



Qualitative interviews to identify burden of illness, impacts and costs associated with surgical site infections

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Aim: To gather qualitative data from patients on the burden, impacts and costs of surgical site infections (SSI) requiring second surgeries. **Patients & methods:** 15 adults with SSIs from spinal (n = 4), knee replacement (n = 3) or hip replacement (n = 8) surgery participated in a focus group or individual interview. Patients completed the PROMIS Physical Functioning (PF) Short Form 10A (PROMIS-PF). **Results:** Patients reported impacts within four primary domains: PF/activity-related; social/emotional; financial/employment; and energy/sleep. The mean PROMIS-PF score was 39.3 (standard deviation = 12.1), over one standard deviation below 50, the US norm. **Conclusion:** SSIs impart a broad and significant impact on patients and their families. These burdens will be important to capture when selecting patient-reported outcome measures for this patient population.

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Approximately, 2–3% of all patients undergoing surgery will acquire a surgical site infection (SSI), of which approximately 50% or more occur after discharge [1]. The incidence of SSI varies among different types of surgery; the most recent 2014 data from the European Centre for Disease Control and Prevention reporting 1.1% of hip replacement surgeries, 0.6% of knee replacement surgeries and 0.7% of laminectomy (i.e., spine) surgeries will result in an SSI [2].

SSIs can have wide-ranging effects on patients. Interviews with 14 patients (including six hip replacements and two knee replacements) diagnosed with a deep SSI, found that patients reported insecurity confronting new signs and symptoms, sudden pain, searching for answers and help, additional suffering due to side effects and impacts on everyday life [1]. Another recent qualitative study among 19 patients with deep prosthetic joint infection, reported that patients experience distress, issues with mobility and lifestyle, losses in physical function and activities of daily living and impacts on psychological and social functioning [3]. In addition, patients with an SSI can also experience a significant economic burden. For example, significant financial costs to the patient in terms of lost time from work and need for primary care resources have been reported [4]. Research to date has focused on the health economic impact, including long-term disability, high costs for patients and their families, increased costs for healthcare systems, longer hospital stays and unnecessary deaths [5,6].

Patients often have low awareness of the risks and consequences of SSIs. Narrative interviews with 17 patients showed that they were poorly informed, and did not know about the causes or risk factors for such infections [4]. Cox and colleagues [7] asked postdischarge SSI patients to complete a survey on information they had been given about SSIs prior to their surgery. Around half the sample (48%) reported that the risk of infection had been discussed at preoperative assessment, and only 31% had been informed of current infection rates for their surgical procedure.

Characterizing the burden, impacts and costs of SSI specifically from the patient perspective is an important area of investigation. Exploring patients' experiences can provide new insights into the overall awareness, concern and understanding of SSIs for this group of patients, and is complementary to epidemiologic data [8]. Understanding these experiences is critical for developing relevant clinical recommendations and interventions, with the aim of improving patient wellbeing and outcomes. Therefore, this study aimed to understand the patient experience by gathering qualitative data to characterize the relevant burden of illness issues and impacts among spinal, knee replacement, or hip replacement surgery patients who have experienced SSIs. This patient population was chosen because the volume of orthopedic surgeries has greatly increased in the last decade, and with the growing number of orthopedic surgeries, the number SSIs is rising as well [9,10]. It is anticipated that findings from this study may aid in the development of a case report form for use in prospective studies to quantify the burdens and impacts of SSIs.

Patients & methods

Design

This was a cross-sectional qualitative study involving a focus group and one-on-one telephone interviews. Both focus groups and interviews were included as options for patients in order to diversify the collection of information and to maximize recruitment. Following completion of the focus group or interview, patients completed a sociodemographic form and a patient-reported outcome measure, which are described below. Patients with SSIs as a result of spinal, knee replacement or hip replacement surgery were recruited, as these are the orthopedic procedures most commonly diagnosed with *Staphylococcus aureus*. The study was approved by the E&I Institutional Review Board (Study number: 15015-01, approval date: 9 March 2015). All study patients provided written informed consent.

