Elective Surgical Delays Due to COVID-19

The Patient Lived Experience

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Background: This qualitative research explored the lived experiences of patients who experienced postponement of elective cardiac and vascular surgery due to coronavirus disease 2019 (COVID-19). We know very little about patients during the novel coronavirus pandemic. Understanding the patient voice may play an important role in prioritization of postponed cases and triage moving forward.

Methods: Utilizing a hermeneutical phenomenological qualitative design, we interviewed 47 individuals who experienced a postponement of cardiac or vascular surgery due to the COVID-19 pandemic. Data were analyzed and informed by phenomenological research methods.

Results: Patients in our study described 3 key issues around their postponement of elective surgery. Patients described robust narratives about the meanings of their elective surgeries as the chance to "return to normal" and alleviate symptoms that impacted everyday life. Second, because of the meanings most of our patients ascribed to their surgeries, postponement often took a toll on how patients managed physical health and emotional well-being. Finally, paradoxically, many patients in our study were demonstrative that they would "rather die from a heart attack" than be exposed to the coronavirus.

Conclusions: We identified several components of the patient experience, encompassing quality of life and other desired benefits of surgery, the risks of COVID, and difficulty reconciling the 2. Our study provides significant qualitative evidence to inform providers of important considerations when rescheduling the backlog of patients. The emotional and psychological distress that patients experienced due to postponement may also require additional considerations in postoperative recovery.

Key Words: qualitative research, COVID-19, patient care

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As the coronavirus disease 2019 (COVID-19) pandemic spreads, health systems across the globe have been grappling with how to continue to care for patients with non-COVID-related health conditions. The pandemic has spilled-over to affect non-COVID patients, with large-scale delays and cancellation of procedures to conserve resources. Cardiovascular procedural care, although frequently considered urgent or emergent, has likewise experienced a significant decrease in volume. The Recent reports from Asia, the United States, and Europe have highlighted not only the lost volume of procedures, but also delays in care for time-sensitive cardiovascular conditions, such as acute myocardial infarction. The Similar effects have been observed anecdotally within our health system and state.

Within the United States (state redacted for peer review) emerged as an early hot spot for SARS-CoV-2 infections. In particular, as of April 1 (state) had experienced nearly 10,000 cases and 340 deaths.⁷ The rapid increase in cases overwhelmed hospitals, particularly in the (redacted) area, and hospitals limited the care of non-COVID-related disease. An executive order from the Governor of (redacted), (redacted), immediately stopped all elective surgery on March 21, 2020. As hospitals grappled with the volume of COVID patients and guidelines from government^{8,9} and societal bodies, 10 many hospitals stopped procedures for all nonlife threatening indications (ie, aortic valve repair, carotid endarterectomy). 11 As the pandemic continued to spread both within the United States and internationally, similar responses were implemented in countries all over the world, with patients left waiting for elective surgery with no idea of how long the surgical delay would be or what the recovery from such a delay would look like.

To further understand how the spillover effect of COVID on patients requiring cardiovascular care, we conducted semistructured interviews of patients who experienced a delay or cancellation of their cardiovascular procedures.

METHODS

Study Design

We aimed to understand the lived experiences of individuals who were scheduled for cardiovascular surgery at (hospital system redacted for peer review) and had their operations delayed due to COVID-19. As a team of social science and clinicians we framed our study as a hermeneutic phenomenology. 12–14 Our research goal fits the methodology

and interpretive philosophy of hermeneutic phenomenology which has consistently demonstrated to be useful in clinical settings. ^{12,15,16} Furthermore, our research team collectively held the sociological goal of verstehen (to empathically understand), as opposed to explaining or describing patient behavior. This study was approved and deemed exempt from ongoing IRB review by the (university redacted for peer review) Institutional Review Board (IRBMED HUM00181477).

Participants and Procedure

Interview participants were selected based on individuals who experienced a postponement in care in cardiovascular surgery and guided by principles in phenomenological research. We contacted individuals from a master list of delayed or cancelled cases, between March 13 and June 1, 2020, maintained at (hospital redacted). Patients were called to assess willingness to participate in a telephone interview and were scheduled for a later date. Three hundred ten patients were scheduled and delayed for surgery; we contacted 74 patients across both cardiac and vascular procedures to produce a more heterogeneous cardiovascular surgical population. Of those 74 patients, 17 declined and 57 agreed to a telephone interview, among whom 47 participated; 10 participants did not answer their phone for scheduled appointment and subsequent phone calls. Forty-seven individuals were interviewed between May 8 and May 23, 2020.

