


The impact of the COVID-19 pandemic on care delivery and quality of life in lung cancer surgery

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Abstract

Background: The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) (COVID-19) pandemic and associated restrictions have altered the delivery of surgical care. The purpose of this study was to explore the impact of COVID-19 on care delivery and quality of life (QOL) from the perspectives of lung cancer surgery patients, family caregivers (FCGs), and thoracic surgery teams.

Methods: Patients/FCGs enrolled in a randomized trial of a self-management intervention for lung cancer surgery preparation/recovery were invited to participate in this qualitative study. Patients/FCGs data were collected separately 1-month postdischarge. Interviews were also conducted with thoracic surgery team members. Content analysis approaches were used to develop themes.

Results: Forty-one respondents including 19 patients, 18 FCGs, three thoracic surgeons, and one nurse practitioner participated in the study. Patient themes included isolation, psychological distress, delayed/impacted care, and financial impact. FCGs themes included caregiving challenges, worry about COVID-19, financial hardship, isolation, and physical activity limitations. Surgical team themes included witnessing patient/FCG's distress, challenges with telehealth, communication/educational challenges, and delays in treatment.

Conclusions: COVID-19 had a varied impact on care delivery and QOL for lung cancer surgery dyads. Some dyads reported minimal impact, while others experienced added psychological distress, isolation, and caregiving challenges. Surgical teams also experienced challenges in the approach used to provide care.

KEYWORDS

family caregivers, isolation, patients, quality of life, telehealth, thoracic surgery

Abbreviations: CRA, clinical research assistant; FCGs, family caregivers; QOL, quality of life; SARS-CoV-2 or COVID-19, severe acute respiratory syndrome coronavirus 2.

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1 | INTRODUCTION

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2 or COVID-19)¹ pandemic has had a profound impact on healthcare in the United States and globally. Older adults and patients with cancer have been disproportionately affected both due to the higher risk of severe COVID-19-related illness in these groups and the interruption in standard medical care.² Lung cancer patients deserve particular consideration as they tend to be older, have high rates of comorbid cardiopulmonary disease, and often undergo treatments that can increase the risk of COVID-19 complications.³ Lung cancer patients also have high levels of caregiving burden.⁴

Even before the COVID-19 pandemic, informal family caregivers (FCGs) played a critical role in supporting their loved ones through lung cancer treatment.⁵ During the pandemic, cancer care delivery has been altered with delays in screening, and treatment with an elevated caregiving burden for FCGs.⁶ At the same time, many healthcare systems have restricted visitor access, thus increasing isolation for patients and making it more difficult to integrate FCGs into decision-making and care planning. This has increased caregiver burden and stress levels.

Medical providers have also experienced significant strain due to COVID-19. Healthcare workers have reported higher levels of anxiety and burnout related to the perceived risk of COVID-19.⁷ In addition, alterations in usual workflows and resources have contributed to work-related stress.⁸ COVID-19-related restrictions have also altered the relationship between providers, patients, and FCGs.

This observational study was conducted as a parallel study to a randomized clinical trial of a dyadic self-management intervention to prepare patients and FCGs undergoing lung cancer surgery.⁹ The time around surgery is particularly stressful for lung cancer patients and FCGs. As the COVID-19 pandemic began impacting the healthcare system, providers noted the standard support mechanisms for patients and FCGs in the perioperative period were being disrupted. To better understand the concerns of patients, FCGs, and providers related to COVID-19, we conducted a qualitative study exploring the impact of COVID-19 on care delivery and quality of life (QOL) from the perspectives of both lung cancer patients/FCGs and the surgical care team.

2 | MATERIALS AND METHODS

2.1 | Intervention, sample, and setting

The parent study which served as a foundation for this qualitative exploration of COVID-19 experiences is a multimedia, self-management, randomized intervention trial to prepare FCGs and patients for lung cancer surgery from a National Cancer Institute-designated comprehensive cancer center in Southern California. During the study, COVID-19 policies in effect at the cancer center did not allow patients to have visitors during inpatient or outpatient encounters with limited exceptions not applicable to

our target population. All study activities for the parent study and COVID-19 related activities received Institutional Review Board approval.