Sample

Purposive sampling, a nonprobability sampling strategy involving the deliberate selection of patients due to some individual or group characteristic [11,12], was utilized. The key advantage of purposive sampling is that it allows for a very specific characteristic or group to be studied [13]. Patients were recruited by a single clinical site in the USA that specializes in orthopedic services. Clinical staff identified potential patients by reviewing charts and the clinic database. Key inclusion criteria: male or female aged ≥ 18 years; diagnosed with a SSI as a result of spinal, knee replacement, or hip replacement surgery that required treatment through surgical intervention; treated for infection at least 30 days ago, and the final surgical procedure was completed within the past year. Key exclusion criteria: patient had experienced a reinfection at the surgical site; and evidence or history of any clinically relevant medical or psychiatric condition which would interfere with completing the study. Eligible patients were contacted by site staff either over the telephone or approached at their regularly scheduled office visit using a screening script to ensure the study was presented in a consistent manner.

Measures

Discussion guide

The focus group and interviews were audio-recorded and conducted by experienced interviewers using standardized discussion guides. Patients were asked about their knowledge and awareness related to the risk of infection prior to surgery, diagnosis, symptoms experienced, and how the infection impacted different aspects of their lives.

Sociodemographic questionnaire

The sociodemographic questionnaire is a brief form designed by the authors for use in this study, and comprised patient characteristics such as age, gender, race and educational background.

PROMIS physical functioning short form 10a

The PROMIS physical functioning short form 10a [14] is a ten-item scale that evaluates current physical limitations. This self-administered instrument asks patients to think about difficulty performing various physical activities on a five-point scale. Patients can obtain a raw score ranging from 10 (severe limitations) to 50 (minimal limitations), which is converted into a t-score, with higher scores indicating better functioning. The standardized t-score has a mean of 50 (the US general population mean) and a standard deviation (SD) of 10 [15].

Clinical case report form

The clinical case report form is a brief form designed for this study to collect information about patients' medical and treatment history, and comorbid conditions. Clinical site staff completed this form.

Data analysis

Descriptive statistics were used to characterize the sample. A content analysis approach was used to conduct a systematic analysis of the interview and focus group transcripts using a qualitative analysis software program, ATLAS.ti (Version 7.1.7, Scientific Software Development GmbH, MN, USA). An initial version of the coding dictionary was developed to assist with the review and analysis of the data based on the discussion guide. The coding dictionary was modified and updated, as needed, throughout the analysis process as new concepts emerged in the data [16].

Results

Patient demographics & clinical characteristics

A total of 15 adult patients who had experienced SSIs as a result of spinal ($n = 4$), knee ($n = 3$), or hip ($n = 8$) replacement surgery participated in one focus group ($n = 3$) and 12 individual telephone interviews. Patient demographics are listed in Table 1. The sample consisted of nine male and six female patients, with a mean age of 56.7 (SD = 10.6) years. The majority of the sample was Caucasian (86.7%).

Patient clinical characteristics are displayed in Table 2. Patients had undergone their initial surgery an average of 10.1 months prior to participating, and had been diagnosed with their infection 8.7 months prior to participation. About 64% of the sample underwent one surgery, and 33% underwent two surgeries to treat their infection. The mean length of the hospital stay after revision surgery was 8.5 days (SD = 10.9).

The mean PROMIS physical functioning short form 10A score for study patients was 39.3, indicating that patients had poor physical functioning as compared with the general US population. Scores ranged considerably (range 14.1–61.7; SD = 12.1), and were lowest for patients that had a hip replacement (mean = 38.3) (Table 1). The mean scores for patients with a spine or knee replacement were 40.6 and 40.1, respectively.