Our interview instrument was developed and informed by both traditional phenomenological interview techniques ^{17,18} and elaborated with active interviewing. ¹⁹ Interview domains and example questions can be found in Figure 1. Participants consented verbally and interviews lasted between 25 and 75 minutes. Interviews were audio recorded on an encrypted recorder, transcribed verbatim, and redacted for all identifying information. Participants were asked to select a pseudonym for the purposes of analysis to humanize patient data. Participants were monetarily compensated for their participation.

Explication of the Data and Rigor

Data were analyzed through iterative steps and informed through a phenomenological methodology. Data explication steps as a path to interpret the lived experience of postponement of cardiovascular surgery are found in Figure 2. We immersed ourselves in the data making observations as memos and highlighting significant statements. We repeated this process for each case in our data bracketing our assumptions at each new case. Second, we sought to find patterns that were identifiable across cases, or structural readings of the data. Finally, we used in vivo metaphors to elicit deeper meanings and lived experiences to arrive at themes.



FIGURE 1. Phenomenological semistructured interview domains with example question.

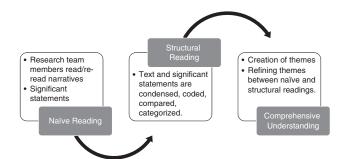


FIGURE 2. Phenomenological hermenutic methodological data explication as informed by Lindseth and Norberg. ¹²

To demonstrate rigor and trustworthiness, we worked as a team to attempt triangulation of our study as we discussed our findings with interdisciplinary frameworks which enhanced our understanding. We used purposeful sampling with potential variations of the data among differing cardiovascular procedures. Finally, because little is known, we entered the field with no preconceptions of the lived experience of living with cardiovascular disease and the uncertainty of COVID-19.

RESULTS

Individuals who experienced the postponement due to the stoppage of elective surgeries report negotiating the tension between a "good" heart and a "good" death. For individuals in our study, the lived experience of this phenomenon had a temporal and linear narrative: cardiovascular surgery meant to reclaim a former self or even a new self through surgical restoration (Table 1). When surgery was no longer on the horizon, individuals were left to negotiate between their bodies and new horizons of a multitude of unknowns of postponement (Table 2). This negotiation resulted in negotiating mortality as if individuals were left with a binary choice of choosing a known and "good" or the risk of entering into the unknown and "bad" COVID-19 (Table 3).

"It's really impacting my life"

Participants in this study spoke at length about their thoughts regarding their upcoming cardiovascular surgeries, the feelings they ascribed to their disease and treatment, and the meanings shaped by these feelings (Table 1). Participants most often spoke to physical and social normalcy when speaking about their bodies. Scheduled cardiovascular surgery was an opportunity to return to "normal" life. Seamus (a pseudonym), aged 70, explains:

It meant I was going to be fixed, and my life was going to be normal...It was going to be a successful operation...If they can get this done, and it is high risk, and it scares the hell out of me. But it's, at the same time, if it fixes it, that's what we're after because it's the quality of life.

Although Seamus does not explicitly state what "fixed" means to him, he does suggest that the anticipated outcome is improved quality of life. Alice, aged 46, further explains quality of life in terms of both her energy, but also her ability to earn a living:

I think I'm going to be so much better...I can't walk across the room without just being exhausted...I get very tired

