

Provider and Patient Perspectives to Improve Lung Cancer Screening with Low-Dose Computed Tomography 5 years after Medicare Coverage: A Qualitative Study

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Abstract

Lung cancer remains the leading cause of cancer-related deaths for both men and women in the U.S. despite the availability of preventive cancer screening for high-risk smokers. This qualitative study of patients and providers from a large ambulatory healthcare system in northern California explored perceptions of lung cancer screening with low-dose computed tomography (LCS-LDCT) 5 years after Medicare coverage to identify modifiable targets to improve the implementation of LCS-LDCT. Between 2019 and 2020, interviews were conducted with 10 primary care physicians and 30 patients from three groups (completed LCS-LDCT, scan ordered but not completed, eligible but no order) using semi-structured interview guides. Providers and patients expressed that they were both aware and supportive of LCS-LDCT but reported little to no shared decision making nor use of a decision aid despite being Medicare requirements. Respondents suggested improvements to LCS-LDCT including incorporating a nurse navigator into the process to ease the burden on providers and provide additional education and counselling about screening and support for tobacco cessation to patients. Given recently expanded guidelines from the U.S. Preventive Service Task Force for LCS-LDCT screening, and the expectation that these new guidelines may be covered by Medicare in the near future, it is important for healthcare systems to understand provider and patient perceptions to further improve the implementation of LCS-LDCT to ultimately reduce lung cancer mortality.

Introduction

Lung cancer is the leading cause of cancer-related deaths for both men and women in the United States.¹ Typically, lung cancer is diagnosed late in the disease process when the 5-year survival rate is only 6.3%.² A significant development in lung cancer early detection occurred in 2011 when results from the National Lung Cancer Screening Trial (NLCST) showed a 20% decrease in lung cancer mortality using low-dose computed tomography (LDCT) compared to chest X-rays for high-risk current or former smokers.³ As a result, lung cancer screening (LCS) with LDCT was recommended to heavy smokers by the U.S. Preventive Services Task Force (USPSTF) in 2013⁴ and covered by Medicare in 2015.⁵ Yet use of LCS-LDCT still remains low with estimates between 3.9–7.3% of eligible individuals having received a LCS-LDCT scan in the previous year.^{6,7}

Given the low uptake of LCS-LDCT, additional barriers exist for patients and providers in the integration of LCS-LDCT into clinical practice beyond Medicare coverage. LCS-LDCT is unique from other preventive cancer screenings (e.g. mammography, colonoscopy) in that it is not targeted to all healthy people on the basis of age. As of April 2021, to be eligible for LCS-LDCT and covered by Medicare one must: 1. be a current or former smoker having quit within the past 15 years, 2. be between 55 and 77 years old, and 3. have a 30-pack-year smoking history. Furthermore, Medicare requires a shared decision making (SDM) visit using one or more decision aids to discuss the risks and benefits of LCS-LDCT for each patient and counseling on the importance of tobacco cessation or cessation maintenance.⁸ These long-term smokers are a harder-to-reach group due to factors including shame over smoking, feelings of victim blaming that

they caused their own troubles, fear of diagnosis, and distrust of the healthcare system.^{9,10} Additional patient screening barriers include lack of awareness, cost concerns, and access issues, while provider barriers include unfamiliarity with LCS guidelines, challenges with eligibility criteria, and skepticism regarding the evidence.^{11,12}

These barriers make implementation of LCS-LDCT in healthcare systems challenging. We sought to understand the perception of LCS-LDCT with patients and providers in a large ambulatory healthcare system 5 years after Medicare coverage. As lung cancer screening is more widely implemented in the U.S., it is critical to understand perceptions of LCS-LDCT at the patient and provider levels to identify and address modifiable barriers for LCS-LDCT.

Methods

Setting and Recruitment

The study was conducted at Sutter Health, a large, multispecialty healthcare delivery system in northern California that serves approximately 3.5 million patients across 22 counties and is representative of the underlying catchment area: 45.6% non-Hispanic white, 15.6% Hispanic, 16.5% non-Hispanic Asian, 4.7% non-Hispanic Black, and 17.4% non-Hispanic other as of 2020.¹³ Sutter Health began offering LCS-LDCT to patients in 2012.