2.2 | Procedures

Participants enrolled in the parent study were eligible for the qualitative COVID-19 study 1-month postdischarge. Patient eligibility criteria included: (a) diagnosis of lung cancer or presumed lung cancer (as determined by surgeons); (b) scheduled to undergo surgery for treatment; (c) an FCG enrolled in the parent study; (d) age 21 years or older; (e) able to read or understand English or Chinese. FCG eligibility for the study included: (a) a family member or friend identified by the patient as being the primary care provider before and after surgery; (b) a patient/care recipient enrolled in the study; (c) age 21 years or older; and (d) able to read or understand English or Chinese. Questions related to the impact of COVID-19 on QOL of patients and FCGs were administered via telephone and an online survey between August 15, 2020 and May 6, 2021. Semi-structured interviews on the impact of COVID-19 on cancer care were conducted with providers between January and February 2021.

A total of 37 respondents (19 patients and 18 FCGs) participated in the study. Four patients and one FCG were interviewed by telephone, 15 patients, and 17 FCGs provided responses using an online survey through REDCap. Of the responses provided by telephone, two patients and one FCG were interviewed by a clinical research assistant (CRA) and the CRA documented the responses in REDCap. The two remaining patient telephone interviews were audio-recorded and transcribed verbatim by a CRA. The study principal investigator (VS) determined the recordings could be transcribed accurately by the study CRA due to the brevity of the responses. All patients were asked the following questions: (1) How has the COVID-19 crisis impacted your cancer care, your work situation, your income, and your housing? (2) How has the COVID-19 crisis impacted your emotional well-being? FCGs were asked the following questions: (1) How has the COVID-19 crisis impacted your ability to care for your family member or friend before and after their lung cancer surgery? (2) How has the COVID-19 crisis impacted your work situation, your income, and your housing? (3) How has the COVID-19 crisis impacted your physical health and emotional well-being?

Providers were informed of the purpose of both the parent study, the purpose of the interviews, and were invited to participate via waiver of documented consent. A total of four providers (three surgeons and one nurse practitioner; the surgery team at the institution is comprised of three surgeons and two nurse practitioners) offered clinical perspectives on the impact of the pandemic on patients and FCGs' QOL. Interviews were conducted by telephone and audio recorded. Audio recordings were transcribed verbatim by a transcription service. The accuracy of the transcripts was reviewed by a study CRA. All providers were asked the following questions:

(1) How has COVID impacted the preoperative care provided to patients? (2) How has COVID impacted the patient's care during the time of the surgery admission? (3) How has COVID impacted the care of patients after discharge following surgery? (4) What has been the impact of COVID on family caregivers of patients undergoing surgery? (5) What do you think has been the most difficult aspect of caring for surgical patients during the pandemic? (6) What have you found to be most helpful as you care for these patients during COVID? (7) The pandemic began very suddenly, and, in many ways, we had limited time to prepare for the changes that would be necessary for care. As you think about the possibility of future pandemics, what could be done to best protect the quality of patient care?

2.3 | Data analysis

We used a conventional content analysis approach to derive meaning from participants' experiences during the pandemic.¹⁰ We developed codes or themes directly from the respondents' interviews and then used the theory or relevant research to interpret meaning from the data. This process was completed in three phases. Phase 1: Four reviewers (DT, BF, VS, and JK) independently coded the patients, FCGs, and provider interviews. Phase 2: Two reviewers (VS and JK) independently reviewed the patients/FCGs codes and developed content themes. Phase 3: Three reviewers (DT, VS, and BF) reviewed and finalized the themes. Coding and/or theme disagreements were discussed, refined, and resolved. JK who participated in the provider interviews, only coded and developed themes for patients and FCGs. The remaining providers who were interviewed did not participate in the analysis of the patient, FCG, or provider data.