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TABLE 1. Personal Meanings of Surgery					
Theme	Definition	Patient	Exemplary		
Personal mean- ings of surgery	How patients described the significance of the scheduled surgery	Richard, 75	I was ready. I knew it had to be done, and it's been this, like a rollercoaster ride really. I was up, I was positive, and I was ready to go. And I wanted to get it done. And I believe it was late March, I was scheduled for surgery. And it was about 2 days before I was to go, in fact, I had a duffle bag packed. I had everything ready. They called and postponed the surgery because of the virus. So that kind of mentally, you know, kind of knocks you down. So and then it's just been waiting, you know, that's the hard part		
		Lucy, 65	Well, sometimes, I feel like I'm a walking time bomb, but that's not too often. It's when I feel like shit. This is getting, this is going to be bad. But most of the time, I'm okay with it		
		Scott, 77	Well, I might have, I won't have to worry about it anymore. Because I got this thing in my head that if that aneurysm was to burst, I've read, or somebody told me, that you would bleed to death in 15 min, and that's always on my mind		
		Alex, 36	It's very tough to live with heart disease. It's not easy I would love something to be there for me, make me go back to normal life. No matter how long you live, a month, a week, a year, years, I don't know, nobody guarantees how long you live, but I would love to live even one normal heart day with no medications. I would love to		
		Lena, 60	You know, it's really impacting my life. I can't think about, you know, going to Florida, doing anything fun or having the fun life that we were supposed to have with retirement when I'm like this, when I feel like this all the time. It just really sucks I'm not just going to sit and do nothing. I'm going to walk every day. I'm going, I love to ride bicycle. That's my thing. I just love to ride bikesIt's, getting the surgery is going to really change my life for the better		
		Paul, 60	č ,		

quickly...it just got to be where I could work less and less. At one point I was working just enough to take care of my bills.

For some patients, the uncertainty of what might happen to their bodies during everyday activities brought on feelings of being downhearted or blue. Not all participants in this study were just a "little depressed." For example, Jerry, aged 67, describes his clinically treated depression:

I see a psychiatrist and a therapist because depression is terrible...I don't want to talk to anybody, see anybody. Leave

Theme	Definition	Patient	Exemplary
Impact of postponement	Emotional or physical toll of post-poning elective surgery	Gail, 54	But having this hanging in the back of my mind I think, am I going to overwork my heart? Is it going to cause it to act up? It's just kind of, it kind of put the damper on the things that I enjoy I'm sitting here thinking, you know, if I do too much of anything, I could end up having a heart attack, another one, and I says, you know, this is kind of bad. I could sit here and die. And I should be having an operation, you know. So that really kind of weighed on my mind
		Seamus, 70	And then we got to a couple of weeks back, I was here waiting for the phone call anxiously. And every time we get a call in the week, it would be delayed farther and the disappointment and the anxiety, the pressure, it was mounting. And I was not that pleasant a person to be around with this caring that I was getting so wonderfully by my family. But I was wearing people, very much. And pretty diligent about it in the limitations that I have, but I'm trying to be as active, but you don't feel like being active. That's the biggest problem in all of this. And having to wait this amount of time and the delays and the reasons for the delays. And back and forth and the trips to [city]. The ups and downs and the emotional swings have been hard
		Paul, 60	Just that there was more damage that was going on. I mean, like I said, I could feel more symptoms, and I was just worried that the repair would be, would turn into a replacement then. And I still don't really know for sure yet. They may go in there and they may, you know, the doctor looked at the imaging, and, you know, he did just before our conference call last week. And he thought for sure that this would just be a simple repair, but a couple months has passed. I don't know if there's been any more damage. And so it's still kind of like the same thing going back to my father, you know, that they're going to open me up, and they're going to find more there than what existed before
		Ken, 73	Well, it's a little devastating when they say, okay, you need this surgery, and we got to get you in here. And I'm telling my family, I said, hey, I've got everything put to bed, you know, and what's going to happen if I don't make it and this and that. And you go through all those kind of things and it makes you think about if you're not here anymore, what are you going to do? And that's stressful. It really is because, you know, you're really not totally, you know you're going to die But the anticipation of when you're going to go in, nobody is telling you anything. You know, and nobody is saying, hey, we're going to be next month, it'll be two months, and it's just, it's kind of nerve wracking to a degree, and you don't try to think about it that much, but it's still there. You know, so I don't know. If that answers your question or if it doesn't hit me with another one

