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Older adult perspectives on medical decision making and emergency general surgery: "It had to be done."

Claire Sokas, MD[1], **Irene M. Yeh, MD MPH**[3,4], **Kathleen Coogan, BS**[1], **Rachelle Bernacki, MD MPH**[3,4], **Susan Mitchell, MD MPH**[5], **Angela Bader, MD MPH**[1,6], **Keren Ladin, PhD MSc**[7], **Jennifer A. Palmer, MS, PhD**[8,9], **James A. Tulsky, MD**[3,4], **Zara Cooper, MD MSc.**[1,2]

[1]Brigham and Woman's Hospital, Center for Surgery and Public Health, Boston, MA USA

[2]Brigham and Woman's Hospital, Department of Surgery, Boston, MA USA

[3]Division of Palliative Medicine, Department of Medicine, Brigham and Women's Hospital, Boston, MA USA

[4]Dana-Farber Cancer Institute, Department of Psychosocial Oncology and Palliative Care, Boston, MA USA

[5]Hebrew SeniorLife Arthur and Hinda Marcus Institute for Aging Research, Boston, MA

[6]Brigham and Woman's Hospital, Department of Anesthesia, Boston, MA USA

[7]Departments of Occupational Therapy and Community Health, Tufts University, Medford, MA USA

[8]VA Boston Healthcare System, Center for Healthcare Organization and Implementation Research

[9]Boston University School of Medicine, Section of General Internal Medicine

Abstract

Context: Optimal surgical care for older adults with life-threatening conditions, with high risk of poor perioperative outcomes and morality in the months after surgery, should incorporate an understanding of the patient's treatment goals and preferences. However, little research has explored the patient perspective of decision making and advanced care planning during an emergency surgery episode.

Corresponding Author: Zara Cooper, MD MSc, Center for Surgery and Public Health, Department of Surgery, Brigham & Women's Hospital 1620 Tremont Street, Suite 2-016, Phone: (617) 525-7300.

Author Contributions:

Study Concept and Design: Bernacki, Mitchell, Bader, Ladin, Palmer, Tulsky, Cooper

Acquisition of Data: Sokas, Coogan, Cooper

Data Analysis & Interpretation: Sokas, Yeh, Bernacki, Bader, Ladin, Cooper

Preparation of manuscript: Sokas, Yeh, Coogan, Bernacki, Bader, Cooper

Critical Revision of manuscript: Sokas, Yeh, Coogan, Berancki, Mitchell, Bader, Ladin, Palmer, Tulsky, Cooper

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Objective: We sought to better understand older patients' lived experience making decisions to undergo emergency general surgery (EGS) and perceptions of perioperative advance care planning.

Methods: Adults ≥65 who underwent one of seven common EGS procedures with a length of stay >5 days at 3 Boston-area hospitals were included. Semi-structured phone interviews were conducted 3 months post-discharge. Transcripts were reviewed and coded independently by surgeons and palliative care physicians to identify themes.

Results: Thirty-one patients were interviewed. Patients viewed the decision for surgery as a choice of life over death and valued prolonging life. They felt there was "no choice" but to proceed with surgery, but reported that participation in decision making was limited due to severe symptoms, time constraints and confused thinking. Despite recently surviving a life-threatening illness, patients had not reconsidered their wishes for the future and preferred to avoid future advance care planning.

Conclusion: Older patients who survived a life-threatening illness and emergency general surgery report receiving goal-concordant care in the moment that relieved symptoms and prolonged life but had not considered future care. Interventions to facilitate postoperative advance care planning should be targeted to this vulnerable group of older adults.

Keywords

older adults; emergency general surgery; decision making; advance care planning

Background

Emergency general surgery (EGS) is increasingly common among older adults and has high rates of perioperative morbidity and mortality in the first year after surgery.[1] Frailty and comorbid conditions are associated with particularly poor outcomes including loss of independence, discharge to a facility and decline in patient-reported quality of life.[1–4] Prior studies in community dwelling elders suggest that older adults prioritize function over longevity, raising concerns that likely outcomes from highly morbid major surgery may not benefit some older patients and highlighting the need to ensure that surgery is aligned with patient's goals and treatment priorities. [4–8] Given these risks best practice guidelines for communication with older adults about emergency surgery endorse disclosure of surgical problems in the context of a patient's overall prognosis, guiding a conversation about a patient's values related to life prolongation and quality of life.[9,10] A structured framework helps patients explore their values and encourages communication with loved ones and clinicians about their preferences, for both in-the-moment decision making and advance care planning.[10]