3 | RESULTS

Most patients were diagnosed with upper ($n = 13$, 68%) and lower ($n = 4$, 21%) lobe lung cancer. Surgical methods used included minimally invasive methods (robotic-assisted technology or video-assisted thoracoscopic), and open surgery. Sixty-three percent of patients also had hypertension and 21% had coronary artery disease. The majority of FCGs were spouses or partners of patients. Table 1 includes sociodemographic and health characteristics for both patients and FCGs. As depicted in Figure 1, a word map was created from the interviews of patients, FCGs, and providers to denote the impact of COVID-19 on QOL. The word "unclear" was frequently ($n = 78$) used by participants to describe the impact of the COVID-19 pandemic on care delivery and the subsequent themes provide their detailed perspectives.

Five-themes described QOL experiences of lung cancer surgery patients during the COVID-19 pandemic: isolation, mental and emotional distress, delayed and impacted care, financial impact, and minimal impact on QOL (Table 2).

TABLE 1 Lung cancer surgery patients ($N = 19$) and family caregivers ($N = 18$) demographic and health characteristics.

Characteristics	Patients	FCGs
Age (years) ^a	67 (65, 71)	64 (59, 67)
Gender, n (%)		
Female	7 (37%)	11 (61%)
Male	12 (63%)	7 (39%)
Ethnicity, n (%)		
Yes	8 (42%)	6 (33%)
No	11 (58%)	12 (67%)
Race, n (%)		
White or Caucasian	13 (68%)	12 (67%)
Black or African American	1 (5.3%)	2 (11%)
Asian	3 (16%)	3 (17%)
Other ^b	2 (11%)	1 (5.6%)
Education, n (%)		
<High school diploma	3 (16%)	-
High school diploma or GED	5 (26%)	4 (22%)
Some college	4 (21%)	5 (28%)
College degree	3 (16%)	3 (17%)
≤Graduate degree	4 (21%)	4 (22%)
Vocational School	-	2 (11%)
Marital Status, n (%)		
Single	-	2 (11%)
Married	15 (83%)	14 (78%)
Partnered	-	1 (5.6%)
Divorced	2 (11%)	1 (5.6%)
Widowed	1 (5.6%)	-
Employment, n (%)		
Part-time	1 (5.3%)	2 (12%)
Full-time	2 (11%)	5 (29%)
Unemployed	-	2 (12%)
Retired	14 (74%)	7 (41%)
Other ^c	2 (11%)	1 (5.9%)
Income, n (%)		
≤\$50,000	5 (28)	4 (24%)
\$50,001 to \$75,000	3 (17%)	5 (31%)
\$75,001 to \$100,000	3 (17%)	1 (6.2%)
Greater than \$100,000	7 (39%)	6 (38%)
Religion, n (%)		
Protestant	5 (26%)	5 (29%)
Catholic	7 (37%)	7 (41%)

(Continues)

TABLE 1 (Continued)

Characteristics	Patients	FCGs
Jewish	2 (11%)	1 (5.9%)
Other	4 (21%)	2 (12%)
No religious affiliation	1 (5.3%)	2 (12%)
Smoking status, n (%)		
Current smoker	1 (5.3%)	–
Quit less than 6 months	1 (5.3%)	3 (17%)
Quit more than 6 months	8 (42%)	4 (22%)
Never smoked	9 (47%)	11 (61%)

^aAge, n (median).

^bRace, Other: Latino/a, Central American Indian.

^cEmployment, Other: Workers' compensation, out on medical leave after should repair surgery, retirement, and self-employed.

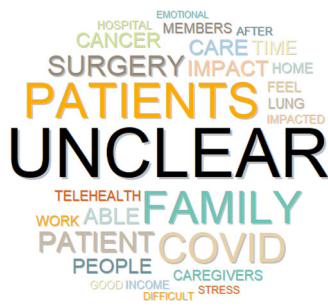


FIGURE 1 Overview of lung cancer surgery patients, family caregivers, and providers/' perspectives on the impact of coronavirus disease 2019 (COVID-19) on quality of life.

3.1 | Theme 1: Isolation and impact on social support

Patients experienced isolation from family and friends due to stay-at-home orders and the no visitation policy at the cancer center. Family members were not allowed to visit patients after surgery or attend clinic appointments which negatively impacted patients' social support. While some patients attempted communication with their family using virtual mediums like Zoom teleconferencing, the experience proved to be ineffective for some.

