

# In their own words: recovery after emergency general surgery in the older patient

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## ABSTRACT

**Objectives** Emergency general surgery (EGS) conditions, such as perforated intestines or complicated hernias, can lead to significant postoperative morbidity and mortality. We sought to understand the recovery experience of older patients at least 1 year after EGS to identify key factors for a successful long-term recovery.

**Methods** We conducted semi-structured interviews to explore recovery experiences of patients and their caregivers after admission for an EGS procedure. We screened patients who were aged 65 years or older at the time of an EGS operation, admitted at least 7 days, and still alive and able to consent at least 1 year postoperatively. We interviewed the patients, their primary caregiver, or both. Interview guides were developed to explore medical decision making, patient goals and expectations surrounding recovery after EGS, and to identify barriers and facilitators of recovery. Interviews were recorded and transcribed, and we used an inductive thematic approach to analysis.

**Results** We performed 15 interviews (11 patients and 4 caregivers). Patients wanted to return to their prior quality of life, or 'get back to normal.' Family was key in providing both instrumental support (eg, for daily tasks such as cooking, driving, wound care) and emotional support. Provision of temporary support was key to the recovery of many patients. Although most patients returned to their prior lifestyle, some also experienced depression, persistent abdominal effects, pain, or decreased stamina. When asked about medical decision making, patients expressed viewing the decision for having an operation not as a choice but, rather, the only rational option to treat a severe symptom or life-threatening illness.

**Conclusions** There is an opportunity in healthcare to provide better education for older patients and their caregivers around instrumental and emotional support to bolster successful recovery after emergency surgery.

**Level of evidence** Qualitative study, level II.

## INTRODUCTION

Emergency general surgery (EGS) diseases are unexpected and serious surgical diseases such as symptomatic hepatobiliary disease, complicated hernias, acute gastrointestinal disease such as bleeding, ischemia, obstructions and perforation, and severe infections that require surgical drainage or debridement.<sup>1,2</sup> Forty per cent of these admissions occur in patients over 65 years, and the likelihood of surgical intervention rises exponentially with age.<sup>3</sup> Older individuals are more likely to develop EGS

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Emergency general surgery in older patients leads to high morbidity and mortality, but the long-term patient experience is not well understood.

## WHAT THIS STUDY ADDS

⇒ Family caregivers, friends, and church members are essential parts of postoperative recovery after emergency general surgery in providing instrumental, emotional, and spiritual support.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The transition from hospital to home can require high-intensity informal caregiving, and there is an opportunity in healthcare to better educate patients and their caregivers around the expectations for instrumental and emotional support.

conditions, and they bear a disproportionate burden of associated mortality and morbidity.<sup>3,4</sup>

Unlike elective surgery, EGS conditions in the older individual often lead to mortality or a dramatic disability cascade, as older patients have a poorer prognosis than younger patients with the same disease processes.<sup>5–7</sup> A study by Smith *et al* tracked community-dwelling Medicare beneficiaries with EGS conditions who underwent an operation on hospital day 1 or 2; 12% of this cohort died in the hospital, 14% died in the ensuing 9 months; in that same 9-month time frame, 10% had moved permanently to a nursing facility or a long-term acute care facility. In total, 32.3% of the cohort had either death or permanent loss of independence within a year.<sup>8</sup> Few studies have examined the long-term experiences of patients who survive. It is unknown if survivors of emergency general surgery have lasting changes in their quality of life from their disease.

The goal of our study was to examine the patient and caregiver experience for older adults who recovered after a serious emergency general surgery condition, from at least 1-year postsurgery. Our goal was to identify potential facilitators or barriers to a high-quality recovery and explore whether their recovery met their expectations, with a particular focus around medical decision making and the patient's recollection about their

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understanding of risks and benefits at the time of surgical decision-making.

## METHODS

We conducted semi-structured interviews to explore the recovery experiences of patients and their caregivers after admission for a major emergency surgical procedure. We screened patients who were at least 1 year from the surgical procedure and were 65 years or older at the time of surgery. To qualify for the study, the patient had to have an index inpatient stay of 7 days or longer for the EGS hospitalization. The patient had to be alive and without cognitive impairment. The patient, their primary caregiver, or both could consent to be interviewed; each participant was given a small stipend for enrollment.

