes – horror stories, physical effects, psychological effects, effect on families, feelings of relief, not blaming the hospital, and lack of support after discharge. Numerous articles describe SSIs as being 'distressing' for patients. This study reveals the extent of the distress, with patients describing feeling 'utter despair' and 'wanting to die'. These symptoms continued for months after patients had been discharged from hospital.

## Introduction

Surgical site infections are relatively common, with 5% of surgical patients developing an SSI, although studies which include post-discharge follow up suggest much higher rates (Reilly et al 2006; Tanner et al, 2009; Leaper, 2010). There is extensive literature on this subject, which mainly focuses on interventions to reduce SSI, surveillance methods and the costs of SSI. Many articles refer in passing to the 'distress' caused to patients by SSIs (Wolcott et al, 2008; Hughes and Mardell, 2009; Ashby et al 2010), yet the effect of SSIs on patients has largely been ignored. A comprehensive literature search was undertaken to find qualitative studies of the patient experience of SSIs. A search of Medline, Cinahl, British Nursing Index, ASSIA, Scopus and Zetoc identified only one study which used a qualitative approach to explore the patient experience (Andersson et al, 2010). Andersson et al's study was conducted among 14 patients in Sweden and found that pain, isolation and insecurity were the patients' greatest concerns. Other studies of the patient experience of SSI take a quantitative approach often using quality of life score as an assessment tool (Whitehouse et al, 2002; Cahill et al, 2008). Quality of life assessments require patients to provide scores, usually from 1–4, in response to questions about aspects of daily living such as pain or mobility. Scores can then be compared against patients in a control group.

In a study of patients with orthopaedic joint replacements, Cahill et al (2008) found satisfaction, pain, stiffness and social function were statistically significantly worse among patients with infected joints. A similar study, also among orthopaedic surgery patients, found physical function and changes in role function were significantly impaired in patients with SSIs compared to patients without SSIs (Whitehouse et al, 2002).

However, this approach of reducing patients' experiences to a numerical score may depersonalise the experience, making empathy more difficult. The ability to see patients as people is important to hospital staff, especially operating room staff, who have little contact with patients after their surgery.

The aim of this study was to explore the effect of SSIs on patients using qualitative methods to provide an in-depth understanding of the lived experience of suffering an SSI.

## Methods

A qualitative study using unstructured interviews was considered to be the most appropriate design.

### Study setting

This study was conducted at a large trust in England comprising three acute hospitals. Patients who had developed SSIs were invited to participate in an interview to discuss their experiences. NHS ethical approval and NHS trust approval were granted for the study. Participant confidentiality was assured and all data were anonymised.

### The sample

The last 50 patients identified through the trust's SSI surveillance programme during the previous six months were sent an invitation pack which included a study information sheet, an invitation to participate in the study and a positive reply slip with a response paid envelope. Patients who replied to the invitation to participate and met the study criteria were recruited to the study. The inclusion criteria were that patients must be:

- identified as having a surgical site infection (any classification) in the previous six months
- an inpatient or has been discharged

**Table 1. Details of participants' SSIs**

Surgical category	SSI classification	Number
Orthopaedic	Deep or organ space	3
	Superficial	1
Large bowel	Deep or organ space	8
Cardiac	Deep or organ space	3
Caesarean section	Deep or organ space	2

- able to provide informed consent
- able to participate in an interview – has no speech or hearing impairment and speaks English
- over 18 years of age
- live within 20 miles of city centre

#### Interviews and analysis

The interview was unstructured and began by asking patients in an open-ended manner to talk about their surgery and their wounds. This allowed patients to provide an initial narrative, which was then followed up with targeted questions to elicit more depth (Wengraf, 2004). All interviews were carried out by one researcher. The first three interviews acted as pilot interviews and transcripts were reviewed by the research team to approve the process. Interviews lasted around one hour and were audio taped. Interviews were transcribed and thematic content analysis was used by three members of the research team to group the data into themes.

#### Findings

Seventeen patients responded to the invitation and agreed to be interviewed. Patient demographics are shown in Table 1. Sixteen patients had been discharged and one patient was a hospital inpatient.