Results of the qualitative interviews

Knowledge & awareness of infection risks

Most patients were aware of a general risk of infection after surgery, this information coming from their consent form or a conversation with a healthcare provider. Two patients said they had no knowledge or awareness that infection was a risk. Despite general awareness of most patients, they reported they had no or minimal understanding of the specific type of infections for which they were at risk or the ramifications of such an infection. As two patients stated:

Spine patient: *"I was aware that there was a possibility of infection with any surgery. As far as staph what that means, no, that was a Google adventure that happened. If you want the downward spiral of every negative outcome, just Google staph infection."*

Hip patient: *"I wasn't aware of what had to transpire after they found the infection. Because they had to take my hip out and put in what they call spacers. . . . He never told me what they were going to do. He just said he was going to take care of it and clean it out. I had no idea. So I woke up without a hip."*

Burden & impacts of SSI

The analysis of patients' experiences by surgery type showed the emergence of impacts within four major domains (Table 3).

Physical functioning & activity-related

All of the patients mentioned that the infection had impacted their physical functioning and daily activities. The majority of patients spoke about increased pain and numbness, described as: 'constant', 'severe', 'sharp' and 'excruciating'. Almost all reported difficulties with the most basic aspects of physical functioning such as standing, walking and getting out of bed. One patient stated:

Table 1. Patient characteristics.

Characteristic	Overall (n = 15)	Spine (n = 4)	Knee (n = 3)	Hip (n = 8)
Age, years (n = 15)				
Mean (SD)	56.7 (10.6)	50.0 (17.8)	65.0 (7.9)	57.0 (4.0)
Median	59.0	52.0	62.0	58.0
Range	30.0–74.0	30.0–66.0	59.0–74.0	51.0–62.0
Gender, n (%)				
Male	9 (60%)	3 (75.0%)	1 (33.3%)	5 (62.5%)
Female	6 (40%)	1 (25.0%)	2 (66.7%)	3 (37.5%)
Ethnicity, n (%)				
Hispanic or Latino	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Not Hispanic or Latino	15 (100%)	4 (100%)	3 (100%)	8 (100%)
Race, n (%)[†]				
Black or African-American	1 (6.7%)	0 (0.0%)	0 (0.0%)	1 (12.5%)
White	13 (86.7%)	4 (100%)	2 (66.7%)	7 (87.5%)
Other	1 (6.7%)	0 (0.0%)	1 (33.3%)	0 (6.7%)
Living situation, n (%)				
Living alone	2 (13.3%)	0 (0.0%)	1 (33.3%)	1 (12.5%)
Living with a partner or spouse, family or friends	12 (80.0%)	4 (100%)	2 (66.7%)	6 (75.0%)
Other	1 (6.7%) [‡]	0 (0.0%)	0 (0.0%)	1 (12.5%) [‡]
Employment status, n (%)				
Employed, full-time	7 (46.7%)	2 (50.0%)	1 (33.3%)	4 (50.0%)
Unemployed	1 (6.7%)	0 (0.0%)	1 (33.3%)	0 (0.0%)
Retired	4 (26.7%)	1 (25.0%)	1 (33.3%)	2 (25.0%)
Disabled	3 (20.0%)	1 (25.0%)	0 (0.0%)	2 (25.0%)
Education, n (%)				
Secondary/high school	4 (26.7%)	1 (25.0%)	1 (33.3%)	2 (25.0%)
Some college	2 (13.3%)	1 (25.0%)	0 (0.0%)	1 (12.5%)
College degree	5 (33.3%)	0 (0.0%)	2 (66.7%)	3 (37.5%)
Postgraduate degree	4 (26.7%)	2 (50.0%)	0 (0.0%)	2 (25.0%)
PROMIS PF short form 10A				
Mean (SD)	39.3 (12.1)	40.6 (11.0)	40.1 (3.8)	38.3 (15.3)
Median	38.7	39.1	38.7	39.1
Range	14.1–61.7	28.8–55.3	37.2–44.4	14.1–61.7

[†]Not mutually exclusive categories.
[‡]Other lives with sister-in-law.
PF: Physical functioning; SD: Standard deviation.