We used semi-structured interviews to qualitatively understand patient and provider perspectives on barriers and facilitators to LCS-LDCT. The interviews were one part of a larger mixed-methods study on the implementation of LCS-LDCT at Sutter Health with results reported elsewhere.^{7,14}

We developed interview guides for both patients and providers based on findings from the quantitative analyses of this mixed-methods study (see Appendix for guides). Provider interviews asked about knowledge of LCS-LDCT, attitudes toward screening guidelines, perspectives and experiences using LCS-LDCT as a screening test for lung cancer, tobacco cessation counseling efforts, SDM, and the best ways to help patients make decisions on LCS-LDCT. Patient interviews asked about awareness of LCS-LDCT, facilitators and barriers to screening and understanding of results, perceptions of pros and cons, experiences with smoking cessation, and ways to improve physician-patient communication. All participants provided written informed consent prior to the start of the interview. All study materials were reviewed and approved by the Sutter Health Institutional Review Board.

For provider interviews, we identified providers with high and low LCS-LDCT referral/order rates from across the system, defined for our organization as above 12% vs. below for eligible patients (Table 1). To be eligible for an interview, providers had to practice at least 20 hours per week in Sutter Health facilities and have seen at least 20 guideline-eligible patients. We emailed 45 providers initial recruitment information with up to three additional requests. Two researchers (MM and JL) conducted 10, hour-long

provider interviews, either in person (6) or over the phone (4) between January and December 2019 and participants received a \$150 gift card for their time.

For patient recruitment, potential participants were identified from eligible study providers using electronic health records (EHRs). We focused on 3 patient groups: 1. those who received an LCS-LDCT order and completed the screening; 2. those who received an LCS-LDCT order but not completed; and 3. those who never received an LCS-LDCT order despite evidence of eligibility in the EHR. Additionally, because of interviewer language, patients had to be able to speak and read English to participate in the interview. Patients were sent initial recruitment materials via USPS mail, and up to 3 reminder letters. We contacted 282 patients and conducted 30 interviews – 14 in-person and 16 over the phone. Patient interviews were conducted by MM and/or JL between April 2019–December 2020 and lasted 45–60 minutes. All patients received a \$40 gift card for their time.

Analysis

Both patient and provider interviews were audio-recorded and transcribed for accuracy. Qualitative analyses were managed using Dedoose 9.0. We created a codebook using thematic analysis which allowed an inductive approach to exploring the data and for ideas to emerge from the data. Initial coding reflecting the source data was created and grouped into associated clusters. These clusters and the inter-relationships were summarized into emergent themes, and the emerging themes, based on the research questions, were determined as a group. The team discussed, addressed, and resolved disagreements for each step of the analysis in a series of meetings. Initial themes were discussed with the wider research team, amended, and renamed until a consensus was reached. Any new data that did not fit into the existing themes were highlighted and discussed further, with subsequent amendments to the final themes. Following the compilation and analysis of data, the initial results were presented to the whole research team, including the study Advisory Board. Their input and comments were further incorporated to improve the accuracy, completeness, and usefulness of the information in the final analysis. Patient and provider interviews were coded separately, but general themes were aligned to develop a cohesive coding scheme for providers and patients. MM and JL both reviewed and coded text samples to create the initial codebook; MM did all coding; JL and CS reviewed the findings and further validated the coding.

Demographic characteristics for patients and providers were obtained from EHR and administrative data.

Results

We interviewed 10 providers and 30 patients. Participants' demographic characteristics are shown in Table 1. The median age of patient participants was 70, and more than half were women, non-Hispanic white, and former smokers with Medicare coverage. We interviewed 13 (43%) patients from group 1, 9 (30%) patients from group 2, and 8 (25.7%) patients from group 3. The average age of participating providers was 49.3, and the majority were non-Hispanic white, female, and in Family Medicine.