However, adhering to practice recommendations remains challenging. Patient-physician relationships must be established quickly, and communication around goal-concordant care is difficult when the onset of severe illness is sudden and unexpected.[1,7] Despite these factors, there is little data on how patients experience making decisions to undergo emergent surgery to guide such discussions and highlight opportunities for improvement. Instead, existing literature relies on indirect measurements. Interviews with surgeons offer insight

into surgeons' assessment of treatment options for seriously ill patients, their prognostic estimates of long-term survival and function, and how this internal monologue guides discussion with the patient and family.[11,12] Proxy measurements, including functional status and independence, have been operationalized as patient-centered outcomes in clinical registries,[4,13] and interviews with older adults explore their preferences for treatment and end-of-life care in the setting of a hypothetical acute severe illness.[6,7] However, none of these outcomes replace the first-hand experience of patients who have survived an intervention for an acute, life-threatening surgical diagnosis.

To address this gap, we interviewed older adults alive three months after emergency general surgery to better understand their experience as a survivor of a life-threatening illness. Our primary objectives were to elucidate how patients perceived in-the-moment decision making for emergency surgery and their perceptions of advance care planning in context of their recent life-threatening illness.

METHODS

Overview

Participants/Recruitment—We recruited older adults who received care at one of three Boston teaching hospitals (two tertiary and one community) between December 2018 and August 2019. We prospectively screened hospital records to identify patients who met the following eligibility criteria: English-speaking ≥65 years who underwent one of seven common emergency general surgery procedures that make up 80% of EGS morbidity and mortality (partial colectomy, small bowel resection, cholecystectomy, operative management of peptic ulcer disease, lysis of peritoneal adhesions, appendectomy and laparotomy), length of stay > 5 days discharged alive.[14]

Patients were contacted three months post-discharge via mail and phone and were provided recruitment information. This study was approved by the Partners Health Care Research Committee IRB.

Interview Guide and data collection—A semi-structured interview guide was developed, based on literature review and clinical experience, by an acute care surgeon (ZC) with input from an inter-disciplinary team with expertise in surgery, critical care, geriatrics, palliative medicine, and qualitative research. The goal of the guide was to understand how patients approach treatment decisions for acute surgical conditions, as well as probes to assess patient experiences with advanced care planning. Semi-structured 45-minute interviews were conducted by phone to explore the lived experience of the patient throughout the emergency general surgical care episode, including pre-operative, peri-operative, post-operative and post-discharge. Verbal informed consent was obtained at the beginning of each interview. Interviews were conducted by two trained research assistants, audio recorded and transcribed verbatim.

Following identification of eligible patients, chart review was performed to collect: demographic information (age, gender, marital status, race/ethnicity, comorbidities) in-hospital care (diagnosis, operation, length of stay, ICU stay), discharge destination, advance

care planning (code status, health care proxy, proxy relationship, presence of additional advance directive documentation (e.g. completed MOLST form- Massachusetts Order for Life Sustaining Treatment), comorbidities and complications. Charlson comorbidity index was calculated from comorbidities.[15] Complications including any of the following most common events as defined by the American College of Surgeons National Surgical Quality Improvement Program: surgical site infection, pneumonia, cardiac event, urinary tract infection, renal failure, venous thromboembolism or readmission.[16]

Analysis—Interpretative phenomenological analysis (IPA) using NVivo qualitative software (Version 12) was completed to "give voice" to the experience of participants and to contextualize findings.[17,18] A preliminary codebook was developed by two coders from different disciplines (CS-general surgery, IY-palliative care), who independently coded the interview transcripts and met regularly to review coding discrepancies. This iterative process allowed new themes to emerge, existing themes to be refined, and consensus to be achieved on disagreements. Sampling continued alongside refining of the codebook until thematic saturation was reached.[19,20] Following development of the codebook, members of the multidisciplinary research team independently reviewed the codebook to assess its credibility.[21] Once the final codebook was developed, the transcripts were re-coded by the first author (CS).