Two parallel interview guides were developed (one for patients and one for caregivers). Interview guides explored three main topics: (1) goals and expectations around recovery; (2) facilitators and barriers to recovery; and (3) understanding of the medical decision-making process. Our interview guide had specific questions about the process of informed consent for the operating room, as the authors felt this interaction would show a potential opportunity for improved communication and goal-setting. Interviewers tested the questions on non-study participants and the guide was iteratively revised to ensure ample opportunities for open-ended discussion with additional probing questions about key issues. The interview guide developed for patients, including examples of additional probing questions, is presented in [box 1](#).

Potential participants were notified of the study via written and mailed communication and then were called by telephone to describe and answer questions about the study and enroll the patient for interview. Interview times were arranged in advance to ensure adequate time for the interviews, and participants could join by telephone or video using Zoom conferencing software (Zoom Video Communications, San Jose, California, USA). Verbal consent for inclusion into the study was recorded as part of the interview. Interviews were conducted by two trained personnel (PK and BA) and continued until theoretical saturation was reached. Interviews were recorded using Zoom, and recordings were transcribed and anonymized by two authors (DLD, VPH).

Two researchers coded the transcripts in parallel (VPH, MJR) to identify themes, and an inductive thematic approach was used for analysis.<sup>9</sup> The thematic analysis study team (VPH, MJR, KAB, ATP) included three individuals with extensive experience in qualitative methodology, and met iteratively to review and refine coding themes. Information about age, demographics, and surgeries were extracted from the electronic medical record. Caregiver demographics were not recorded. The entire study team contributed to the writing and critical revisions of the manuscript. The level of evidence for this Qualitative study was deemed level II using the methods described in Daly et al.<sup>10</sup>

## RESULTS

In total, 15 interviews were performed, of whom 11 were patients and 4 were caregivers. Three of the four caregivers were spouses of individuals who were also interviewed; the fourth caregiver was a sibling of a patient and, while the patient consented to the sibling interview, the patient themselves declined to be interviewed. The 12 patients focused on in the study ranged in age from 66 to 90 years of age; 4 were men and 8 were women. There were seven white patients, three black patients, one Hispanic patient, and one individual who declined to answer about race.

### Box 1 Interview guide

#### Patient interview guide

##### Topic 1: recovery trajectory

Thanks again for being here, we really appreciate your participation.

1. Could you tell me about your surgery? I would really love to hear about what you know and remember about your surgery.
2. Could you tell me about your experience recovering from surgery?
  - a. Did you have any complications after surgery? Were there any bumps in the road? How did that affect your recovery?
3. How long would you guess your recovery took?
  - a. For a lot of people, after a major surgery, they think about it every day. Thinking back to your surgery, about how long do you think it took before you stopped thinking about it every single day?
4. What is the most important thing to you about recovering from surgery?
  - a. What would you say are the top three things that were important about your recovery?
5. If you could think back to your life before surgery, is there anything that you could do then that you can't do now?
6. Alright, now thinking back again to what your life looked like before injury/surgery: do you rely on others more now than you did before? What is that like for you?
7. Are there things that made it easier or harder for you to recover?
8. Does your surgery continue to affect you day to day? How so?
  - a. For example, does it affect your social life? Social interactions? Family life? Your ability to accomplish daily tasks?