The data from the interviews are presented within the following themes:

- Patients' horror stories
- Physical effect on patients
- Psychological effect on patients
- Effect on family
- Feelings of relief
- Not blaming the hospital
- Lack of support after discharge

#### Patients' horror stories

One theme which stood out very clearly early on in the interview phase was the 'horror story' told by five of the participants. The term 'horror story' was coined by Bosk in 1979 and is used in narrative research to describe significant negative experiences told by patients (Bosk, 1979). Most of the horror stories focused on hospital emergency admissions, on patients trying to find out what was wrong with them, or having wounds debrided at the bedside.

'I was in excruciating agony, I was crying with the pain. . . . it was pouring out me now. They were using terry towels to mop up the pus and blood and everything that was coming out of the wound. As soon as they put a towel on me they had to unwrap another one because it was soaked. Then they placed a sort of bag on me and it started to fill into the bag because they couldn't keep standing there with these towels.' (Participant 11)

'I was crying, I was just not well at all. I couldn't keep a drink down. The GP came and said what do you expect, you've had

major surgery. I started to think I was going mad, perhaps you are supposed to feel like this. My husband was at his wits end, he didn't know what to do. He called the NHS helpline and they said to buy some anti-sickness tablets from the chemist but they didn't work. He rang the hospital and they weren't very helpful, he rang the ward and they said she has been discharged so there is nothing we can do. Then after three or four days I was getting terrific pains in my stomach and I felt like I had wet myself, there was a lot of blood just gushing out of me.' (Participant 13)

'He had a look at the wound and said I am just going to do a little operation on you. I said 'What !' He said don't worry about it, just stare out the window, lie back and just stare out the window. And he gets his scalpel, he is just mucking about down there and he is pressing down. [ *Interviewer: When you were on the ward ?* ] This is on my bed yes. It's nothing to them is it? He's pressing and it's like bleeding and I said what have you done, he said don't worry. And I am lying there and he is pressing even more and he went are you diabetic and I went no, he said oh it must be the aspirin then. It just wouldn't stop bleeding. And in the end he had got the scalpel and he just cut away all the rubbish, cut it all away and then made this nick and he just released everything that was there. And this nurse, she was like I have never seen this before. This is in a consultant's room and you are having an operation.' (Participant 10)

Noteworthy in these kinds of accounts is the frequency of terms emphasising the severity of the symptoms, 'pouring', 'gushing', 'at his wits end', 'terrific pains', which highlight the sense that these were extraordinary experiences. In tandem with this, participants convey a sense that the response on the part of health professionals was insufficient or surprising. For example, the towels were rapidly soaked and over-the-counter anti-sickness pills were inadequate. This further underscores the severity of the situation.

#### Physical effect on patients

As expected most patients experienced pain as a result of their SSI that was often described as excruciating (Participants 1, 5, 11, 15). This was accompanied by other symptoms such as feeling very weak (Participants 6, 12, 16) and losing substantial amounts of weight, between 1 and 3 stones (Participants 1 and 7).

'I wouldn't have made it without [my family] because at one time I was about ready to give up with the pain' (Participant 14)

'I was in such a lot of pain and it really frightened me.' (Participant 5)

'There is nothing you can do anyway, you are in agony.' (Participant 11)

Several patients also referred to the smell of the wound and exudate which often caused them embarrassment.

'It was really stinking and I couldn't look at it.' (Participant 5)

'It used to smell terrible. My wife would sit here and say poo – it was that bad.' (Participant 6)

'The amount of fluid coming out of it is extremely embarrassing.' (Participant 7)

The symptoms were not short lived and patients continued to experience problems with their wounds long after surgery. Five of the 17 patients were still off work after eight weeks. Treatment was all-consuming for

patients and all of the patients described receiving weeks of district nursing visits interspersed with visits to the hospital and the GP.

'This wound has taken over my life, and in fact both our lives [patient plus spouse].' (Participant 6)

'I thought I was never going to get over it. It just seemed to go on and on.' (Participant 13)

#### *Psychological effect on patients*

In addition to their physical symptoms, participants also reported feelings of mental distress usually associated with depression from chronic illness.