Results

Thirty-one patients were interviewed. The average age was 73.4 years old (SD:5.5); half (51.6%) of patients were men and half (58.1%) were married. Most (83.9%) were white and most (61.3%) had a Charlson comorbidity score ≥2. The most common procedure was laparotomy with bowel resection. The majority (81%) were discharged home. Additional demographic and hospital course information is found in Table 1.

At admission, all patients had a code status documented by the admitting provider in the electronic health record of "confirmed full code" or "presumed full code." Most (61.3%) reported they had a designated healthcare proxy at the time of admission, and 50% had a proxy documented in the EHR. Two patients (3%) had EHR documentation of additional advance care planning.

Decision Making (Table 2)

Patient perception of decision to have surgery—A dominant theme that emerged was patients' perception of having "no choice" but to have surgery. All patients expressed that their treatment preference was to prolong life and reported that surgical intervention was the only option or that they had not been given a decision to proceed with surgery. Patients reflected on the severity of their condition, expressing surprise at the acuity of surgical intervention.

Barriers to Participation in Pre-Operative Discussions—Numerous barriers limited patients' ability to meaningfully engage in in-depth conversations and treatment decisions. Severe symptoms prevented patients from fully engaging and were also an accelerator for action/intervention. Confused thinking confounded their in-the-moment decision making.

Others were stunned by the rapid onset of illness. Patients viewed the consent process for surgery as an affirmation of their treatment preference to prolong life and referred to the risks of surgery as “side effects” of life-saving treatment.

Emotions associated with in-the-moment decision making—Patients were fearful awaiting surgery and could not recall specific people (such as the surgeon) or events. Patients found reassurance in the words and actions of the healthcare team, but in many cases were unable to recall meeting the surgeon, or only recalled general sentiments of a decision-making conversation. In some cases, they expressed regret or self-blame for not presenting for evaluation sooner.

Desired Outcome—Overall, patients viewed surgery as a success because it had prolonged their life. Patients expressed gratitude to the entire healthcare team and a sense of lasting trust in their surgeon.

Advance Care Planning (Table 3)

Previous Advance Care Planning—We asked patients about their treatment preferences and attitudes about advance care planning. Patients focused on the products of advance care planning (i.e. documentation) rather than the process of exploring their own treatment preferences. The majority of patients had identified a family or friend who would make decisions on their behalf. Many patients referred to this surrogate decision maker as their health care proxy and reported having documentation reflecting this decision. Patients felt that by identifying a substitute decision maker, they were successfully transferring responsibility. When asked about conversations with surrogate decision makers about their treatment goals and preferences, patients consistently focused on documentation, rather than communicating their wishes to their surrogate. Patients reported using a variety of ACP documents (e.g. power of attorney for health care, state forms such as Medical Orders for Life Sustaining Treatment (MOLST)) to express their preferences and referred to these documents in lieu of disclosing their thoughts about specific goals and wishes for the future.

Discussion of Goals of Care during Treatment Episode—When asked specifically about discussing their goals of treatment with their healthcare team, patients reported that they were asked to provide information for a healthcare proxy, but denied being asked about their goals and preferences. Despite recalling no direct communication about overall health goals, patients confirmed that the care they received was congruent with their goals and preferences.

Future Advance Care Planning—Patients were asked about their thoughts for future care considering their recent experience with a life-threatening illness and major surgery. During the interview many patients avoided discussing advance care planning or minimized the likelihood and/or risk of a future emergency surgical procedure. However, those who were able to consider a future life-threatening event offered general reflections on their mortality and reported their plan to return to the same hospital in hopes of receiving the same care and having a similar outcome.

Discussion

In this study, we examined patients' perception of "in-the-moment" decision making and advance care planning in the context of an emergency surgery episode. In our cohort, patients had two primary goals: alleviating symptoms and prolonging life. Given this priority, they reported their belief of having no choice but to proceed with surgery. Patients had difficulty recalling additional content in pre-operative conversations due to time constraints, severe symptom burden and impaired cognition in the moment. When asked to reflect on the episode three months later, patients reaffirmed the receipt of goal-concordant care but had not considered future care nor engaged in new advance care planning.

