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## Moving beyond survival as a measure of success: Understanding the patient experience of necrotizing soft-tissue infections

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### Abstract

**Background**—Necrotizing Soft Tissue Infections (NSTIs) represent a devastating spectrum of disease with high case-mortality and resource intensive care. Treatment consists of wide surgical debridement and often prolonged periods of ICU care. Major complications are common. The severity of the disease and the aggressive treatment requirements put survivors at risk for significant long-term sequelae related to the trauma of both disease and treatment. Information about the post-discharge impact of NSTIs on survivors is extremely limited. Qualitative approaches are typically used to explore new phenomena and to capture individuals' thoughts, feelings, or interpretations of meaning and process. Therefore, qualitative methods are ideally suited for hypothesis generation to guide future quantitative study and ensure measured outcomes are patient-centered.

**Materials and Methods**—Semi-structured interviews were conducted with survivors of NSTIs from a single regional referral center. Stratified, purposive sampling was used to select interview candidates based on severity of illness. Descriptive thematic analysis was performed to identify major themes described by the patients.

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**Results**—Interviews with 18 survivors identified 3 primary domains of experience: 1) individual factors, 2) relational factors, and 3) societal factors. These domains were split into two categories: factors effecting the disease process and recovery, and factors that were outcomes of the disease process. Each category yielded between one and seven themes. Themes identified included physical, psychological, relationship, and employment aspects.

**Conclusions**—Patient's reported quality of life was significantly affected by their disease and recovery. The results demonstrate that many outcomes of importance for patients are not easily assessed by traditional measures of outcomes. This work illustrates the multi-dimensional nature of recovery from critical illness, and show that it represents a massive transition period in the lives of survivors that affects the patient, their family, and the patient's ability to interact with society. Interviews with survivors ensure that the patient voice is heard prior to developing tools to assess long-term outcomes.

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## Background

Necrotizing Soft Tissue Infections (NSTIs) represent a devastating spectrum of disease processes with high case-mortality and resource-intensive care. Treatment often includes multiple surgical procedures to remove infected tissue—many times involving limb amputations or creation of large wounds—and prolonged periods of supportive critical care. These patients commonly develop multisystem organ failure (MSOF) and may require dialysis, prolonged intubation, and cardiovascular support. This aggressive care has been successful in lowering the case fatality over the last 2 decades to 16-34%.<sup>1-6</sup> However, little is known about whether this effort has improved long-term outcomes for survivors beyond 30-day mortality rates, and we know nothing about patient quality of life or priorities for assessing outcomes.

Only one study has tracked outcomes beyond the perioperative period, finding that long-term age-adjusted mortality was significantly higher for NSTI survivors when compared with population controls, but this paper alone does not help us understand how well survivors function after disease.<sup>7</sup> Another study found that a high percentage of NSTI survivors have moderately to severely impaired functional status at time of discharge.<sup>8</sup> While this would suggest risk of long-term poor functional status, there is no long term data available to support this assertion.

There is a growing body of literature assessing the long-term functional and psychological outcomes of burn and trauma survivors. Compared to population norms, these patients have been found to have a higher incidence of functional and psychological impairment as well as significant difficulties with return to pre-injury employment.<sup>9-17</sup> The severity of the disease and the aggressive treatment requirements are associated with significant disfigurement, loss of function, and psychological sequelae. Qualitative research methods are particularly suited to gaining a deeper understanding of the patient perspective on factors effecting recovery, the importance of various outcomes, and how to adequately assess satisfactory recovery. In-depth interviews, although not intended for numerical analysis, empower the patient to inform the clinician about the long-term effects of the disease and outcomes that matter. The main goal of this study is to better understand the full scope of patient experience, the long-

term impact of severe disease and intense treatment on health-related quality of life, and specifically to let the patient voice define the areas important for future investigation.

## Methods

Tong and colleagues have developed a widely-accepted checklist to guide qualitative research methods, and the Consolidated Criteria for Reporting Qualitative Research (COREQ) was used in constructing our protocol.<sup>18</sup> We developed an interview guide (Addendum A) with the following domains of investigation: 1) general quality of life, 2) physical function, 3) social function, 4) psychological function, and 5) relationships. We included open-ended questions regarding patient perceptions on each of these general domains and ways that patients perceived elements of each to be different since their illness. We also began and closed all interviews with an invitation for the patient to describe the most important aspects of disease and recovery.