Hip patient: *"I was unable to do anything physically around the house, I had to pay someone to mow my lawn. . . yeah, it was horrible. . . I couldn't have been prepared enough for it, I really didn't realize it was going to be so bad."*

Some patients complained about the inability to exercise, especially those who had previously had a highly active lifestyle. A decline in overall strength that affected physical functioning was also reported. One patient stated:

Spine patient: *"I lost all the muscle tone in my lower back. I wasn't anywhere near as physically capable as I was after the first surgery, because I had done a lot of work to build up the muscles before the surgery."*

The burden and impact of SSIs on daily activities, including showering or bathing, were also discussed by over half the sample. Patients commonly reported difficulties with toileting and dressing. One patient stated:

Hip patient: *"I had to depend on my daughter and my husband to get up and down the stairs, because I couldn't do that by myself. So bathing, shower, all of that had to be on somebody else's schedule."*

Table 2. Patient clinical characteristics.

Characteristic	All (n = 15)	Spine (n = 4)	Knee (n = 3)	Hip (n = 8)
Time since initial surgery (mean months, [SD], range)	10.1 (4.5) 4–18	10.3 (3.3) 6–14	8.3 (5.1) 4–14	10.8 (5.2) 4–18
Time since SSI diagnosis (mean months, [SD], range)	8.7 (3.9) 3–14	9.3 (4.4) 3–13	6.7 (4.7) 3–12	9.3 (3.7) 3–14
Type of SSI, n (%)[†]				
Superficial	1 (6.7%)	1 (25.0%)	0 (0.0%)	0 (0.0%)
Deep	12 (80.0%)	2 (25.0%)	2 (33.3%)	8 (100.0%)
Organism type [‡]	12 (80.0%)	4 (100.0%)	3 (100.0%)	5 (62.5%)
Patient hospital stay, mean (SD), range				
Mean time for hospitalization after initial surgery (days)	2.6 (1.8) 1–6	4.3 (1.5) 3–6	1.7 (0.6) 1–2	2.3 (1.8) 1–6
Mean time for hospitalization after revision surgery (days)	8.5 (10.9) 1–45	6.5 (3.1) 4–11	3.3 (1.5) 2–5	11.4 (14.5) 1–45
Patient discharge location after initial surgery, n (%)				
Home	14 (93.3%)	3 (75.0%)	3 (100%)	8 (100%)
In-patient rehabilitation	1 (6.7%)	1 (25.0%)	0 (0.0%)	0 (0.0%)
Patient discharge location after revision surgery, n (%)				
Home	10 (66.7%)	2 (50.0%)	2 (66.7%)	6 (75.0%)
In-patient rehabilitation	5 (33.3%)	2 (50.0%)	1 (33.3%)	2 (25.0%)
Treatment for infection using antibiotic medication, n (%)				
Yes	15 (100%)	4 (100%)	3 (100%)	8 (100%)
Treatment for infection using surgery, n (%)				
One surgery	9 (60.0%)	3 (75.0%)	2 (66.7%)	4 (50.0%)
Two (or more surgeries)	5 (33.3%)	1 (25.0%)	1 (33.3%)	3 (37.5%)
Missing	1 (6.7%)	0 (0.0%)	0 (0.0%)	1 (12.5%)
Type of surgery as a form of treatment, n (%)[†]				
Irrigation and debridement	11 (73.3%)	4 (100%)	1 (33.3%)	6 (75.0%)
Wound vacuum dressing	1 (6.7%)	1 (25.0%)	0 (0.0%)	0 (0.0%)
Closure over drain	1 (6.7%)	0 (0.0%)	0 (0.0%)	1 (12.5%)
Joint replacement/revision	6 (40.0%)	1 (25.0%)	2 (66.7%)	3 (37.5%)
Exchange of modular parts	1 (6.7%)	0 (0.0%)	0 (0.0%)	1 (12.5%)
Component removal	2 (13.3%)	0 (0.0%)	1 (33.3%)	1 (12.5%)
Delayed primary closure	1 (6.7%)	1 (25.0%)	0 (0.0%)	0 (0.0%)
Antibiotic spacer	3 (20.0%)	0 (0.0%)	1 (33.3%)	2 (25.0%)
30-day complications after revision surgery (as part of treatment), n (%)				
30-day re-admission, n (%) yes	2 (13.3%)	1 (25.0%)	0 (0.0%)	1 (12.5%)
30-day return to OR, n (%) yes	2 (13.3%)	1 (25.0%)	0 (0.0%)	1 (12.5%)
Patient body mass index (kg/m²)				
Mean (SD)	35.5 (5.3)	36.0 (7.8)	34.0 (1.0)	35.9 (5.4)
Median	34.0	37.0	34.0	35.5
Range	26.0–45.0	26.0–44.0	33.0–35.0	29.0–45.0
Pre-existing comorbid conditions (prior to infection diagnosis), n (%)[†]				
Anxiety	4 (26.7%)	2 (50.0%)	1 (33.3%)	1 (12.5%)
Arthritis	5 (33.3%)	1 (25.0%)	1 (33.3%)	3 (37.5%)
Coronary heart disease	2 (13.3%)	0 (0.0%)	0 (0.0%)	2 (25.0%)
Chronic obstructive pulmonary disease (emphysema, chronic bronchitis)	1 (6.7%)	1 (25.0%)	0 (0.0%)	0 (0.0%)