Theme	Definition	Patient	Exemplary
Fear of COVID- 19	Expressed concerns of COVID-19	Jeremiah, 68	Well, the risk of it bursting, which I live through all the time, I know, I understand that. Okay. But it sounded like to me, if I went into the hospital and had this operation done, that I was going to catch COVID-19 and die within two weeks. That's the way it sounded when all this stuff started out
		Marie, 65	· · · · · · · · · · · · · · · · · · ·
		Lena, 60	Just knowing that you have a heart condition is unnerving. You know what I mean? It's unnerving. It's annoying. It hurts your feelings. It makes you kind of feel sorry for yourself. It, because that's something very personal that you just deal with in your own mind, every day. You know what I mean? It's something that you wish you didn't have to get fixedBut I'm not like, I mean, if I was having, I'm not fainting or anything like that. If I were fainting every day, or if I had chest pain, I would go right to the emergency room. I would say, you know, heck with COVID-19. If I don't get in there, I'm going to die. You know what I mean? I'm going to have to take my chances
		Hal, 67	I mean, my joke is, if I die, I want it to be from a cardiac-related cause, not a virus. You know, that would be ridiculous going through everything that I have done, going in and being killed by a virus, as opposed to the surgery
		Elsbeth, 68	I don't know, a few weeks ago and asked if I wanted to have surgery in the next, you know, the next week or so, and I, or did I want to wait until the end of May, first of June? And I said, at that point, you know, I really think that I'd rather wait. As much as I want it done, those nurses are overwhelmed right now. They don't need another person in there. Let's hope this starts calming down, and they get a breather before, you know, people are coming in for surgery. So as much as I want it done, I want to be smart about it too
		Shannon, 74	But if somebody said come in tomorrow, I don't care if it was the toe doctor or whoever, I would go have it done because, yes, I'm tired of the stress. No one realizes the stress. And like I said, I do have the chest pains all the time, but they go away. They just come and go. And I figure if they just go that's all right. I'm just hoping that it would make a difference but it could also kill me, you know, so, but I would have it done tomorrow if I could. Whoever would do it and whoever wouldn't kill me in the process
		Sophia, 56	And then the Coronavirus hit. Everything came to a stop. I couldn't have my surgery. I'm literally afraid to have my surgery now, and I'm just going day by day on prayer and hoping that nothing breaks off, that these blood thinners that I was given every since I was diagnosed help me out, and, you know, that I don't have anything fatal attack my system

me alone, and I would love to go find a tall building to jump off of...

M.E.B.: ...what about...your health causes you to feel so downhearted?

The legs. I was exceedingly active before this AAA blew up... And it's hard to wrap your head around the fact that you are now half a man.

As Jerry describes, the mental impact of his physical condition was so severe that he recognized the need for help. Participants in our study described a vast array of the physical and emotional toll that living with a cardiovascular issue took on their lives.

In other instances, living with cardiovascular disease resulted in a deep emotional toll that patients describe in vivid detail. Patients often describe surgery as the paramount of hope to a better quality of life. Alice, aged 46, provides more understanding of what it means to live with a poorly functioning mitral valve:

It's not an easy way to live. I'm very aware of everything I'm doing to not overexert myself, because I don't know what the limitations are on my heart valve and what kind of issues I could have...I don't know when that moment would be...

Alice explained, not knowing "when that moment would be" of overdoing activity on the heart was described by

other patients as a "walking time bomb" (Lucy, aged 65). The impact of living with a cardiovascular condition extended beyond the uncertainty of its physical toll. Many patients described the emotional impact of living with a cardiovascular condition.

"A repair to replacement"

Participants in our study shared a myriad of burdens and concerns about their bodies due to postponement (Table 2). Patients often spoke at length in their narratives about the "uncertainty" and "fearing what you don't know" (Scott, aged 77). For some patients, the distress of not knowing how their condition was deteriorating was at the forefront of the conversation. Paul, aged 60, describes this distress:

I could definitely feel my health declining...you're just kind of waiting with no set schedule date in your mind...I didn't know how long this was going to last...So where we at now as far as when do we go from the point of just having a repair to a replacement? You know, when is my health going to diminish that, to that point?

For Paul postponement of his mitral valve repair meant that he could potentially face a more invasive procedure. The notion that he could "feel" his "health declining" had an emotional impact while he sat and waited for his procedure. As Table 2 describes, participants experienced this uncomfortable tension of knowing a solution exists to

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physical suffering, yet unable to see or grasp the solution during the delay. Gail, aged 62, elaborates:

I'm sitting here thinking, you know, if I do too much of anything, I could end up having a heart attack, another one, and I says, you know, this is kind of bad. I could sit here and die. And I should be having an operation, you know.