## Setting

Our institution is a Level 1 trauma center with a 5-state catchment area. Between 90-120 patients are admitted for care for NSTI yearly, representing nearly 10% of NSTI cases seen nationally. A cross-sectional cohort of patients treated for NSTI at a single institution between 2007 and 2010 were identified from hospital records using International Classification of Disease, version 9 (ICD-9) diagnostic codes. Chart review confirmed the diagnosis based on operative findings and stratified patients by severity of disease based on the following criteria: number of surgical procedures, ICU days, limb amputation, involvement of hand, face, or genitalia, and incidence of renal or multi-organ failure. Hospital records and publically available vital statistics records were used to identify current survivors.

## Participants

Stratified purposive sampling was used to select candidates for interview, concluding when saturation was achieved. Greater representation was given to more severely ill patients because of an *a priori* assumption that they are at greatest risk for significant changes related to survival and recovery. As such, patients with significantly longer ICU stays, greater number of surgical debridements, amputations, or involvement of face, hand, or genitalia were prioritized. After receiving a detailed description of the research study, volunteers provided oral informed consent. We attempted to contact 26 patients, of which we spoke to 20 and 2 declined to participate. This research study was approved by the University of Washington Human Subjects Division Institutional Review Board.

Eighteen semi-structured key informant interviews were conducted. All interviews were performed via telephone at a time pre-scheduled with the subject after consent was obtained. Participants were informed that the interviewer was interested in their experience of recovery after NSTI and the impact of the disease on their life. Interviews lasted between 20 and 65 minutes. Interviews were recorded and transcribed.

All transcripts were used in the data analysis. One interview included the NSTI survivor and their spouse; another included the survivor's mother. We interviewed 7 men and 11 women.

Two infections involved the face, three involved the perineum and genitals, two involved the hand, and two involved the foot; the remainder involved proximal extremities and/or trunk. Demographic and clinical characteristics of our interviewees can be found in Table 1.

## Data Analysis

Because the clinicians involved in this study (T.H., H.E., E.B.) have extensive experience in caring for patients with NSTI, and well-formed opinions about which factors are important to post-recovery quality of life, the interviews were performed by a non-clinician member of the team with prior research interview experience (N.I.). Prior to initiating interviews, training was conducted with experienced qualitative researchers at the Seattle Quality of Life Group (SeaQOL). Descriptive, thematic analysis with an inductive approach was used to identify major themes directly from the interview data. The broad domains from the interview guides were used as a basis for initial coding. Transcripts were read and audio-recordings listened to several times to identify common-word and or phrases with similar meaning to develop and classify initial concepts. The researchers developed a coding scheme based on discussion of these concepts. Data were managed using a software spreadsheet and manually coded. All interviews were coded by two members of the research team (T.H., N.I.). An iterative process was used through the first few interviews to resolve differences in researcher interpretation of content and further refine the codebook, which was used for all interviews. Initial interviews were re-coded following finalization of the codebook. Following coding and analysis, participants were contacted and asked to comment on our findings and clarify any misinterpretations.

## Results

18 interviews with a median follow-up of 4.2 years (SD 1.6 years) were performed. The following three primary domains were identified: 1) individual factors, 2) relational factors, and 3) societal factors. Each of these three domains was split into two categories: factors affecting the disease process and recovery, and factors that were outcomes of the disease process. Each of these categories yielded between one and seven themes.

### Individual Factors Affecting the Disease Process

Many survivors expressed the opinion that their personal outlook on life significantly affected their recovery. One described his past experiences surviving Vietnam and recovering from drug addiction as giving him a will to survive and belief that he could get through anything, he said *“I am a survivor. I just can't lay down, curl up and die; it just isn't in me.”* Several survivors described the most important thing to a good recovery being a positive outlook on life. A representative statement from one survivor was *“...a positive outlook. I can't say enough for that. I honestly believe that the more positive a patient is the sooner and better they will recover.”*

## Individual Outcomes of Disease

### Change in Value of Life

Nearly all survivors describe an increased value place on life. One stated that he “*developed a greater appreciation for life.*” Survivors articulated that understanding their own proximity to death in illness has long-lasting implications for their subsequent experience of daily life. One survivor summarized it by saying “[*i*]t was so close that I might have died then, so the experiences that I have now are much richer on account of that.”