[†]Not mutually exclusive categories.

[‡]Organism indicated in chart included: n = 2 for the following: *Escherichia coli*, *Staphylococcus aureus*; and n = 1 for the following: MRSE, anaerobic gram positive and MRSA, pepto *Streptococcus magnus*, *Serratia marcescens*, *S. aureus* and *Staph marcescens*, *Staphylococcus epidermidis* and MRSA, *Streptococcus agalactiae*. MRSE: Methicillin-resistant *Staphylococcus epidermidis*; SD: Standard deviation.

Table 2. Patient clinical characteristics (cont.).

Characteristic	All (n = 15)	Spine (n = 4)	Knee (n = 3)	Hip (n = 8)
Depression	6 (40.0%)	2 (50.0%)	1 (33.3%)	3 (37.5%)
Diabetes	4 (26.7%)	1 (25.0%)	1 (33.3%)	2 (25.0%)
Heart disease	1 (6.7%)	0 (0.0%)	0 (0.0%)	1 (12.5%)
Hypertension	10 (66.7%)	3 (75.0%)	3 (100%)	4 (50.0%)
Myocardial infarction	1 (6.7%)	0 (0.0%)	0 (0.0%)	1 (12.5%)
Other	13 (86.7%)	3 (75.0%)	3 (100%)	7 (87.5%)
None	1 (6.7%)	1 (25.0%)	0 (0.0%)	0 (0.0%)

[†]Not mutually exclusive categories.

[‡]Organism indicated in chart included: n = 2 for the following: *Escherichia coli*, *Staphylococcus aureus*; and n = 1 for the following: MRSE, anaerobic gram positive and MRSA, pepto *Streptococcus magnus*, *Serratia marcescens*, *S. aureus* and *Staph marcescens*, *Staphylococcus epidermidis* and MRSA, *Streptococcus agalactiae*. MRSE: Methicillin-resistant *Staphylococcus epidermidis*; SD: Standard deviation.

The inability to complete daily activities was not always strictly related to immobility; fatigue also played a role. Patients who had infections subsequent to hip surgery generally had the most severe impacts on their physical functioning, often related to the placement of a spacer in the joint while the infection was treated.

Personal, social & emotional

Almost all of the patients reported some type of personal, social, or emotional impact related to their infection. This included an inability to participate in social activities, such as attending planned activities and awards ceremonies with their children. Feelings of isolation were also reported. One patient described the social impact as such:

Hip patient: *"The only person I was really seeing was my husband. I wasn't really up to having people over. So here I am, I've got this thing in my arm, I feel like crap, I'm not really getting showered, per se. It just really, I didn't really see anybody. They'd call, my friends called, or even then they didn't want to disturb you, you might be sleeping, so they don't want to call you and bother you. It's more like I had to reach out to them. . . cards, I would get cards and things that way, but you're sort of very isolated, it causes isolation."*

Relationships with partners also were impacted for many patients, with the spouse having to compensate in areas of parenting and household chores. Patients commonly mentioned that this 'burden' included driving the patient to medical appointments and helping them with feeding and personal hygiene. Despite this burden, some patients reported that they better recognized the value of their relationships with their spouses, bringing them closer as a family.