3.2 | Theme 2: Psychological distress

The traditional stressors of having surgery were compounded by the restrictions and impact of the pandemic. Several patients experienced emotional distress due to isolation from family, and the general population, as well as their awareness of the high mortality rates from COVID-19 infections. Patients were afraid of getting COVID-19 from family members, and family members worried about unintentionally infecting patients with the virus. The possibilities of a cancer recurrence, a compromised immune system, and potential death from the virus brought a heightened acknowledgment of one's mortality.

3.3 | Theme 3: Impacted and delayed care

Two patients noted experiencing severe delays in treatment. For example, one patient's delays in treatment by several weeks prompted their change from a different hospital to receive care.

3.4 | Theme 4: Financial impact

Patients experienced financial hardship through decreased earning potential, furloughs, layoffs, and voluntary early retirements. These financial burdens magnified the usual financial toxicity associated with serious illness. Others were not financially impacted by the pandemic because of workers compensation wages, continual employment, and homeownership assets.

3.5 | Theme 5: Minimal impact on cancer care, work situation, income, or housing

Fortunately, 32% of patients experienced minimal perceived impacts on care, employment, income, or housing during the pandemic.

For FCGs, six themes emerged: hindrances to the caregiving role, protecting patients from COVID-19, financial hardship, isolation, physical activity limitations, and minimal impact on QOL (Table 2).

3.6 | Theme 1: Hindrance to caregiving role

The visitation policies enforced during the pandemic prevented FCGs from participating in the usual care discussions provided to patients after thoracic surgery including postoperative information about chest tubes, pain management, and several other postoperative care needs that involve FCG support. FCGs felt unprepared to manage care after discharge because they had not been present in the hospital setting.

3.7 | Theme 2: Protecting patients from COVID-19

FCGs also developed an increased awareness of public health safety protocols to prevent transmission of the COVID-19 virus to patients. Precautions are taken included hand washing, masking, disinfecting, and sterilization of frequently used surfaces, social distancing, quarantining, and/or limiting visitors to patients' homes.

3.8 | Theme 3: Financial hardship

FCGs experienced decreased income and housing insecurities due to the pandemic. The shelter in place orders prevented FCGs from

TABLE 2 Lung cancer surgery patients, and family caregivers' perspectives on the impact of COVID-19 on quality of life.

Impact on patients	
Theme	Quote
Isolation/impact on social support	"At first it was ok, but as time has gone on it has become more difficult and isolating from family and friends."
Psychological distress	"Having had cancer surgery and the months leading up to the surgery were already stressful without the added stress of Covid-19. Being restricted and fearful of going out in general population is emotionally distressing."
Impacted/delayed care	"My cancer care had a major impact because the original doctor I was going through could not schedule my surgery. There were several weeks of time that delayed my care, and I had to jump ship, and went to City of Hope. I was able to have surgery there."
Financial impact	"I was furloughed, and I took a voluntary lay off because my work was not following protocol and I didn't feel safe. So, I am currently not working. I went ahead and retired before I wanted to. It hasn't really affected my income too bad, salary decreased by about maybe 10%. From that 10%, I figure is my commute time and gas. I was able to retire and collect social security and other benefits. It did not affect my housing. We bought a house over 24 years ago and have never taken any money out of it. So, our house payments are very minimal."
Minimal impact on cancer care, work situation, income, or housing	"It did not affect our work or income. Housing is still good. It didn't affect any of our mortgage."
Impact on family caregiver	
Theme	Quote
Hindrances to caregiving role	"The uncertainty of not knowing the truth, unable to go to doctors. It impacted me emotionally because I could not attend in person, and physically because it added more stress."
Protecting patients from COVID-19	"COVID-19 has not much impacted my ability to care for my family member before and after her lung cancer surgery. Maybe just more cautious and more aware of keeping everything more cleaner and more sterile. Staying home, avoiding contact with people so as not to bring any virus or infectious agent home."
Financial hardship	"I was laid off from work and we had to sell our home in CA and move to KS."
Isolation	"The hardest part for both of us is not being able to hug the kids and our grand-daughter."
Physical activity limitations	"Yes, my physical health and emotional well-being have been impacted because of the restrictions on outdoors activities."
Minimal impact on caregiving, work situation, income, or housing	"My wife and I have been very diligent in keeping ourselves healthy by exercising at home, gardening at home, do some home repair, reading, meditating, basically keeping busy so that we won't lose our mind from staying at home due to COVID-19. Always staying positive not letting negativity bring us down. We are physically and emotionally healthy."