### Depression

Several survivors described symptoms consistent with some level of depression during or following their initial recovery. One survivor whose flank and abdomen were severely scarred described the belief that “*life’s over, I can’t tie my own damn shoes.*” Another young survivor expressed the feeling that she is “*no good anymore.*” Another noted that over time she lost interest in daily activities, she stated that “*as time progressed I fell into a deep depression.*” This was in spite of her self-described initial elation at having survived.

### Post-Traumatic Stress

Another common topic was the trauma of the disease and of the recovery. Several patients described symptoms consistent with post-traumatic stress, relating flashbacks and nightmares. A representative statement was “*I had nightmares about the ICU for several months*” and “*when we hear about somebody getting this on TV...I relive it...it’s horrible.*” Several described hyper-vigilance after sustaining new wounds, even ones perceived as minor. One described his current behavior by saying “*every time I get so much as a scratch, I am running for the antibiotic ointment...and I just watch it for days afterwards.*” A few survivors also described avoidant behavior, saying things like “*I don’t want to be around people anymore because that is how I got the infection.*”

### Pain

Several survivors commented on the presence of chronic pain and its effect on quality of life. One said “*there are days when I can’t even bear to get dressed because in my scars to nerves tingle like electricity shooting them.*” Another said that touching her scar was like “*getting a little electric shock.*” They described days that their level of pain prevented them from accomplishing basic tasks or enjoying life.

### Sexual Difficulties

We interviewed three patients, two females and one male, who survived Fournier’s—an NSTI of the perineum and genitals—and both women described significant changes in their sexual life and decreased enjoyment. They described both ongoing pain and difficulties after wound healing took place; one summarized it by saying “*it affected my sex life allot...there’s a lot of scar tissue there.*” The male did not describe any significant change to sexual function or pleasure; he noted only the obvious scars from skin-grafting.

## Physical Function

Survivors noted that loss of mobility or loss of limb severely limited their physical abilities. A survivor who lost her leg said *“it's life changing, all of the things you can't do anymore. You can't go dancing again, won't be able to swim again, won't climb a mountain again, won't go hiking again, won't walk through the grass again. It's just a lot of things.”* Another survivor described the inability to perform familiar tasks, *“...what you do when you use a hand saw, well I basically cannot do that anymore”* and the physical adaptations required to perform these tasks: *“I was painting a bulkhead at about shoulder level and I realized...I couldn't hold my arm up very well anymore. All I did was take my other arm and put my hand underneath my elbow to hold my right arm up to where it needed to be and then all I needed to do was move it from my elbow out to my wrist. These are easy compensations, but they happen all the time.”*

## Changes in Behavior

Survivors described various ways that the disease and recovery had affected changes in their regular behaviors and activities. The three common sub-themes identified were: fear of infection, changes in dress, and changed in social activities.

### Fear of Infection

One very common, but not universal, theme identified by patients was a significantly increased fear of infection. Survivors expressed increased concern with handling objects in daily life saying things like *“I don't even want to touch a shopping cart.”* They also described behaviors intended to decrease the chance of subsequent infections, one recounted *“when I went anywhere I took disinfectant wipes with me and I would wipe down anywhere I was going to sit, anything I was going to touch.”*

### Changes in Dress

Several survivors also described changes in the way they dress, primarily intended to cover or conceal their scars. One said *“I can never wear shorts anymore.”* Another described the change in her swim attire during the summer: *“when I swim now I always wear a swim skirt or swim shorts...never just a regular swimsuit anymore.”*

### Changes in Social Activities

Some survivors described changes in their leisure activities as a result of physical problems, one expressed sadness about *“never getting to really dance again.”* Still others described changes independent of their physical ability. Two survivors described a decreased desire to be around others; one said, *“I spend a lot more time alone now.”*

## Relational Factors Affecting Disease Process

### Social Support

The importance of social support networks in affecting recovery was universal. Patients that felt well-supported by family and friends felt that it was a vital part of their personal recovery, one stated *“everybody from group of friends visited me and encouraged me. They*