Our findings corroborate those of Nabonzy et al. who conducted focus groups with community dwelling seniors and asked them to consider a hypothetical choice between emergency surgery and palliative care.[7] Similar to our cohort of older patients actually faced with a similar decision, subjects in the Nabozny study considered the choice for surgery almost entirely as binary life and death decision and did not incorporate future health states (functional dependence, nursing home residence) in their calculus.[7] Our study builds upon this prior work and underscores the importance of alleviating uncontrolled symptoms in the choice for surgery. Best practice recommendations emphasize the "ideal" pre-operative discussion includes dialogue on the impact of the surgical and non-surgical treatments not only on survival, but also function, burden of care, and living situation. In our cohort, patients were appropriately oriented to the life-limiting nature of their illness and its causality with their current state of distress, expressed a goal of prolonging life, and accepted the surgeon's recommendation for surgery. Notably absent from their "in-the-moment" thinking was the potential aftermath of surgery including physical and cognitive decline, loss of independence or nursing home care. They reported intense affective states – fear, pain, discomfort, confused thinking – that significantly impaired their ability to comprehend and participate in any discussions about the technical aspects of surgery or the impact on future health states other than life or death. With this mindset, patients rejected the notion that they were given a choice, or that there was even a decision at hand –only one treatment option would prolong life. They expressed implicit agreement to the surgeon's treatment plan that would prolong life and relieve their poorly controlled symptoms. Unfortunately, the inability for patients to hear about future states in the most acute phase of care creates the potential for patient-provider communication gaps during the post-operative period, due to differing perspectives between the surgeon and patient on the extent to which proceeding with surgery reflects patient buy-in to all associated care.[6]

Compounding these difficulties with high-stakes decision making are the imperfect capture of advance directives in the EHR and patient report of limited previous experience with advance care planning. Discrepancies between patient preferences and EHR documentation of advance directives is an established barrier to the delivery of quality care.[22] All patients in this cohort were recorded as "presumed full or full" code, without insight into whether this was confirmed with that patients; at least one patient reported a conflicting code status ("I think I have a DNR.") Only half of patients in this cohort had documentation of a surrogate decision maker in the EHR, and conversations about future care with their intended surrogate decision makers focused on code status discussions but avoided defining goals of

care with respect to quality of life; very few had additional advance directives. Additionally, patients do not recall discussing their individual health goals with their family or providers in the post-operative setting, and when queried three months post-discharge dismissed engaging in new ACP as irrelevant to their current health state. Unfortunately, it is very relevant -- in the year after surgery, older adults who have undergone EGS remain at high-risk of poor outcomes, with 30% one-year mortality and high rates of healthcare utilization and days away from home. [23,24] These poor outcomes suggest that older adults who survive hospitalization after emergency general surgery are an extremely vulnerable population, particularly for poor quality end-of-life-care, and are an ideal target for advance care planning discussions.[25]

The findings of this study can help clinicians understand limitations to ACP prior to surgery and advance ACP discussions after surgery. It is important to explore patient's overall health goals and confirm the presence of any advance directives in the pre-operative setting, while remaining cognizant of limitations in the acute setting. Patients may be limited in their ability to fully participate in high-quality decision making while they are physically and emotionally distressed. Thus, patient's treatment goals should be revisited and confirmed after surgery and also in the event of unexpected complications that lead to changes in health states that may change patient priorities. Surgeons can further establish expectations regarding recovery and explore patient health goals, thus promoting awareness about the need for ACP and encouraging ongoing communication between patients and healthcare providers, two behaviors which have been associated with improved rates of ACP participation.[26]