Abbreviation: COVID-19, coronavirus disease 2019.

working or resulted in reduced wages due to less employment hours. For one business owner, revenue decreased 30%–40%, and another respondent was laid off, prompting the selling of their home and relocation to another state.

3.9 | Theme 4: Isolation

Social interactions with family and friends were minimized which resulted in feelings of isolation and longing to connect with loved ones. FCGs identified this time of recently learning of the patient's lung cancer diagnosis as a very stressful time in which they would generally rely on the support of family and friends.

3.10 | Theme 5: Physical activity limitations

FCGs' physical health was negatively impacted due to the restrictions on outdoor activities. One FCG, who contracted COVID-19, discussed the stressors related to learning new behaviors to accommodate pandemic norms of living and interacting with others.

3.11 | Theme 6: Minimal impact on caregiving, work situation, income, or housing

Many FCGs (61% of participants) reported being able to cope with the demands of the COVID-19 pandemic. Some reported benefits

such as working from home which allowed them to spend more time with the patient. Several caregivers identified coping strategies to deal with their stress including gardening, home repairs, reading, and meditation were helpful in improving the overall health and wellbeing of patients and FCGs.

Four themes described the impact on cancer care delivery for patients' preoperative care, postoperative hospitalization and discharge from the perspectives of the thoracic surgery team, including a nurse practitioner and three thoracic surgeons (Table 3).

3.12 | Theme 1: Psychological distress

Providers acknowledged the psychological distress experienced by cancer patients which were compounded by restrictions on visitation due to the pandemic. Patients already have a great deal of distress from their lung cancer treatment. The experience of being diagnosed with lung cancer during the time of the pandemic added a significant layer of additional stress and anxiety. The absence of visitors and caregivers, especially for non-English speaking patients was challenging during the preoperative period.

Providers observed patients experiencing isolation postoperatively as well as the negative psychological consequences of visitation policies enforced during the pandemic. While the use of videotelephony applications was useful for some patients, older patients had challenges using technology to connect with family members after surgery. Patients also have less respiratory capacity after surgery, which puts them at higher risk for negative COVID-19 outcomes. This reality for some patients led to increased anxiety and stress post-surgery.

3.13 | Theme 2: Dissatisfaction with care

Providers felt that anxiety related to the consequences of the pandemic resulted in less patient satisfaction about their care. Increased emotions around patients' desires to be vaccinated and the staffs' inability to provide vaccinations led to negative emotional reactions. The visitation restrictions which deviated from pre-pandemic care delivery norms also decreased patients' satisfaction with their care. Providers also reported anger from patients and belligerence on strict hospital policies about maintaining public health mandates (i.e., masking).

3.14 | Theme 3: Delayed diagnosis and treatment (surgery)

Procedures implemented to reduce the spread of COVID-19 delayed surgery for some patients. It increased the travel burden with multiple trips to the cancer center and prolonged the preoperative process with requirements of additional diagnostic testing, including COVID-19 testing before procedures. Some patients received

preoperative care through telehealth which decreased their travel burden but limited face-to-face contact with their providers. Providers also suspect some individuals with early-stage disease are not being diagnosed and those that were diagnosed months before the pandemic have experienced delays in their treatment due to the pandemic. For example, providers found some patients had delays in pulmonary function tests (PFTs) due to requirements of COVID-19 testing before undergoing the tests.