'I felt really down, utter despair.' (Participant 1)

'Not happy, very unhappy actually at times.' (Participant 6)

'There was a stage when I just wanted to die.' (Participant 13)

Patients who had SSIs following caesarean sections had the additional 'burden' of having to look after a baby. One participant felt so overwhelmed that she was worried about developing postnatal depression:

'I had [post natal depression] with my first little boy. And I said [to the GP] I am panicking that it's coming back and she said I can see you are really struggling but I think a lot of that is to do with physical health. I was getting really I can't cope. I can't cope, I can't do this.' (Participant 5)

#### *Effect on family*

It was not just the participants who were affected, the whole family unit experienced some changes. Several participants described how their role within the family changed as a result of the SSI and how other family members had to take on the burden of caring for them. This also led to additional stress.

'It was always me that did all the cooking, did everything really. I had to tell him how do things, simple things, and even drew a diagram of the washing machine to stick the washing on.' (Participant 2)

'[My family] were also looking at me not having seen me like that, I was always the strong silent one.' (Participant 10)

Two respondents stated that their partners had taken time off work to look after them, and they were worried about getting better before their temporary 'carer' went back to work. This was especially acute in participants who had SSIs following caesarean sections.

'[My husband] had quite a lot of time off work because of it . . . to look after me . . . longer than was expected. He had to take longer off work.' (Participant 8)

'My main worry was I am not going to be able to look after the kids. My husband was only off for two weeks.' (Participant 5)

In one case a participant and spouse struggled to cope with everyday tasks around the home because the person with the SSI usually acted as a carer for the other, and therefore the effects of the SSI impacted on the general ability of both parties to perform everyday tasks:

'He normally gets me in and out the bath and things so it has affected me immensely.' (Spouse of Participant 7)

Family members also found the experience distressing. One participant repeated a conversation she had with a neighbour after her

wound had healed. The neighbour told the participant how the participant's adult daughter used to come round to her house and cry.

'It was quite traumatic. My daughter has got a friend who lives over the road and her mum said to me when she saw me just recently, oh yes we had lots of little talks and she was over here crying and stuff.' (Participant 13)

'My youngest saw [the open wound] quite a lot as she visited me a lot in hospital. She had a bad nightmare over it one night. I didn't know it was like that – open, so you're looking at the flesh.' (Participant 17)

Here, the participants described how their infection had repercussions for their immediate social network and for wider sets of relationships, for example between family members and people in the neighbourhood.

#### *Feelings of relief*

Despite having experienced serious wound infections and being incapacitated for months, the participants focused on the greater outcome of having survived heart attacks and cancer and were just 'grateful' (Participants 4, 8 and 11) to be alive.

'I am still alive and I am only too grateful to still be here.' (Participant 4)

'The fact that I have got rid of my cancer you almost forget about [the infection].' (Participant 6)

Participants did not blame the hospital staff for their wound infections and most praised the NHS staff for the care they received and were supportive of the NHS.

'If somebody in my presence criticised the NHS I would take them apart.' (Participant 7)

'The doctor came around about 4 days after and I said – you're my hero. Which he was. . . I count him as my saviour. He's marvellous. I'm very happy.' (Participant 17)

Thus, despite the difficulties arising from the infection, participants expressed considerable gratitude, praise of the staff and continued loyalty to the NHS.

#### *Not blaming the hospital*

Most participants did not consider the hospital responsible for their wound infections. However, they implied that if they had acquired 'infections like MRSA' (Participant 9) then they would have held the hospital responsible.

'I would be cross because it should be a preventable disease and I'm sure my family would have been very cross as well had I picked up that type of infection.' (Participant 12)

'I would have been really cross because they know enough about it to take precautions against it. So if it does happen it means the training isn't getting through to people because everybody, even people who don't have much contact with hospitals have heard of MRSA.' (Participant 16)

'I wanted to know how I got my infection in the first place. I wouldn't have been very happy if I'd got that (MRSA) as well, not at all. It's down to cleanliness.' (Participant 17)

The fact that the infection was not a meticillin resistant *Staphylococcus aureus* (MRSA) infection effectively defused the participants'

attributions of blame and the potential for anger at the institution. In participants' minds, the acquisition of an SSI did not appear to be strongly associated with seeing the hospital to be at fault.