##### Topic 2: goals and expectations

9. Thinking about all the different aspects of your recovery, did your recovery go how you expected? Did it line up with what you were hoping for?
10. Is there anything that you wish had gone differently with the hospitalization process?
  - a. Thinking about all the different things that happened during this process—you came to the hospital, had to hear a diagnosis and plan, go through a consent/permission process, had to be hospitalized afterwards, went home or to a rehabilitation facility...
  - b. Is there anything else that stands out to you?
11. Did you sign the consent form yourself? (ie, sign the blue sheet of paper before the surgery)
  - a. Do you remember the conversation about the possible risks and benefits of surgery? What were your thoughts at that time?
  - b. If you don't remember that conversation, did your family member make the same decision you would have made if you were able to?
12. Did you go to a rehab facility? What was that experience like? Did you know that this was a possibility before surgery?
  - a. If not—how was the first month or so at home?
  - b. What about after getting home?
13. Given everything you've been through with your health and surgery, let's pretend you have a magic wand and could

Continued

## Box 1 Continued

change any aspect of the process or experience. What, if anything, would you change for someone going through the same thing in the future? This is, after all, why we're here talking—to learn how we can do better—and we are so grateful for you taking the time to help us make that happen.

14. Is there anything else we haven't talked about?

**Caregiver interview guide**
**Topic 1: recovery trajectory**

Thanks again for being here, we really appreciate your participation. Before we begin, could you tell me the name of your loved one who had surgery?

1. Could you tell me about (fill in name of loved one)'s surgery? I would be grateful to hear about what you know and remember about their surgery.
2. Could you do your best to tell me about their experience recovering from surgery?
  - a. Did they have any complications or 'bumps in the road' after surgery?
  - b. (If yes) How did that affect their recovery?
3. How long would you guess their recovery took?
  - a. For a lot of people after a major surgery, they think about it every day. Thinking back to that time surgery, about how long do you think it took before (fill in name of loved one) stopped thinking about it every single day?
4. What do you think is the most important thing to (fill in name of loved one) about recovering from surgery?
  - a. What would you say are the top three things that were important to them about their recovery?
  - b. And as their caregiver, what would you say are the most important things to you?
5. If you could think back to (fill in name of loved one)'s life before surgery, is there anything that they could do then that they couldn't do after surgery?
6. Did/Does their surgery continue to affect them in their day-to-day life?
  - a. (If yes) How so?
  - b. (*Possible probes*) For example, does it affect their social life? Social interactions? Family life? Their ability to accomplish daily tasks?
7. Alright, now thinking back again to what (fill in name of loved one)'s life looked like before injury/surgery: did they come to rely on others more after the surgery than they did before?
  - a. What do you think that experience has been like for them?
8. Can you think of things that have made it easier or harder for (fill in name of loved one) to recover?
  - a. What can you tell me about those things?

**Topic 2: goals and expectations**

9. Thinking about all the different parts of (fill in name of loved one)'s recovery, do you think that their recovery went how they expected? Did it line up with what they were hoping for?
  - a. How about you, as their caregiver or proxy? Did (fill in name of loved one)'s recovery meet your expectations or hopes?
10. Thinking about all the different things that happened during this process—(fill in name of loved one) came to the hospital, had to hear a diagnosis and plan, go through

Continued

## Box 1 Continued

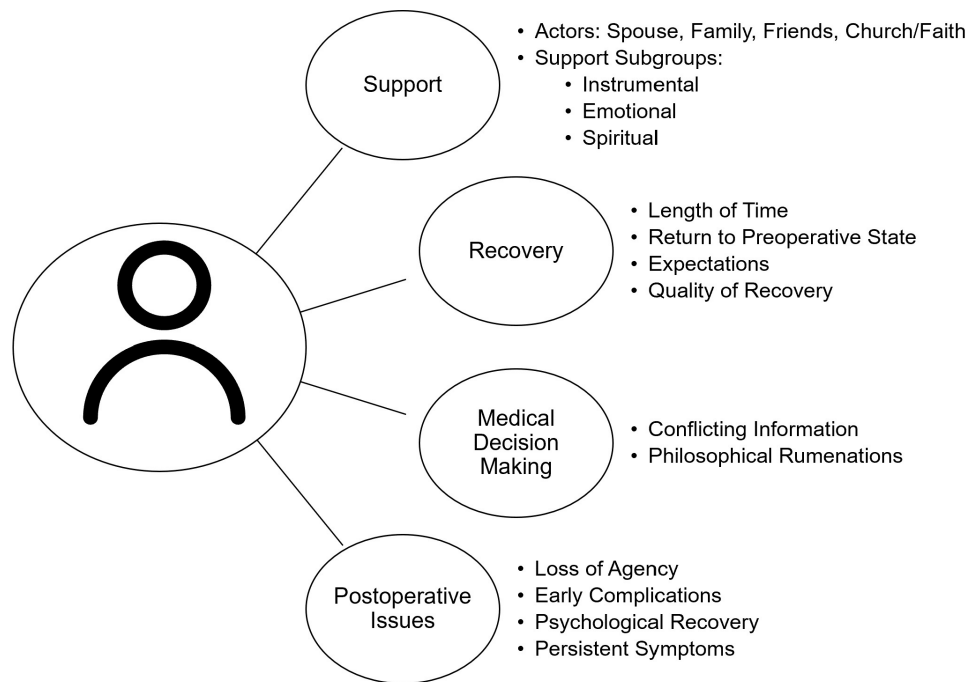
a consent/permission process, had to be hospitalized afterwards, went home or to a rehabilitation facility... Is there anything that you think (fill in name of loved one) wishes had gone differently with the hospitalization process?