Limitations

There are a few limitations to this study. First, the sample of patients interviewed is not generalizable to all older adults facing decisions about emergency general surgery. As enrollment targeted patients based on age and EGS procedure, the number of patients with a potentially operative condition who did not undergo EGS is unknown. The characteristics of this cohort are reflective of the population this hospital network serves. Further research is essential to explore the experiences of older EGS patients from different geographic, racial, and socioeconomic backgrounds. While our efforts give voice to a vulnerable group that has not previously been interviewed – that of patients who have survived EGS – we were unsuccessful in recruiting the sickest patients who died shortly after surgery or were still in post-acute care facilities who may have reported different experiences and acknowledge the potential for response bias among those who chose to participate; of 103 patients approached to participate, 31 enrolled and completed interview, 5 were known to have died, 16 never returned a call and 57 patients declined to participate; of these, 17 declined to participate due to health concerns. For patients who had declined initially due to inconvenience or initial health concerns, we asked for permission to perform serial follow-ups, but were only able to re-recruit 2 patients. Finally, the consent process itself was not observed in this study and thus we cannot address how capacity was assessed at the time of consent for our subjects nor directly comment on the goal-elicitation process. Future studies will require additional resources to support fieldwork to directly reach the most vulnerable patients. In addition, recall bias is always possible when asking participants to reflect on past experience.

Conclusion

Understanding the lived experience of older adults who have undergone emergency general surgery gives voice to their experience and contextualizes their in-the-moment decision making. In these emergencies preoperative conversations exploring goals of care and future health states are limited by patients' symptom and cognitive burdens. Surgeon-initiated advance care planning in the post-operative period may be an effective strategy for increasing this vulnerable population's participation in ACP and helping prepare them for postoperative care and future healthcare decisions.

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References

1. Havens JM, Peetz AB, Do WS, et al. The excess morbidity and mortality of emergency general surgery. J Trauma Acute Care Surg. 2015;78(2):306–311. doi:10.1097/TA.0000000000000517 [PubMed: 25757115]
2. Oresanya LB, Lyons WL, Finlayson E. Preoperative assessment of the older patient: A narrative review. JAMA - J Am Med Assoc. 2014;311(20):2110–2120. doi:10.1001/jama.2014.4573
3. Palmer R The Acute Care for Elders Unit Model of Care. Geriatrics. 2018;3(3):59. doi:10.3390/geriatrics3030059
4. Berian JR, Mohanty S, Ko CY, Rosenthal RA, Robinson TN. Association of loss of independence with readmission and death after discharge in older patients after surgical procedures. In: JAMA Surgery. Vol 151. American Medical Association; 2016. doi:10.1001/jamasurg.2016.1689
5. Taylor LJ, Johnson SK, Nabozny MJ, et al. Barriers to Goal-concordant Care for Older Patients with Acute Surgical Illness. Ann Surg. 2018;267(4):677–682. doi:10.1097/SLA.0000000000002282 [PubMed: 28448386]
6. Nabozny MJ, Kruser JM, Steffens NM, et al. Patient-reported Limitations to Surgical Buy-in. Ann Surg. 2017;265(1):97–102. doi:10.1097/SLA.0000000000001645 [PubMed: 28009732]
7. Nabozny MJ, Kruser JM, Steffens NM, et al. Constructing High-stakes Surgical Decisions. Ann Surg. 2016;263(1):64–70. doi:10.1097/SLA.0000000000001081 [PubMed: 25563878]
8. American College of Surgeons GSVP. Optimal Resources for Geriatric Surgery.; 2019.
9. Taylor LJ, Johnson SK, Nabozny MJ, et al. Barriers to Goal-concordant Care for Older Patients With Acute Surgical Illness. Ann Surg. 2018;267(4):677–682. doi:10.1097/SLA.0000000000002282 [PubMed: 28448386]
10. Cooper Z, Koritsanszky LA, Cauley CE, et al. Recommendations for best communication practices to facilitate goal-concordant care for seriously ill older patients with emergency surgical conditions. Ann Surg. 2016;263(1):1–6. doi:10.1097/SLA.0000000000001491 [PubMed: 26649587]
11. Cauley CE, Block SD, Koritsanszky LA, et al. Surgeons' Perspectives on Avoiding Nonbeneficial Treatments in Seriously Ill Older Patients with Surgical Emergencies: A Qualitative Study. J Palliat Med. 2016;19(5):529–537. doi:10.1089/jpm.2015.0450 [PubMed: 27105058]
12. Kulkarni SS, Briggs A, Sacks OA, et al. Inner Deliberations of Surgeons Treating Critically-ill Emergency General Surgery Patients. Ann Surg. 11 2019:1. doi:10.1097/sla.0000000000003669
13. Berian JR, Zhou L, Hornor MA, et al. Optimizing Surgical Quality Datasets to Care for Older Adults: Lessons from the American College of Surgeons NSQIP Geriatric Surgery Pilot. J Am Coll Surg. 2017;225(6):702–712.e1. doi:10.1016/j.jamcollsurg.2017.08.012 [PubMed: 29054389]