#### *Lack of support after discharge*

Although most participants were positive about the care they received, many were concerned about a lack of support after discharge. Patients felt frightened and were unsure about who to contact when they started to develop symptoms of SSIs.

'It's quite frightening when you go home [with an SSI] and there is no back up.' (Participant 13)

'Because it was a weekend you don't know who to ring. I had been discharged. I didn't know what to do.' (Participant 5)

Several patients believed having a telephone helpline would have allayed some of their fears.

'If someone came round and said to you as you were discharged right here are some numbers, a list of all the things you could go through if there are any problems, but they just discharge you . . . it's frightening when you come home and there is nobody.' (Participant 13)

## Discussion

The purpose of this study was to enhance the data from quantitative studies and add to the findings from the one qualitative study by showing the human side of SSIs (Whitehouse et al, 2002; Cahill et al 2008; Andersson et al, 2010). Carrying out narrative interviews with patients has been widely used within the National Health Service to improve service delivery (Bridges and Nicholson, 2008). Exposing the patients' experience of SSI is necessary to engage with healthcare staff, many of whom rarely see the devastation caused by SSI. This is especially pertinent for staff working in the operating room, where most of the SSI preventative measures such as antibiotic prophylaxis, patient warming and maintaining a sterile field are implemented. An understanding of patients' experiences may increase compliance with the implementation of interventions to reduce SSIs.

This study found the disruption to patients and their family was all-consuming. The pain and 'stinking' leaking wounds lasted for weeks and months leaving patients feeling in 'utter despair' and 'wanting to die'. Even after patients had been discharged from hospital their treatment continued in the community with daily, weekly and fortnightly visits from district nurses. Patients' spouses took time off work to become carers, and new fathers had to care for mothers, new babies and older siblings. The psychological stress on patients and their families was immense, coping with the infection as well as the financial costs of being off work. These symptoms have also been described in other studies of patients with other healthcare associated infections (Tarzi et al, 2001; Andersson et al, 2010).

Surprisingly, patients did not blame the hospital and praised the nurses, doctors and the NHS, stating that they were just glad to be alive. This contrasts with studies of patients who contracted MRSA

while in hospital (Skyman et al, 2010). Perhaps the crucial difference is that MRSA is perceived by patients and the general public to be caused by 'dirty hospitals' (Easton et al, 2009) whereas the patients in this study did not appear to believe their SSIs were a result of failings within the hospital. It would be interesting to see how the awareness of SSI among the general public compares with their awareness of MRSA.

Other studies exploring patients' experiences of surgery found communication was extremely important, with fear of the unknown causing additional anxiety (Lie et al, 2010; Chan et al, 2011). On a related theme several patients in this study were concerned about a lack of support after they were discharged from hospital and were worried about who to contact with any problems. It may be possible to prevent this by providing information sheets with contact telephone numbers. Some work could be done to identify what information patients need at discharge. In addition, the patients' concerns about not having anyone to contact raises some interesting questions around the public perception of healthcare providers in the community, such as general practitioners or walk in clinics. This issue was also identified in a study where 145 patients were interviewed after day surgery (Mottram, 2011). Using almost identical quotes to those found in this study, patients praised the hospital staff but felt post discharge care was poor.

#### *Implications for clinical practice*

This study proposes that providing patients with information at discharge about normal wound healing, abnormal healing and SSIs may prevent or reduce the fear patients experience at home. Providing a contact link person may also prevent the problems around SSI diagnosis where patients attempted to seek advice from GPs, hospitals and telephone helplines. This may also identify SSIs earlier and prevent hospital emergency admissions.

#### *Limitations*

Participants were drawn from three hospitals within one trust and their experiences may be unique to the one trust and not generalisable to other trusts.

## Conclusion

In summary, this study describes the pain, stress and suffering caused from living with a surgical site infection and how this can take over the life of patients and their families long after they have been discharged from hospital.

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## Conflict of interests

None declared.

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