- a. Is there anything else that stands out to you?
11. Did (fill in name of loved one) sign the consent form themselves? (The consent form is the blue sheet of paper before the surgery.)
  - a. Did (fill in name of loved one) remember or participate in the conversation about the possible risks and benefits of surgery?
  - b. What were your thoughts at that time?
  - c. Did you, or (fill in name of loved one)'s family member who signed the form, make the same decision (fill in name of loved one) would have made if they were able to?
12. Did (fill in name of loved one) go to a rehab facility?
  - a. (If yes) What was their experience like? Did they know that this was a possibility before surgery? Did you?
  - b. ii. (If no)—How was their first month or so at home?
  - c. Is there anything that you think (fill in name of loved one) wishes had gone differently after getting home?
13. A big part of why I'm talking with you today is to learn how we can do better. Thank you again for taking the time to help us make that happen. Thinking about everything (fill in name of loved one) went through with their health and surgery, let's pretend there was a magic wand that you could use to change any aspect of the process or experience. What, if anything, do you think that they would change for someone going through the same thing in the future?
14. Is there anything that I haven't asked you about yet that you think is really important that I know about you or (fill in name of loved one)'s experience?

Six patients were married and six were divorced. Operations included two laparoscopic cholecystectomies for cholecystitis or pancreatitis, one ventral hernia repair for a small bowel obstruction, and eight laparotomies for peritonitis or bowel obstruction. Interviewed caregivers included three men and one woman. Our coding schema is presented in [figure 1](#). Key themes identified through analysis include: social support, recovery, medical decision making, and postoperative issues. Illustrative quotes are presented throughout the manuscript.

**Support**

The need for support in the post-EGS recovery period was a key enduring theme throughout the interviews. Analysis identified three social support subthemes: instrumental, emotional and spiritual support. For participants describing the post-EGS recovery period, discussions included challenges with a temporary loss of independence, with some patients having permanent changes in their level of independence. Emotional support was also key to recovery, as caregivers felt it was important that the patients did not feel like a burden while recovering. For some patients and caregivers, their spirituality was believed to be critical to recovery. From the caregiver point of view, it was important to offer assistance: "I would drive over there and make sure, you know, 'you need anything, you good?'" (caregiver of 70s, male). Individuals also appreciated when those around had a positive attitude, as one patient noted that the "Attitude of



**Figure 1** Themes identified from analysis.

*those around you definitely makes a difference. It's very contagious*" (80s, female).

### Instrumental support

Participants described a loss of agency with reliance on others to accomplish instrumental daily tasks such as laundry, cooking and driving as important for their recovery. Family provided the bulk of the day-to-day caregiving. Instrumental support included temporary co-habitation, adult caregivers taking time off from work, assistance driving while a patient was home-bound, food preparation, and daily chores. One patient stated, "after surgery, I admit I was relying more on people... I wasn't able to drive... it's not like you're doing what you want to when you're in your own house, so you know I had to be dependent on them" (60s, male). One patient related, "I rely on my husband more...I don't have to do any dishes and [don't ] have to worry about that" (80s, female). Patients also noted that friends, neighbors, and individuals from religious support systems also provided instrumental support, stating, for instance, "my neighbors would go to the store for me, or my son" (80s, female) or "People in our neighborhood brought food over, mainly soup because that's what I love" (80s, female). Often, this loss of agency was temporary, with individuals regaining the ability to care for themselves.