*were actually pretty important to [my recovery].” Another survivor said “Truly, to recover from a life threatening illness like that it takes the support of others. I don't think I would have made it through it without people helping me.” Conversely, patients that did not feel well-supported by family and friends described the negative effects this had on their recovery, saying “No one really came to see me in the hospital and that was another part that was really depressing to me. I felt like I really didn't have any friends at that point.”*

## **Relational Outcomes of Disease**

### **Family Post-Traumatic Stress**

Survivors who had family present during their illness and recovery emphasized the significant stress placed on their loved ones. While survivors repeatedly mentioned that they do not remember the time period during their most critical illness, they also expressed that this period was most vivid for their family members. One said, *“this was a very traumatic thing for them. And I don't think they've gotten over it.”* Others reported that their spouses and partners exhibited symptoms consistent with post-traumatic distress including flashbacks, nightmares, and avoidant behavior. One spouse shared, *“there was a lot of trauma for me, too.”* A survivor mentioned, *“during the first months out of the hospital, and while I was in, they [family] had nightmares about me in the ICU.”* Another survivor described her spouse having difficulty watching news coverage for cases of NSTI recently reported in the southeastern United States during the summer of 2012.

### **Changes in Family Dynamic**

Several survivors reported significant changes within family roles following their illness. Some who were parents described their children taking on more parental roles. One stated, *“they treat me like a china doll,”* while another said her children *“tend to be more watchful of me. They pay attention to sleeping habits, my diet. They mother-hen me a little bit-sometimes excessively.”*

### **Changes in Social Circles**

Survivors who described a perceived lack of support or involvement from their friends at the time of illness almost universally related a distancing of those relationships. Many framed this alteration in relationships as stemming from a sense of abandonment by perceived close friends. A representative statement was *“we just grew apart afterwards because I don't call them and we don't even talk anymore.”*

We interviewed two survivors who had been intravenous drug users at the time of their infection; both described their infection as the impetus to quit drug use and to remove themselves from that social circle. One stated that her infection *“kind of like snapped me out of my drug use...it pulled me back into reality.”* Another described her former relationships as *“a bad influence...the reason I was using drugs”* and stated that after surviving her infection she *“couldn't be around them...I pushed them away.”*



## Societal Factors Affecting Disease Process

### Wheelchair Accessibility

Two survivors who used a wheelchair either temporarily or permanently commented on the difficulties they encountered with wheelchair accessibility, both in their own home and in public, and the difficulty and frustration that poor access caused them. The parent of one survivor described *“when she came home the wheelchair didn't go through the door and I had a heck of a time getting her into the house. I couldn't get her in the side door where I had one of those portable ramps. So I moved the ramp to the front but that was too steep because of the steps. Then when I got her in here she couldn't get in the bathroom. The door was too narrow, so I went to one of the home supply places and got a little portable toilet thing. And that was kind of tough because they are kind of icky. So she did that for almost two weeks.”*

## Societal Outcomes of Disease

### Changes in Employment

Several survivors expressed a significant alteration to their lives due to changes in employment or loss of employment following their disease, although these were not uniformly negative. One survivor had only recently changed careers and been hired at the time of her infection, she subsequently lost her job and has been unable to return to work and had to move back in with her mother, describing it as very difficult *“to lose independence.”* But another survivor, whose injury occurred on the job, was made a quality-control supervisor and became responsible for workplace safety. He expressed significant satisfaction at the new direction his employment took. Two other survivors described the loss of employment for their spouse during their illness and recovery. One shared that her spouse *“refuses to go back to the job he has so now he's unemployed. He won't take a job where he is going to be gone for any length of time...he has to be home every day.”*

## Discussion

We sought to use in-depth interviews with NSTI survivors as a way to gain a more complete understanding of the range of patient experience of disease and recovery. Not surprisingly, due to our experience with caring for patients with NSTIs, we found that survivors' reported quality of life was significantly affected by their physical function and ongoing pain. We also found significant survivor focus on the effect the experience had on their family and other relationships. These results demonstrate that many outcomes important to patients are not easily quantifiable and/or are not assessed by traditional measures of outcomes. This work illustrates the multi-dimensional nature of recovery for a critically ill patient, and that this recovery does not occur in a vacuum, but occurs in the broader psychosocial context of the survivors, their families, friends, and society.