Three-quarters of patients also provided examples of emotional impacts, including: sadness, depression, difficulty adjusting, feeling unprepared for additional surgeries, loss of independence, embarrassment and fear and/or anxiety. These emotions were often directly related to the infection (e.g., fear for health/life) and also sometimes a consequence of the treatment and recovery process (e.g., embarrassment at being in a wheelchair, needing help with bathroom, etc.).

One patient described the experience in the following way:

Knee patient: *"Well, it was. . . you know, having the infection was a constant not knowing, when I would be okay or if I would be okay. It was a constant worrying and a total lifestyle change. So I think it, I. . . I think it left me probably scarred a lot more emotionally for life than. . . than I realize. It's actually a very traumatic thing for someone to go through I think."*

One-quarter of patients reported no emotional impacts.

Financial & employment status

Most patients reported a significant impact of the infection on their financial status. Costs included: making additional co-pays (e.g., physical therapy), transportation costs to one's own vehicle or transportation service fees (e.g., Uber) for frequent appointments, modifications to the home (e.g., ramp installation), and renting or buying equipment such as lift chairs, wheel chairs and special beds. Some patients experienced financial hardship, such as the inability to pay their medical bills or meet other financial obligations, as a result of the additional surgery. One patient stated:

Table 3. Summary of impacts

Concept	Patients														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	Hip					Spine					Knee				
Physical functioning															
Pain/discomfort/numbness	X	X			X	X	X	X	X	X	X				X
Decline in strength (core, overall body)						X		X	X		X	X			
Tiredness/fatigue/lack of energy	X	X	X		X				X		X				X
Muscular issues (tightness, spasms, decline in tone)	X			X				X	X						
Other symptoms		X			X			X		X		X		X	
Get out of bed								X							
Standing			X	X		X	X	X	X	X				X	X
Walking (e.g., to store, dog)		X	X	X	X	X	X	X	X	X			X	X	
Getting out of a chair		X	X												X
Getting up off the floor	X														
Getting down on one knee	X														
Climbing stairs	X	X		X			X	X						X	X
Get in and out of a car		X					X	X						X	
Not being able to exercise/dance				X						X				X	
Daily activities															
Toileting			X	X		X				X					X
Showering or bathing			X	X		X	X			X	X		X	X	X
Dressing (shoes off, wearing baggy clothes)	X		X			X		X							
Fatigue-related inability to do things			X						X		X				X
Meal/food preparation								X					X	X	X
Washing clothes													X	X	
Cleaning/chores						X	X								X
Shopping		X		X		X		X							
Driving						X									
Stay home for appointments/medical services				X					X						
Personal life/relationships															
Relationship with partner							X		X	X	X		X	X	
Relationship with children				X										X	
Social															
Missing holidays/important life events	X			X											
Difficulty visiting friends/going out (friends, church, etc.)		X	X	X		X	X			X			X	X	X
No social life						X	X			X					X
Isolation			X	X				X	X						X
Emotional/psychological															
Mentally not ready for another surgery							X								
Adjustment difficulties					X			X		X					
Embarrassment – help with daily tasks/bathroom/wheelchair						X									
Loss of independence			X	X	X	X		X			X				X
Stress													X		
Fear/anxiety			X	X				X		X			X		
Sadness			X					X		X					
Depression				X		X				X			X		
Financial															
Paying additional costs (i.e., co-pays, physical therapy, transport, modifications to home)	X		X	X	X			X	X	X			X	X	

Table 3. Summary of impacts (cont.).