One patient noted that when there was a gap in instrumental support, she saw it as a source of stress:

I can't clean my rooms... I can't move the heavy doors. I can't do much at all... my husband and son were supposed to take over cleaning... But they haven't and it's a horrible mess here and dirty and just... I hate living in these squalor conditions but there's nothing I can do (70s, female).

### Emotional support

Patients and caregivers both described that family members and other friends and members of their community provided emotional and psychological support. Caregivers who were interviewed generally did not relate feeling burdened by these

responsibilities but noted that they felt it important to make sure the patient knew that their illness was not a problem or a burden. One caregiver expressed, "I was happy to be in the waiting room, so I that I could be there for him" (caregiver of 70s, male), and another stated, "[Caregivers should] try to be engaged in a way that [patients] don't view their sickness as a problem to everyone" (caregiver of 80s, female). One patient who had been recently widowed prior to her surgery stayed with her daughter for 8 or 9 months, stating that "it was nice to be with my daughter and son-in-law because I'd be coming home to, you know, to an empty home" (60s, female).

### Spiritual support

Patients who had strong faith cited this spiritual support as essential to recovery. One patient stated, "We believe in prayer, both my husband and I plus our whole family, so we do believe that that has made a difference in my recovery, in my thinking, as to being positive" (80s, female). Religious belief can be an anchor to positive thinking for patients and caregivers, as noted by one patient who had persistent severe pain after surgery: "There's too much pain, I don't know why I stay alive. I don't stay alive for me, I do for my patients and I'm the visitation pastor at my church" (70s, female).

### Recovery

#### Recovery goals and expectations

Patients shared a common goal of returning to their prior quality of life, or to 'get back to normal.' Patients often defined 'normal' as relative to how their EGS disease impacted their prior life. If the EGS admission had led to physical disability and weakness, 'normal' included walking and being able to live independently. "Your strength, your health, you just want to be... back to what you were before" (60s, male). One patient noted that her main issue with the EGS condition was the development of difficulty with bowel movements, and therefore 'normal' was having a bowel movement. Another caregiver noted that the patient,



himself, was usually the caregiver for others, and ‘normal’ was being able to take care of others again, rather than relying on others to take care of him. One interviewee noted that, in order to regain their prior lifestyle, “*you had to put the work in*” (60s, female).

### Time to recovery

Patients and caregivers related a wide range of recovery timelines. One male patient who had a prolonged medical hospital stay but had his operative procedure the day before discharge related that he had essentially immediate recovery: “*A couple of days after the surgery, I totally forgot about it! It was like a non-issue*” (70s, male). Other patients who had more physical limitations noted that recovery often took months, and some patients never recovered to their prior level of functioning. Interviewees noted that patience, for both patients and their caregivers, was extremely important during that time frame, and that extra time must be allowed due to the patient’s older age with a slower time frame needed for recovery compared with a younger person. As one patient stated, “*I knew that the healing process was going to take a fair amount of time and just to realize, I had to prepare for that time*” (70s, male). Psychological effects of the timeline to recovery were also evident. One female patient noted that she developed despair which was related to not only a long timeline but uncertainty about whether she ever recover: “*When I did start moving around and doing things I was real weak, just, could hardly stand up for long and do things. So, I didn’t recover really, I’m still real weak and tired and it never got better*” (70s, female).

### Quality of recovery

Interviewees also reported a wide range of the quality of recovery. While many patients noted no long-term effects from their recovery, others noted lingering symptoms. One patient explained, “*My bowels seem to be different now. I have some... some episodes of maybe getting a little bit impacted. And sometimes just some stomach aching and a little diarrhea... sometimes I got to work around my activities and where I go, depending on what my bowels are doing*” (80s, female). Another noted that “*I kind of feel like I lost my element, like all my stamina*” (60s, male). One patient who had a particularly difficult recovery described, “*I just stayed inactive in the recliner for weeks until the pain subsided*” (70s, female). This particular patient noted that she had a history of chronic pain prior to surgery but attributed persistent pain and resulting debility to lack of adequate prescription of pain medication in the immediate postoperative period.