The effect of a positive attitude on recovery that was noted by several survivors bears some exploration. This theme was only noted by survivors who self-described as having a positive outlook on life. The potential detrimental effect of a negative outlook was never identified by survivors we interviewed. However, the research team noted that survivors who seemed



to have a more negative outlook on life seemed to describe greater difficulty in recovery and post-disease adaptation. These differences are likely explained via differences in survivor personality, life-experience, and family environment among others. Any evaluation of personality-driven differences in outcomes would be quite difficult to evaluate prior to initiation of treatment, since most NSTI patients arrive at the hospital *in extremis*, with limited opportunity for baseline assessment.

Survivors' descriptions of limitations in physical function were not surprising to us given the nature of the invasive and extensive debridements undertaken and our own assumptions regarding the long-term effects of the disease, but we did note some interesting distinctions. Overall, we found less subjective emphasis placed on physical function and its effects on quality of life than we expected, except among amputees, and a strong focus on sexual difficulties by two survivors of Fournier's gangrene. We did note differences in survivor assessment of physical abilities based upon their apparent outlook on life -- that is to say, survivors who seemed to have a less positive outlook on life also seemed more likely to ascribe insurmountable difficulties in terms of physical function. The survivor who described the physical adaptations he needed to make to paint above shoulder level had a more positive affect than the survivor who described an inability to walk in the grass or dance. When exploring physical function and its effect on quality of life, the latter survivor seemed to focus more on what she could not do or on what was impossible, whereas the former survivor focused on how he had to adapt or how it was more difficult. Although we cannot make any inference based on our limited interview data, the correlation between pre-discharge psychological and personality assessments and long-term health-related quality of life might help to better explore this perceived association.

Long-term psychological consequences of the disease were emphasized by several survivors; they described symptoms of significant depression and post-traumatic stress. Importantly, because of the open-ended nature of the discussions with patients, we discovered that most survivors were quick to note the extreme stress their illness had placed on their loved ones. This allowed us to explore the potential ramifications for partners and family members and to identify evidence of post-traumatic stress in the survivors' partners. Although prior research has studied the incidence of post-traumatic stress in survivors of critical illness and found it to be quite common, very few have explored this phenomenon amongst family members.<sup>19</sup> Our patient interviews stress the importance the patients themselves place on this aspect of recover, and highlights the need to determine the incidence and severity of family and partner post-traumatic stress symptoms, and whether targeted intervention teaching coping strategies and providing family support during the period of critical illness could impact these symptoms in duration or intensity. Furthermore, would assistance provided to the family positively impact the survivor's assessment of long-term quality of life?

The changes in relationships described by survivors came in three general forms, with the first being changes in family dynamics. None of the survivors we interviewed expressed any significant satisfaction or displeasure with the alterations in their family interactions. It seems reasonable that some of the patterns described, such as reversal of parental roles, might have serious ramifications for some patients, however among survivors interviewed,

the pattern was neither positive or negative. The second general relational change described was the distancing of friendships perceived to be important at the time of illness. Some survivors who described a lack of visitors or support during recovery from friends expressed clear bitterness as they described abandonment, while others seemed to express resignation and sadness at what they perceived to be misjudged relationships. Generally, the perceived lack of social-support and subsequent loss of relationship was judged to have negative effects on happiness and quality of life. But not every relationship lost was perceived as negative, however. Both survivors who were IV drug users at the time of infection described their illness as the impetus to quit IV drug use and leave the social circles where that behavior was common. For both of these survivors, the change in social circle was clearly felt to be a positive change.

Changes in employment among survivors or their family were also identified by survivors as important to both recovery and ongoing quality of life. Although we cannot quantify how commonly survivors are unable to return to work, several noted that either they or their spouses lost jobs during the period of illness and/or recovery and have been unable to return to work. Not all changes in employment were negative, however. One survivor noted that his company re-organized and essentially created a job position dedicated to monitoring and improving workplace safety in response to his infection. This survivor noted significant satisfaction with his new work and did note that it likely would not have occurred had he not become ill.