Concept	Patients														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	Hip					Spine					Knee				
Reduced income (self)				X		X	X								
Reduced income (spouse)										X					
Financial hardship						X	X	X					X		
Insurance coverage (no additional payments made)		X	X								X	X			
Employment															
Taking additional time off from work than planned	X			X		X	X					X	X		
Difficulties in being self-employed						X			X			X			
Treatment interference in doing job															X
Lost work/taking early retirement			X	X									X		
Supportive and understanding employer					X	X	X								X
No impact on job (i.e., retired or on social security disability)					X			X		X	X				X
Fatigue or lack of energy															
Mental fatigue													X		
Feeling drained									X						
Tiredness	X	X	X			X									
Lack of energy			X						X		X				X
Sleeping issues															
Difficulty falling asleep		X							X	X			X	X	
Medication (i.e., sleeping pills)										X					X
Pain and discomfort						X	X			X					
Renting or buying equipment to aid sleep						X	X		X						

Hip patient: *"I will say this to you, that now I have hospital bills and doctor bills through the roof. And this is where I feel now I don't know, I'm like trying to pay a little bit, but like I said I'm limited as far as finance."*

Others reported that their financial status was not impacted as their insurance took care of any medical bills. Impacts of employment were also discussed by patients. The length of recovery time from the infection varied, ranging from 2 weeks to 3 months. Reduced income as a result of having to take additional time off from work added to the financial burden. Spouses also often had to take additional time off to care for the patients. Taking early retirement, resigning from their job and being unable to work due to the infection were some of the impacts discussed by employed patients. One patient described his employment ramifications such as:

Knee patient: *"Well, the staph infection basically took me out of the game. When I was in rehab, it took me out of work, put additional stress on my wife and friends, and... and eventually led to me losing my job."*

Some patients felt that the infection did not impact their employment status, as they were either already retired and/or were on social security disability, which covered the costs.

Fatigue or lack of energy & sleep disturbance

Patients reported that the infection resulted in fatigue, reporting that the infection had ‘taken a lot out of them’ both mentally and physically, using terms such as feeling ‘tired’, ‘wiped out’, ‘drained’ and having ‘no energy’. The increased tiredness was attributed to: staying inactive and/or in bed for long periods of time, being unable to sleep, sleeping more than usual, and/or the antibiotics used to treat the infection. One patient described their experience with fatigue and their energy level in the following way:

Spine patient: *"For me, it was the most draining experience I've ever had, just I think the drugs alone. At one point, I called a friend who is a nurse, and I said I don't think that they're being honest with me because I've*

never felt this wiped out. Like, with the PICC line, I'd do the routine, the whole thing, spread out the whole jam and then do it, and it's like watching the bars of a cell phone drop. Like you just have no energy."

Patients also described that their sleeping patterns changed while recovering, some sleeping a lot because of the antibiotics, others having difficulty falling asleep. Others stated that they were not able to sleep and had to take medication to sleep each night, often due to ongoing pain and discomfort. Inability to find a comfortable sleeping position because of wound vacuums and/or spacers often contributed to sleep disturbances. One patient described their sleep difficulties in the following way:

Spine patient: "Through this all your sleep is completely impacted. So it's not like you ever get a decent night's sleep. On top of sort of all of these physical disabilities, now it's like I've got a tail, and I've got to sort of manage all this other stuff and I can't even sleep well because I've got this tube coming off my back. Or I've got this or I've got that. So there was a point where it's just like you get worn down."

Other

Some patients stayed in a residential rehabilitation center following their revision surgery. Some patients mentioned purchasing and sleeping in a recliner, hospital bed, or lift chair. Others made changes to their homes, including: having special cushions made, installing railings, and having additional steps and/or a ramp built outside of their home. Nearly, all patients reported receiving assistance from a family member or neighbor to help them conduct their daily activities. Nearly, all of the patients reported receiving assistance at home following their surgeries. This often consisted of a visiting nurse coming to the patient's home and checking incisions, changing dressings, providing medication reminders, and checking vital statistics. Medication was also delivered at home for those patients who were unable to collect these.

Other impacts that were reported included feeling discomfort and soreness. In addition, patients' awareness of infection risks in hospitals, rehabilitation centers and nursing homes increased, leading to: constantly washing hands, using a sanitizer regularly, not touching things after others had touched them, and using paper towels instead of a towel.

Discussion

The findings from this study suggest that infected spinal, knee replacement and hip replacement surgery patients experience a range of burdens and impacts as a result of their SSIs. The experiences varied across patients, although generally, the results indicate that SSIs have a considerable impact on patients and their families. The findings of the current study are consistent with past research reporting that different aspects of the patients' lives were affected as a result of their infection [1,3]. The impacts of the revision surgery and infection were elucidated in greater detail in the present study compared with previous studies.