14. Scott JW, Olufajo OA, Brat GA, et al. Use of national burden to define operative emergency general surgery. JAMA Surg. 2016;151(6). doi:10.1001/jamasurg.2016.0480
15. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. J Chronic Dis. 1987;40(5):373–383. doi:10.1016/0021-9681(87)90171-8 [PubMed: 3558716]
16. Bilimoria KY, Liu Y, Paruch JL, et al. Development and evaluation of the universal ACS NSQIP surgical risk calculator: A decision aid and informed consent tool for patients and surgeons. J Am Coll Surg. 2013;217(5):833. doi:10.1016/j.jamcollsurg.2013.07.385 [PubMed: 24055383]
17. Bazeley P, Jackson K. Qualitative data analysis with NVivo. 2013. NVivo qualitative data analysis software; QSR International Pty Ltd. Version 12, 2018. Accessed May 20, 2020.
18. Larkin M, Watts S, Clifton E. Giving voice and making sense in interpretative phenomenological analysis. doi:10.1191/1478088706qp062oa
19. Morse JM. Data were saturated. … Qual Health Res. 2015;25(5):587–588. doi:10.1177/1049732315576699 [PubMed: 25829508]
20. Schwarze ML, Kaji AH, Ghaferi AA. Practical Guide to Qualitative Analysis. JAMA Surg. 2020;155(3):252–253. doi:10.1001/jamasurg.2019.4385 [PubMed: 31995144]
21. Guest G, MacQueen K, Namey E. Validity and Reliability (Credibility and Dependability) in Qualitative Research and Data Analysis. In: Applied Thematic Analysis. SAGE Publications, Inc.; 2014:79–106. doi:10.4135/9781483384436.n4
22. Walker E, McMahan R, Barnes D, Katen M, Lamas D, Sudore R. Advance Care Planning Documentation Practices and Accessibility in the Electronic Health Record: Implications for Patient Safety. J Pain Symptom Manage. 2018;55(2):256–264. doi:10.1016/j.jpainsymman.2017.09.018 [PubMed: 28943360]
23. Lee KC, Sturgeon D, Lipsitz S, Weissman JS, Mitchell S, Cooper Z. Mortality and Health Care Utilization among Medicare Patients Undergoing Emergency General Surgery vs Those with Acute Medical Conditions. JAMA Surg. 2019;155(3):216–223. doi:10.1001/jamasurg.2019.5087
24. Lee KC, Streid J, Sturgeon D, et al. The Impact of Frailty on Long-Term Patient-Oriented Outcomes after Emergency General Surgery: A Retrospective Cohort Study. J Am Geriatr Soc. 2 2020:jgs.16334. doi:10.1111/jgs.16334
25. Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. N Engl J Med. 2010;362(13):1211–1218. doi:10.1056/NEJMsa0907901 [PubMed: 20357283]
26. Fried TR, Redding CA, Robbins ML, Paiva A, O'Leary JR, Iannone L. Stages of change for the component behaviors of advance care planning. J Am Geriatr Soc. 2010;58(12):2329–2336. doi:10.1111/j.1532-5415.2010.03184.x [PubMed: 21143441]

Key Message:

Older adults who undergo surgery for a life-threatening condition perceive “no choice” but to have surgery, and three months post-surgery have often avoided future advance care planning. This study is a novel exploration of the patient perspective of undergoing high-risk surgery in an emergency situation, and its insights are imperative to assist with decision making and advance care planning in the peri-operative period.

Table 1.