The methodology of our study obviously limits the ability to draw firm conclusions, but this was not our goal, but rather to gain insight from patients into the full range of experience and use this information moving forward to guide future investigation. Another limitation of our study is the under-representation of intravenous drug abusers among our interview subjects. Historically, IV drug abusers account for 30-40% of NSTI patients at our institution, but only two of our subjects had a history of IV drug abuse, and both had subsequently stopped using IV drugs. The experiences, long-term outcomes, and priorities among NSTI survivors who continue IV drug use may be very different. Finally, we did not specifically ask survivors about divorce, or other separations in romantic relationships. Survivors and their families clearly described the period of illness as a major source of stress. Divorce rates are commonly higher for people undergoing significant stress and transition. We did not explore this potential outcome; however it is plausible that with a larger group of interviews it may have been brought up by survivors.

This work illustrates that, in order to more fully assess long-term outcomes and quality of life for survivors of NSTI—and we think, by extension, other critical illness such as severe burns—researchers must assess for physical, psychological, and relational sequelae. Traditional outcomes such as in-hospital or 30-day mortality -- or even functional impairment scales -- while important to the clinician, fail to capture the real impact of NSTI from the perspective of the patient. We found that survivors emphasized the effects of their disease and recovery not only on themselves, but on their family, friends, and role in society. We must be cognizant of not only assessing and caring for the patient, but also the patient and important relationships together in one context. Recovery from critical illness can represent a massive transition period in the lives of survivors that significantly affects the

patient, their family, and the patient's ability to interact with society. It is clear that the complex interplay of these factors are influential on patient-reported outcomes and quality of life. Giving voice to the challenges faced by patients and understanding them is a major step towards identifying ways we can not only maximize survival, but minimize the long-term burden of disease on our patients and help them have the best quality survival. Importantly, this patient-first methodology has important implications in determining what outcomes to assess across the gamut of medical and surgical disease. The data gathered from these interviews will be used to guide the choice and/or development of assessment tools for use in future research into long-term outcomes for NSTI survivors.

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## Appendix A: Qualitative Interview Talking Points & Sample Questions

Reintroduce yourself.

Goal is to hear from the patient about their experience, not to ask/answer specific questions

We have questions to help start a conversation, but encourage patient to lead wherever they feel is important.

General QOL

- What does quality of life mean to you?
- How has surviving an NSTI affected your quality of life, or perception of what quality of life means?
- How is your life different or the same as it was before?
- Is anything noticeably better now than it was before?

Personal

- If you were seeing a new doctor, what are the important questions he/she should ask you to better understand what it means to survive an NSTI?
- How has your NSTI affected your spiritual life?

Social Support

- How has the issue of support from family and friends played into your experience with NSTI?
- Would you tell me how you think support or lack of support from friends and family has affected your quality of life since your NSTI?

Psychological

- How have you dealt with any negative emotions that may have come up during your recovery?

- How would you say that the scars from your NSTI have affected your sense of self-confidence? How have you handled that?

#### Functional/Activities

- Has your ability to perform daily tasks such as shopping, cleaning been effected by your NSTI?
- How has your NSTI affected your hobbies or leisure activities?
- What do you find most difficult now? How is this different or the same from before your NSTI?

#### Relationships

- How has your social life changed since your NSTI?
- How has your NSTI affected your intimate relationships?
- How has your NSTI affected your family life?

#### Financial

- How has your NSTI affected you work life?  
Are you able to work in same industry, salary level, etc.  
How di your employer respond to your illness?

#### Wrap-Up

- What would you say are the three most important things relevant to your recovery?
- Is there anything we haven't talked about or I haven't asked that you wish we had?

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**Table 1**  
**Demographic and Clinical Characteristics**

<b>Gender (Men/Women)</b>	7/11
<b>Age (years, Range(Mean))</b>	20-63(42)
<b>Follow Up (years, Range(Median))</b>	3-6 (4.2)
<b># Married</b>	6
<b>LOS (days, Range(Median))</b>	6-70 (35)
<b>ICU LOS (days, Range(Median))</b>	2-47 (12)
<b># Intubated</b>	14
<b>Intubated Days (Range(Median))</b>	0-18(5)
<b># Surgeries</b>	2-12(7)
<b># Amputations</b>	3
<b># Requiring Skin Graft Procedures</b>	5
<b># Requiring Renal Dialysis</b>	3
<b># Requiring Plasmapheresis</b>	1

Legend: LOS = Length of stay