3.15 | Theme 4: Concerns and lack of education on COVID-19 risk factors

The lack of knowledge of COVID-19 risk factors impacted patients' postoperative recovery. Providers encouraged patients to be "more careful or take extra precautions" after surgery because a COVID-19 infection could impact their recovery or place the patient at serious risk of death. Before the pandemic, providers recommended patients engage in physical activities, such as walking outside, but most patients were not willing to leave their homes, which may prolong their recovery period. Lastly, providers stressed the importance of educating patients on COVID-19 risk factors because normal side effects of lung cancer surgery like dry cough, chest pain, and shortness of breath are similar to symptoms of COVID-19 infection.

Five themes described providers perspectives of the impact of COVID-19 on FCGs of patients undergoing lung cancer surgery (Table 3).

3.16 | Theme 1: Frequent communication with surgical team

As FCGs were not allowed to visit the cancer center during the pandemic, providers sometimes discussed treatment and recovery plans with patients, FCGs, and other family members separately often leading to gaps in information and misunderstandings. Providers recognized the importance of clear communication to ensure postoperative care and symptom management by FCGs post-discharge and the lack of consistent communication was seen as a major concern.

3.17 | Theme 2: Psychological distress

There were several psychological stressors experienced by FCGs including stress, guilt, or worry about potentially exposing patients to COVID-19 and lack of connection to the care team which hindered their caregiving role. Providers suggested educating FCGs on COVID-19 safety protocols may reduce their stressors by allowing more interactions with patients. The lack of interactions with the care team left FCGs more stressed about their caregiving role and unprepared on how to support patients after surgery.

TABLE 3 Providers' perspectives on the impact of COVID-19 on quality of life for lung cancer patients and family caregivers.

Impact on patients	
Theme	Quote
Psychological distress	"It's definitely an added level of stress and then postoperatively definitely because patients have less respiratory capacity than they did before the surgery. So, it's definitely a major concern to them (unclear) to have to worry about COVID and know that they are at even a higher risk of as they were preoperatively."
Dissatisfaction with care	"I think that part is kind of difficult. I do find that sometimes patients are a little bit more short with you or are unhappy with the care or we have patients that are unhappy about why we can't give them a vaccination even though we have no control over that. So, people are upset about things like that, that we have no control over."
Delayed diagnosis and treatment (surgery)	"They have to undergo extra testing, so all of our patients have to undergo now preop COVID testing, so that's additional trips for people who are traveling further away and it's time sensitive. So, let's just say if we order it in you know, three days and then something changes after that three days and the surgery is postponed, they would have to repeat that test. There's definitely more testing that goes on."
Concerns and lack of education on COVID-19 risk factors	"I think one thing about having this added level of stress (unclear) is that for a patient that has lung cancer surgery, the usual, the normal postoperative course they actually get a lot of the symptoms that COVID patients get. So, we have to do a fair amount of education and let patients know the difference between the normal postoperative cough and something that they should be concerned about and I think is from the patient's perspective, it could be very stressful because (unclear). They have to cough, and then to them they may be worried that (unclear) know when to worry about COVID and when to be reassured that this is a normal postop course."
Impact on family caregivers	
Theme	Quote
Frequent communication with surgical team	"You have to have the conversation with the patient and then you have to have the conversation with their significant other and then maybe their daughter. So, it's sometimes multiple phone calls a day to different people who cares about the patient."
Psychological distress	"I think the caregivers are really impacted. It's a disconnect. Patient's families used to be in the hospital and being with their loved ones and feeling like they're connected with the care team. And that is so different now (unclear) impacted them. I wouldn't be surprised if there was data showing that there's more stress. Like they can't see the patient when they're in the hospital. (unclear) stressful and then when the patients go home because they haven't been there with them, they may feel more stress because it's like (unclear) where before the patient's family was in the hospital and was (unclear). But now it's like that's foreign to me."
Lack of social support for patients and isolation for FCGs	"They wind up being isolated caregivers because they're caring for their loved one and they don't want them to get sick after having undergone surgery or cancer treatment. So, things along those lines, a lot of isolation among family caregivers socially."
Education on COVID-19 risk factors and prevention strategies	"That's why a lot more education ... you have to review like this is what you should do if you have any symptoms. Don't go near the patient. You got to wait this certain amount of days. And of course, all the questions that comes with that, like patient family members would be like oh you know what, I have a sore throat today. What do I do now?"
Impact of telehealth use on FCGs:	
Telehealth communication*	"So, what I try to do is I always try to have a family member on the phone or on FaceTime. If the patient's phone allows it, so they could actually see the things that I'm talking about and feel more a part of the conversation."
Telehealth burden on healthcare professionals*	"I do like telehealth, I feel like it allows the patient to be seen without having to trouble them about like driving here or something like that, but I do feel like it's more work on the team because there's a lot of now background things that happen before the telehealth like obtaining their CT scans and things like that that have to be done by our team instead of by like (unclear) radiology. Before it's a team effort, but now it's very much just like the physician and maybe the nurse practitioner. And I think it just takes a little bit of ...it's going to be a little bit of time before everything is running smoothly just because we're all learning. But I think telehealth is very much just the provider and the patient."