Demographics

Cohort, N=31	**%**
Age (mean[SD])	73.4
Sex	
Female	48.4%
Male	51.6%
Married	58.1%
Race	
Caucasian	83.9%
Charlson comorbidity ≥2	61.3%
Length Of Stay (median [IQR])	8 [6–14]
Procedure	
Laparotomy	58.1%
w/bowel resection	38.7%
Cholecystectomy, Laparoscopic	32.3%
Admission to Intensive Care Unit	
Yes	19.4%
Discharge Disposition	
Home	80.6%
Long-term acute care facility (Skilled nursing facility, rehab)	19.4%
Any complication [T]	35.4%
Advance Care Planning	
Code Status (full or presumed [*] full)	100%
Advance Directives	
Health Care Proxy (HCP)	61.3%
Documentation of HCP	51.6%
Documentation of goals of care (Medical Order of Life-Sustaining Treatment, Power of Attorney)	3%

[*] Options for code status in EHR include full code, presumed full code, and variations on resuscitation and intubation status, as documented by the admitting provider

[T] NSQIP complications: surgical site infection, pneumonia, cardiac event, urinary tract infection, renal failure, venous thromboembolism, readmission

Table 2.

Decision Making

Thinking about when you got sick with your [DIAGNOSIS], can you tell me what you were thinking when you decided to have surgery?	
Patient perception of decision for surgery	
No choice	"I don't think I decided at all, I think they decided for me. I had a perforated bowel, so I was leaking into my, the rest of my body, so that's never a good thing." -*68YM* "Well it was, really there was no way I could not have surgery. It was something that I didn't really get a yes or no on because if I didn't have surgery, I would have died." -*75YF*
Value prolonging life	"… everybody loves life, so if it's a chance that that wasn't the end all and be all of my life then I would like to live." -*67YF*
Barriers to participation in pre-operative decision	
Acuity/emergency	"I don't think anything, as I said it happened, by the time they operated it was I think midnight or close to it and we had to move fast I guess, so I don't think there was anything different they could have done." -*80YM*
Symptom burden	"I had no choice, I was in constant pain with my stomach not able to move my bowels… and nothing helped me…And so they put an NG [naso-gastric] tube in, probably the worst thing I've ever experienced in my life." -*65YF*
Confusion	"… between the time I got to the emergency ward and the time that I decided to have the surgery, I wasn't thinking too clearly. I was in kinda a fog. Uh a young man, a doctor as far as I know, he sat down with me and went over all of the possible side effects that-that could occur because of this surgery… you know I had a serious problem uh that-that the staff was recommending have the surgery and even though the side effects they described sounded pretty bad, I decided to go ahead with it anyway." -*78YM*
Emotions associated with in-the-moment decision making	
Regret	"I wish I had gone to hospital sooner when I would start having cramps because I was having cramps for about a week before I ever went to the hospital. Maybe if I had gone to the hospital sooner about the cramps I was having and problem about not having a bowel movement then maybe it wouldn't have happened that way. So I think partly, part of it was probably my own fault for not going sooner." -*75YF*
Fear	"Cause I was scared to go to go um under and through all that stuff again, but um like I said, the doctor, I don't remember his name, but he was awesome, he came in and talked to me and I cried and cried, and he talked to me and I cried and cried, and he told me not to worry cause you know he'd do everything, that you know, I'm in the best place, which I believe, it's true." -*68YF*
Desired outcome	"I just wanted it fixed and they fixed it." -*66YM*

Table 3.

Advance Care Planning

Sometimes patients are too sick to let their care team know their treatment preferences when they are hospitalized. Before surgery, what did you have in place to let your family know the type of care you would want if you became too sick to speak for yourself?	
Previous advance care planning	
Documentation of ACP	"I have a living will, everything is spelled out, signed legally, from a lawyer, so it's all very clear." -*76YM*
Transfer of responsibility to surrogate decision maker	"My daughter has all the rights to say yes or no. I took care of her when she was a child, she takes care of me now." -*84YF*
During the treatment episode	
No recollection of review of goals of care	"I mean I think I have a DNR, I have a health care proxy. But my husband said [these documents] really wasn't discussed." -*65YF*
Future advance care planning	
Reflections on mortality	"So, it was emergency, you know it wasn't planned, and it wasn't uh it wasn't welcomed except that it kept me from dying so that's a really good thing [laughs]. When you reach our age, you know you bury parents, you frequently bury you know sibling, you you've you know you've buried friends, you've experienced medical crisis among your relative and friend circles. These are conversations that my generation has, I think." -*69YF*
Avoidance of future	"Oh god I don't even want to contemplate the possibility. I have no idea." -*83YF* "I don't want to think about it. I've had three surgeries, believe me I don't think I would survive another one, but hopefully I won't need one." -*85YF*