Table 1
Characteristics of Patient and Provider Participants

<i>Patient Characteristics</i>	<i>Number (N = 30)</i>	<i>Percent</i>
AGE		
Mean age, years	71	N/A
Median age, years	70	N/A
Age range, years	60–87	N/A
SEX		
Female	17	56.7%
Male	13	43.3%
RACE/ETHNICITY		
African American	1	3.3%
Hispanic/Latino	2	6.7%
White	20	66.7%
Other	2	6.7%
Unknown	5	16.7%
SMOKING STATUS		
Current smoker	4	13.3%
Former smoker	26	86.7%
PRIMARY INSURANCE STATUS		
Medicare FFS	15	50%
Medicare HMO	7	23.3%
Medicaid/Medi-Cal	2	6.7%
Private	5	16.7%
Unknown	1	3.3%
PATIENT GROUP		
Group 1 (received LCS-LDCT order and completed screening)	13	43.3%
Group 2 (received order, but have not completed screening)	9	30%
Group 3 (no order)	8	26.7%

<i>Patient Characteristics</i>	<i>Number</i>	<i>Percent</i>
	(N = 30)	
<i>Provider Characteristics</i>	<i>Number</i>	<i>Percent</i>
	(N = 10)	
REFERRAL/ORDER RATES		
High ($\geq 12\%$)	4	40%
Low ($< 12\%$)	6	60%
SPECIALTY		
Family Medicine	8	80%
Internal Medicine	2	20%
AGE		
Mean age, years	49.3	N/A
Median age, years	51	N/A
Age range, years	34–62	N/A
GENDER		
Female	9	90%
Male	1	10%
RACE/ETHNICITY		
Non-Hispanic Asian	4	40%
Non-Hispanic white	6	60%

Provider Knowledge, Awareness, and Acceptance of LCS-LDCT

Every provider interviewed said they were aware of LDCT as a screening option for lung cancer and ordered it for eligible patients; however, two did admit to a lack of consistency in their ordering. Providers primarily reported offering screening during annual physicals, wellness visits, and new patient visits, with fewer thinking to suggest it during “appropriate” acute care visits (e.g., for sinus infections or colds). Some providers continued to express skepticism with the data behind LCS-LDCT recommendations, saying that it was still “very early on,” that “we’re still trying to understand the data,” and, as a result, that the screening recommendation was inconclusive and “not very well established.”

Provider Difficulties with Eligibility Criteria

All provider participants were aware of the eligibility criteria for LCS-LDCT, though some noted having to frequently look it up to ensure they accurately remembered all components. A commonly cited difficulty was the discrepancy between the upper age limit allowed by the USPSTF and Medicare – 80 vs. 77, respectively. Another provider noted the difficulty in calculating pack years and how this complicated the screening process: “I think the part where this becomes a little subjective is the way you decide to document how many pack years they have. And I think that’s rarely accurate, and since it matters a lot for this, that’s one of the things that gives me a little bit of pause.” Another physician echoed that: “I smoked for five years, but some days I smoked a cigarette, other days I smoked a pack. How do you quantify that?” A commonly cited difficulty had to do with the integration of LCS-LDCT ordering into the current EHR system. Providers noted that key variables, e.g., smoking history, are often missing or inaccurate. Furthermore, despite creation of a “SmartSet” in April 2018 within the EHR to help walk providers through the process of an LCS-LDCT order, only 4 provider participants were aware of and used the SmartSet option at the time of the interview in 2019 and one was aware and chose not to use it because of a general dislike of SmartSets.