"My whole life felt like it was on hold"

For other participants in our study, the physical impact of not knowing where they stood with their cardiovascular condition meant a more burdensome quarantine. Nate, aged 65, explained:

... not that I wasn't frustrated that I had to wait a couple more months...but my whole life felt like it was on hold... People were all going through this quarantine issues, but it was worse for me, because at least if I could've like done home projects or kept active somehow...I felt like an invalid...I suffered with a little bit of depression over it because of the questions in the air how long is this going to happen...and when am I going to get my life back together...?

For Nate, quarantine was "worse" for him because of the compounding impact of living with an unrepaired cardiac condition limited his ability of what kind or how much physical activity he could do at home to cope making him feel like an "invalid."

Other patients describe feeling sidelined because of COVID-19 patients. Gladys, aged 74, elaborates:

It's just the idea of sitting in a chair at night, and you might think the phone is going to ring and say, hey, come on down to [the hospital] and we're going to fix you up, and you never hear nothing...When the virus came in, they took everybody else that needs care, they took it away.

Other patients echo this sentiment that "they took surgery away" and Richard, aged 75, described the ups and downs of waiting:

It's like getting punched in the stomach...Mentally, I was ready to go. Let's go, I'm ready, you know, and let's get this done. And then to have the rug pulled out from underneath you...

"If I die, I want it to be from a cardiac-related cause"

Several patients described the unusual scenario of being caught between fear of the virus and living through a pandemic with a cardiovascular condition (Table 3). Hank, aged 69, offered insight:

I mean, I got no problem going to the hospital, but just like... this news is just depressing...they've got me afraid that anything and everything I do, I'm going to die...It makes me feel like...I walk outside and there's going to, they got a bull's-eye on me, and they're going to shoot me.

Hank intimated that he was a target of COVID because of his health status. This "bulls-eye" is, at least in part, due to the way he understands how the media discusses high-risk individuals.

Participants cardiovascular conditions and delayed surgery were not the only source of fear for patients in our study. The constant and ongoing uncertainty of rapidly changing information about COVID-19 in relation to patients surgery often felt like the gamble of "all-in-poker" (Seamus). Many patients describe something similar to this gamble, where they felt like they were taking the chance of dying from either a cardiovascular condition or COVID-19. Jeremiah, aged 68, who cancelled his own surgery, did so because he weighed the benefits of surgery against the cost of surgery during a global pandemic:

I figured having the surgery, I was signing the death warrant...I feel if I waited it out, I was extending my life... the risk of it bursting, which I live through all the time, I know, I understand that...But it sounded like to me, if I went into the hospital and had this operation done, that I was going to catch COVID-19 and die...

Other participants feared catching COVID-19 from the health care workers themselves and so wanted nothing to do with surgery. Lena, aged 60, walks us through how she thinks about her own safety after cardiac surgery during a pandemic.

I think there is nothing worse than having a major surgery when there is like a pandemic...it freaks me out to even think about it...I personally want to wait now, if I can, until after there's a vaccine...but I don't know if I can wait that long...

Lena, expressed an understandable distrust of the invisibility of the virus and not knowing if health care workers are interacting with COVID-19-positive patients, which is enough for her to wait as long as she possibly can.

Although many patients feared COVID-19, some did not want to add burden to frontline workers and health care system. Elsbeth, aged 68, offered insight to this standpoint:

[My surgeon] asked if I wanted to have surgery in the...next week...or did I want to wait...And I said...I really think that I'd rather wait. As much as I want it done, those nurses are overwhelmed right now. They don't need another person in there.

Other patients concurred offering, "there are bigger problems than...my own surgery" (Anika, aged 55).

The idea that one was more likely to catch COVID-19 at a hospital as opposed to the community was shared by several patients in our study. An overwhelming majority of patients were "relieved" (Nolan, aged 67) to have their surgeries postponed because they understood the risk of entering into a hospital. Sophia, aged 56, elaborates:

I was terrified thinking I would have to go in [to the hospital] and get this surgery when there was a bunch of...coronavirus in the hospital...The odds are pretty good of getting the coronavirus while you're in the hospital...that's where it is. It's in the hospital...it could be at your neighbor's house, you know, but you'll never be at your neighbor's house.