(Continues)

TABLE 3 (Continued)

Impact on patients	
Telemedicine as standard of care*	"I think having really good telehealth, tele video, infrastructure. I think make sure that patients in general feel safe getting healthcare. I think there needs to be a lot of focus from like the patient's perspective. In particular, when it comes to cancer screening and processes so that way patients have a medical condition that requires multidisciplinary care (unclear) during a pandemic so that care isn't delayed."

Abbreviations: COVID-19, coronavirus disease 2019; FCGs, family caregivers.

*Sub-categories of Theme 5: Impact of telehealth use on FCGs of lung cancer surgery patients.

3.18 | Theme 3: Lack of social support for patients and isolation for FCGs

Patients did not receive in-person social support from their FCGs during and sometimes after hospitalization. This increased the burden on caregivers after discharge because they lacked the baseline knowledge of the health status of the patient after surgery. FCGs were also self-isolating to protect patients from contracting the virus after surgery. While providers attempted to include FCGs using technology, information was often lost in translation. The consequences of not having FCGs present included patients not being prepared for surgery; breakdown of shared decision-making process between the care team, patients, and FCGs; and delayed treatment due to patients' refusal to undergo surgery without the presence of their FCGs at the hospital.

3.19 | Theme 4: Education on COVID-19 risk factors and prevention strategies

FCGs' education on COVID-19 by providers included prevention strategies, symptom management, and directions on when and how to quarantine and where to get tested. Knowledge of the difference between COVID-19 symptoms and other minor respiratory viruses was emphasized; and providers noted FCGs required additional guidance on how to locate testing centers.

3.20 | Theme 5: Impact of telehealth use on FCGs of lung cancer surgery patients

To minimize care disruptions due to the absence of FCGs, various telehealth modes of communication were used, including the use of conference calls, FaceTime, and WhatsApp. Providers partnered with FCGs to ensure information about the patients' care was understood and allotted opportunities for questions to be answered. For example, before discharge the care nurse or nurse practitioner called the patient's FCG and described the care process at home allotting an opportunity for clear communication and guidance to support both groups. While these processes were opportune alternatives to improve communication, overall, the providers felt that it does not replace the value of inpatient face-to-face care.

Telehealth is a supportive strategy for patients and FCGs but burdensome on healthcare professionals. The convenience of telehealth benefited some patients and FCGs, especially those traveling long distances for consultation and follow-up care. Younger patients were more at ease with using technology while older patients required more guidance and support. A telephone call was easier to navigate for some patients compared to more advanced communication tools but decreased the interpersonal connection between patients, FCGs and providers. The added responsibilities of providers included technology support and obtaining patient diagnostic results before telehealth appointments.

The COVID-19 pandemic "elevated" the use and need for telemedicine. Despite the challenges of the COVID-19 pandemic, telemedicine will likely be included as standard of care for years to come. The convenience of telehealth may continue to change the healthcare landscape for patients and providers. While adoption by patients will be critical to support efforts to develop a telemedicine infrastructure at a cancer center, FCGs and the care team should also be consulted.