Patients with total hip replacement infections, and to some extent total knee replacement infections, tended to have greater impacts on their mobility. This may have been a result of the antibiotic spacers and additional surgeries that were used for treatment of many of the hip patients. Spinal surgery patients reported fewer impacts on their daily activities. They may have been so significantly impaired prior to the surgery that even despite their infection, decrements in this area were less noticeable. There was limited sample size to assess more minor differences in the infection-related experiences across surgery location groups.

Many of the burdens and impacts were inter-related. For example, patients reported that their issues associated with mobility resulted in feelings of isolation as they could not leave their house or visit with friends. The isolation was associated with feelings of sadness and/or depression. The impacts were often wide-ranging and most patients experienced impacts across several, if not all, of the domains that have been described.

It is interesting to note that although it was expected that many of the impacts would be directly related to pain and mobility issues, some patients also described that their limitations were a direct consequence of fatigue. For example, some patients reported that although they were mobile and could physically perform activities of daily living, they were still unable to complete tasks or work productively due to the fatigue that they experienced.

There are several limitations to the current study. Patients were recruited from a single site for convenience. Recruitment for the study was more difficult than anticipated because many eligible patients refused to participate stating that they were unwilling to revisit and discuss the negative experiences and emotions that they had experienced as a consequence of their SSIs; this attests to the gravity of the impacts. This is a clear selection bias, in that perhaps patients that were not as profoundly affected were the ones that chose to participate in this study.

It is possible that the impacts experienced by our population of interest are more serious and burdensome than reported by patients herein. In addition, the possible presence of recall bias should also be noted, due to time that had elapsed between the infection diagnosis and the interview. However, as surgery is a significant event in most people's lives, many can remember the details related to it [17]. Finally, as no control group was interviewed, it is unknown if some of the reported impacts may have been attributed, at least in part, to the initial surgery. The study was strengthened by including a diverse group of patients with infections after knee, hip, or spinal surgeries, as they were able to provide information on a range of burden of illness and impact issues.

Conclusion

To our knowledge, this is one of few studies to directly examine the impact of SSIs as a result of spine, knee, or hip replacement surgery in an in-depth manner and directly from the patient perspective. The results suggest serious and wide-ranging impacts that are experienced by the patients who contract these extremely severe SSIs. These findings will be used to develop a case report form for use in prospective studies to quantify the burdens and impacts of SSIs.

Summary points

- Characterizing the burden, impacts and costs of postoperative infections specifically from the patient perspective is an important area of investigation.
- Exploring patients' experiences can provide new insights into the overall awareness, concern and understanding of surgical site infections (SSIs) for this group of patients, and is complementary to epidemiologic data.

Methods

- This was a cross-sectional qualitative study involving a focus group and one-on-one telephone interviews with patients that had SSIs as a result of spinal, knee replacement or hip replacement.
- Patients also completed the PROMIS physical functioning short form 10a, a ten-item scale that evaluates current physical limitations.

Results

- A total of 15 adult patients who had experienced SSIs as a result of spinal (n = 4), knee (n = 3), or hip (n = 8) replacement surgery participated in one focus group (n = 3) and 12 individual telephone interviews.
- The mean PROMIS physical functioning short form 10A score for study patients was 39.3, indicating that patients had poor physical functioning as compared with the general US population.
- Patients mentioned that the infection had impacted their physical functioning and daily activities, they experienced changes in their sleeping patterns while recovering, they reported some type of personal, social, or emotional impact related to their infection, they reported that relationships with partners were impacted, and that they experienced a significant impact from the infection on their financial status.

Conclusion

- The findings from this study suggest that infected spinal, knee replacement and hip replacement surgery patients experience a range of burdens and impacts as a result of their SSIs.

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Ethical conduct of research

The study was approved by the E&I Institutional Review Board (Study Number: 15015-01, Approval Date: 9 March 2015). All study participants provided written informed consent.

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