There were patients who related persistent symptoms which led to permanent changes in their ability to perform some tasks. Examples of persistent effects included walking slower, persistent difficulty with bowels, permanent inability to drive a car, and persistent pain/fatigue which rendered an individual unable to perform daily chores. One patient stated, “*I just don’t drive anymore. So that I do miss*” (60s, female). Patients who had a long recovery trajectory with regained independence expressed gratitude for the return of strength and independence: “*My strength is back. I am very thankful ... I’m on this side of it and I’m taking good care of myself*” (80s, female).

### Medical decision making

While a few patients had clear recollections about having a detailed discussion about risks and benefits, many of our interviewed patients had limited memories of the consent process. One patient relayed, “*I did sign the consent, I signed my last name twice... they showed me that later, you know, whenever I*

*was well. But I did sign that... I don’t remember signing. I don’t remember talking*” (60s, female). The decision for having an operation was often not viewed as a ‘choice,’ but rather the only rational option to treat a severe symptom or life-threatening illness, such as sepsis/septic shock, unbearable pain (in peritonitis), or intractable vomiting (in bowel obstruction). “*I just wanted to get well. And the only way I could get well is to have surgery. The doctor came in and talked to me and told me that that was something they had to do. So I went along with it*” (90s, female).

While patients tended to consider the operation as necessary, one patient noted that if her disease recurred, she was unsure if she would make the same decisions: “*I still feel sorry for myself... I just, I don’t know what I would do if this happened to me again, because it was heck going through that*” (70s, female).

Patients had particularly clear memories of instances when physicians or other care providers provided conflicting recommendations. One patient remembered that two surgeons provided conflicting time frames for ostomy reversal. “*...she was talking about 6 months [for an ostomy bag] and the look on my face it was...well the other doctor said it would be less time*” (60s, male). Another patient relayed having a complication for which one surgeon recommended a reoperation and another surgeon recommended non-operative management. This patient recalled being encouraged to sign a consent form even though a final decision about whether the operation was to proceed was not made yet, “*in case we need to do surgery we can take you in there. And I kind of reluctantly said, I don’t wanna be rushed into it*” (60s, male). Memories of having conflicting recommendations given by medical personnel were described vividly.

### Postoperative issues

Patients and their caregivers discussed having a number of post-operative issues which ranged from short-term to persistent. One caregiver remembered that the patient “*had little setbacks, being stubborn, pulling out his urine tube...*” (caregiver of 70s, male). The patient who had persistent pain issues recalled having severe perioperative pain described as, “*horrible pain, when I did wake up... I wanted to jump out the window...*” (70s, female). One patient had trouble dealing with the chronic wound and ostomy care needed after surgery. The patient stated that, “*I was having some trouble with the ostomy care at first too. I just really was not prepared to handle it*” (60s, male).

Psychological effects were noted by a few patients. One patient noted that physical weakness and pain was “*a crushing blow to be on your back like that*” (60s, female). For example, one caregiver related that the patient would have “*bad dreams... he would tell me he was scared that he was going to pass away*” (caregiver of 70s, male).

## DISCUSSION

Our study highlights the key experiences of older adults who undergo an emergency general surgery, as perceived at 1 year following the index admission. Key thematic findings we derived from analysis focus on patients relying heavily on family caregivers for support throughout the recovery period, and patients sharing a common goal of ‘going back to normal’. The specifics of recovery from the patient perspective were wide-ranging. Patients’ reflections were often shaped by their memories of leaning on their family to fill their instrumental and emotional needs.