4 | DISCUSSION

This study underscores the importance of recognizing the impact of COVID-19 on cancer care delivery and QOL for both patients/FCGs and thoracic surgery teams. Although some patients/FCGs reported minimal impact on their care, COVID-19 was reported by many to have a moderate to substantial impact on the care experience. Our findings confirm observations from other studies, including a recent systematic review on patient and FCG experiences with cancer care during the pandemic.^{6,11} Isolation/lack of social support due to visitation policies, delays in receiving care in the community, additional distress to emotional well-being in perioperative care, financial burden, and fear of COVID-19 infections were common themes in this qualitative study focused on a surgical oncology population. Importantly, during the immediate postoperative period, while patients were recovering in the hospital, patients experienced heightened emotional distress secondary to no visitation policies.

For dyads, previous research from our team and others suggests that patients and FCGs are often concerned about each other's well-being during treatments; patients are concerned about burdening FCGs, while FCGs make the patient's well-being their priority rather

than their own self-care.¹²⁻¹⁵ The pandemic has, in many ways, resulted in the additional burden of unintentional infections between the dyads and also heightened awareness of one's mortality. For FCGs, evidence suggests that the caregiving role in lung cancer often results in high levels of burden and distress for the caregiver.^{16,17} COVID-19 specific policies created additional emotional distress for FCGs, who were not permitted to attend clinic visits with patients or visit patients in the hospital following surgery. While the policies were put in place to prevent transmission, it also created an additional burden for FCGs.¹⁸ Financial hardship was a common theme for patients and FCGs; this finding is aligned with the growing awareness of financial toxicity in cancer.¹⁹ In our cohort, financial hardships were characterized by reduced wages, housing insecurities, decreases in business revenues, and in some situations, layoffs or furloughs. These hardships may have both short- and long-term implications on the cost of cancer care and the ability to pay for out-of-pocket bills associated with cancer treatments.²⁰

The COVID-19 pandemic also resulted in significant challenges in the delivery of surgical oncology care worldwide from the surgical team's perspective.^{3,21,22} Care team members (thoracic surgeons and NP) were not only witnesses to patients' and FCG's emotional distress from facing a cancer diagnosis and a pandemic but experienced care delivery challenges and a higher level of patient frustration and anger directed at the providers.⁸ From a cancer care perspective, this also manifested as a higher number of delays in screening, diagnosis, and treatment.^{23,24}

Since the early days of the pandemic, most if not all cancer centers pivoted from in-person care visits to telehealth.²⁵ While telehealth provided flexibility in traveling to care, challenges remain as observed in our findings and other studies.^{21,26} Many patients and families, including older adults with cancer, may experience challenges with technology use.²⁷ Care teams dedicated more time to educating patients and FCGs on preparing for surgery and recovery, and the education was presented separately to patients and FCGs due to visitation policies or additional telehealth sessions were needed to communicate with FCGs. The somewhat more fragmented approach in communication with dyads, despite the surgical team's best efforts, impacted patients' preparation before surgery, shared decision-making, and delays in treatment. These findings suggest alternative strategies could be considered to maintain social distancing and communication. For example, resources could be included to have videoconferencing capabilities while patients are recovering in the hospital yet be able to "see" their families without being physically present. Postoperative care and discharge teaching could be provided simultaneously to patients in-person and families remotely through telehealth/telephone. These strategies must be developed with attention to the needs of all partners in the surgical care delivery process: patient/families, surgeons/surgical team, nursing team, discharge management team, and so forth.

In conclusion, as summarized in Figure 1, the impact of COVID-19 on care delivery and QOL for dyads facing lung cancer surgery varied; some dyads perceived little to no impact on care delivery and QOL, while others experienced added emotional distress, isolation, and

challenges with telehealth due to COVID-19. Importantly, surgical teams also experienced challenges in the approach used to provide care.^{8,23,28} As the pandemic continues to evolve, further observational research is needed to evaluate the impact of COVID-19 on dyads' psychological wellbeing, level of preparation for lung cancer surgery, shared treatment decision-making, financial distress/toxicity, and delays in screening/diagnosis/treatment. The expansion of telehealth in thoracic surgery will continue to change the care delivery landscape, and future studies should identify best practices in the use of telehealth that is least burdensome with high benefits for patients, FCGs, and thoracic surgery teams.

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