Sophia speaks to larger issues of control and safety. She suggests that COVID-19 "could be at your neighbor's house" however, Lena has control over entering into different spaces such as a neighbors. To Lena, sick patients are concentrated

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in a place and so she has less ability to regulate her physical distancing.

DISCUSSION

We attempted to explicate the experiences of 47 patients whose cardiovascular surgeries were postponed due to COVID-19. Our research demonstrates the delay of elective procedures had a significant impact on the well-being, physical health, and emotional health on our patients. Furthermore, patients in this study report that dying from the "devil they know" was more desirable than the unknown. We identified several components of the patient experience, including the need for patients to reconcile their desires to undergo surgery and the prospect of improved quality of life with the risks associated with perioperative infection with SARS-CoV-2. Participants often described an understanding of the necessity of the delay and the associated risks with an early return to elective surgery for the community/state, but each participant also described the experiences of the tradeoff between this risk and the individual risk of progression of their disease or even simply continuing to live at their current level of quality of life.

An important and primary goal in surgical care is to relieve physical suffering. For these patients, physical suffering was compounded by emotional suffering: not only by the disruption of care, but by the delicate balancing act patients described to manage their symptoms amidst the uncertainty of disease progression. Extensive research in palliative care examines issues like this as existential distress in patients.^{21,22} Existential distress or suffering is the turmoil that patients face when confronted with the end of life that threatens a psychological sense of safety. For some patients who coped less well, this meant ideating suicide or the constant din of a vascular reality: "is it gonna burst?" For those who fared better through the existential distress, they made sense of their predicament by diminishing and situating their suffering in deep philosophical meaning and altruism—to them, there were bigger social problems than their surgery.

We caution against arguments that patients are merely resilient.²³ Resiliency should not mitigate the real consequences of patient suffering and existential distress. For a large proportion of patients in our study, they viewed this suffering as the result of the instability created by delayed procedures as making a choice between 2 deaths: the "good" death of cardiac/vascular disease or the "bad" death of COVID-19.^{24,25} Patients in our study openly acknowledged the implication of death due to surgical postponement. When considering how we move forward in patient care, the notion that disease could end their life was the trade-off they were willing to make to avoid death by COVID-19 and should inform how providers discuss surgery with patients. We might also consider how we discuss these risks of not seeking medical care, when medical care very well may restore a life.

Understanding the lived experiences of individuals with life-threatening disease may contextualize excess mortality reporting. Reports in the United States and United Kingdom in particular have begun to report on excess mortality during COVID-19.^{26,27} Although much is unknown about excess

deaths, it is reasonable that our data may illuminate the experiences of individuals who may have not sought out needed care and managed symptoms at home in lieu of hospital care. Our results suggest an additional component to consider: emotional and psychological distress of access to needed care during a pandemic.

We recognize several limitations in our study. First, our timing of interviews provides only a snapshot at one point in time of patients lived experience. Patients in our study had nearly 7 weeks to process their predicament and some patients had already been rescheduled or called to reschedule near the end of our data collection. Calling earlier in the postponement may have provided more nuanced results. Second, we sampled from 1 hospital and experiences may not be uniform across health systems, regionally, or internationally. We oversampled in order to compensate for our geographic restrictions. Subsequent studies should expand their sampling framework. Third, because we reimbursed individuals for their time they invested in our research, we understand that this may be viewed as biased results.

Our phenomenological study of patients during COVID-19 provides an early understanding of how patients navigated through the uncertainty of their postponed cardiovascular procedures. We found that patients defined surgery as a remedy to disease and a mechanism that would restore normalcy to their lives. Although some patients navigated through the uncertainty with ease, a large majority of patients were distressed because of the precariousness of their physical and emotional state. In addition, patients juggled the 2 uncertainties of dying from their cardiovascular disease or from COVID-19. Interestingly, most viewed hospitals as unsafe places that should be avoided and preferred to gamble with the risk of delaying their procedure over the risk of exposure to and their perceived certain death from COVID-19. These results should inform our response to not only the COVID-19 pandemic and rescheduling and prioritization of procedures, but also how we respond as a health care system to future crises. Attention to the lived experiences of patients experiencing delays in care will be paramount to preventing unnecessary complications from delay.

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