There has been one prior qualitative study reported on older adults’ perspectives 3 months after emergency general surgery.<sup>11</sup> Their findings were similar to ours and found that patients

shared a common treatment goal of ‘getting back to normal’, and many relied on informal caregiving from family.<sup>11</sup> This study noted that, based on their evaluation, a potential opportunity to improve postoperative recovery would be to develop methods to include caregivers more deliberately into the discharge planning for transitions of care. Social ties and support is known to be critical for psychological and physical well-being, and our study demonstrates the importance of family for postoperative recovery in EGS.<sup>12</sup> Notably, all of the individuals we interviewed had family who provided support at some level; critically, future inquiry might examine the recovery process for individuals who do not have family for support.

Our study was designed to identify potential opportunities for improvement for postoperative recovery. As such, our study inclusion and exclusion criteria were crafted to focus on these patients. We only included patients who had a hospital stay of 7 days or longer, to identify patients who either had a complex hospital course or perhaps would have difficulty with discharge planning, as we believed that these criteria would identify patients with a high likelihood for identifying opportunities for improvement. In addition, we also included patients who survived at least 1 year, which likely identified patients who were healthier and perhaps less frail at the time of admission. While these inclusion criteria perhaps narrowed our population, we believed that this population would provide high-quality first-person accounts of facilitators and barriers to recovery.

Indeed, our study indirectly highlights experiences from patients who did not meet our inclusion criteria: our study generally included patients with positive outcomes, interviewing survivors who were cognitively intact 1 year after surgery. All our patient participants had family on which they could rely. Our findings thus pose the critical question: what happens during recovery if one does not have someone who is willing and/or able to provide instrumental and emotional support? Researchers who reached out to enroll and consent patients noted having spoken briefly to caregivers of patients who were not eligible (due to death or mental status). Researchers additionally spoke to caregivers who would have been willing to be interviewed except that their loved one had passed away; fruitful future research might qualitatively examine the experiences of those who had poorer outcomes.

A future improvement in care could be to systematically identify and include key caregivers throughout the entire treatment process even when an older adult is competent and making their own decisions. Involvement of caregivers for key discussions about medical decision making, discussions about advanced directives, and for discharge planning could help smooth the transition home and mollify some of the emotional distress of recovery, and may give caregivers an improved understanding of their role expectations during the patient’s recovery. This discussion could include time to recovery, specific expectations about need for assistance, and realistic expectations about functional recovery. This way, if caregivers are unable or unwilling to assist, other avenues or resources can be considered.

Another possible avenue to help bridge gaps for patients with instrumental and/or emotional needs could be peer support groups, which have been used in other complex medical conditions with promising results.<sup>13–16</sup> Within the field of acute care surgery, trauma peer mentors and peer support groups have been used, and utilisation of these and similar services have been demonstrated to have positive effects on adherence to care plans.<sup>13–17</sup> Social support has also been demonstrated to be key to recovery after cardiac surgery and cardiac interventions.<sup>18–19</sup> Although these populations differ from the older emergency

general surgery population, these patients share some parallels including the disruption to their daily lives related to an unexpected life-threatening illness.

Our study revealed that, although the timing and quality of recovery varied, a key recovery facilitator for older patients was reliance on spouses, other family, and friends for support for daily tasks and emotional support. There is an opportunity in healthcare to better align patients and caregivers throughout the process about posthospital discharge needs and expectations to bolster successful recovery. One participant (caregiver of 80s, female) said it best: “*In a real sense, we are team players, the medical people and myself, with a common objective. And that’s to see an individual be restored.*”

**Contributors** VPH, KAB, and ATP conceived of the study. VPH, PK, KAB, and ATP developed the interview guides. PK and BA performed study enrollment and performed interviews. VPH, DLD, PK, and BA performed and/or transcribed interviews. VPH, MJR, KAB, and ATP performed coding, thematic analysis and developed coding themes. All authors contributed to manuscript writing and critical reviews of the manuscript. VPH is the guarantor of this manuscript and accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

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**Competing interests** None declared.

**Patient consent for publication** Not applicable.

**Ethics approval** This study was approved by the MetroHealth System Institutional Review Board (study ID IRB20-00991). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** No data are available. This is not a clinical trial and we are not planning to make data available.

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