Patient Awareness of LCS-LDCT and Feasibility of Screening

Seventy three percent of patient participants (22 out of 30) said they were aware of LCS-LDCT and of the 22, 86% reported that they had completed at least one scan (19 patients). One eligible patient who was aware of LCS-LDCT but had chosen not to be screened said they would rather “[put] my head in the sand” about their lung cancer status. Interestingly, 8 of the 17 patients in groups 2 and 3 self-reported that they had completed LCS, while 3 patients in group 1 claimed they had not. Of those who offered an opinion on how frequently LCS-LDCT should be brought up and discussed by a provider, 15 felt once a year at the physical was appropriate, while 9 thought it should be mentioned at any visit. One patient strongly opposed having it brought up at every visit saying: “I think the doctor’s primary objective is to present at annual physical...but to do it at every visit, because I’ve got to come in and see her for my diabetes...I’ll find another doctor...some people like to get beat over the head with a baseball bat. Not me.”

For patients who had undergone screening, all said the process was extremely easy and fast. In most cases, once the order was placed by the physician, the radiology department reached out to the patient directly to schedule the actual scan, and scan locations were said to be conveniently located. Results were primarily sent to the patient electronically, with a provider note interpreting the findings. Some patients also noted that the provider included a schedule for additional scans. Though the patients interviewed were insured (Table 1), respondents expressed that a small cost of screening (e.g. co-pay) would be okay but any significant out-of-pocket costs would present a barrier to screening as they perceived the eligible population to largely consist of older adults on fixed incomes.

Perceived Benefits and Risks of LCS-LDCT

Both providers and patients most frequently mentioned the same benefits of LCS-LDCT as early detection of lung cancer, that it can support smoking cessation, and impact patient peace of mind. Regarding early

detection, providers and patients noted the importance of catching cancer “at an earlier stage than normally when people would...be diagnosed” (provider) and “catch[ing] something in time, before it got out of hand” (patient) as the most important reason to do LCS-LDCT. With smoking cessation, both groups felt that LCS-LDCT forces smokers to “[think] about the risk of the smoking a little bit more” (provider) to ultimately help people with their cessation. One patient expressed this sentiment after receiving a LCS-LDCT that “this is a good boot in the butt, telling me I’ve only stop smoking 20-some days, but [I’m] not going to pick up another cigarette.” Patients also pointed out the benefit of peace of mind about their cancer status from the scan results and expressed that they “wanted to know” the scan findings so they could either “move on with my life” or “put a stop to [worrying about cancer].” Providers similarly echoed this sentiment that the scan would give patients “peace of mind” with regards to their own health and cancer status.

Perceived risks commonly noted by both providers and patient for LCS-LDCT were radiation and patient psychological distress. Providers and patients frequently expressed concern with radiation from CT scans being “a significant exposure to risk for cancer” (provider), especially annually as recommended for LCS. However, some providers did often temper their concerns about radiation by noting how low the exposure was, especially relative to chest x-rays and other CT scans: “The radiation exposure isn’t as, you know, big of a concern because it’s low dose versus traditional CT scanning.” Some providers also commented about the scan causing additional psychological distress for patients: “It’s not easy to counsel people on whether or not have something worked up once you find something small. They always get anxious and you try to make your best guess.” Patients also felt the psychological distress related to the screening, particularly the high rates of “false alarms,” would be difficult and may instead cause some people to forego the scan and “put [their] head in the sand.”

There were a few differences between the main perceived risks for providers and patients. Providers did mention false positives but this was not reported by our patient participants. A few providers expressed some frustration at the number of false positives vs. true positives with this screening – “I’ve probably been doing [screenings] for the last two years or so. I think there’s coming up to be more cons or more risks with the...false positives than the true positives in patients because the ones with lung cancer, which we found ourselves, are people who are symptomatic...from the lung cancer screening I think there’s more...false positives.” Patients instead expressed that they felt that LCS-LDCT may lead smokers to think that they are okay meaning that if a current smoker’s results showed no signs of cancer, they may “say I’m okay. And it won’t have any effect to make them quit smoking. If anything, it would encourage them to keep going.”

LCS-LDCT and Smoking Cessation

Smoking cessation counseling is a required component of the LCS-LDCT process, and providers agreed that LCS-LDCT could act as a “bridge” to discussing smoking cessation and the benefits of quitting smoking. One provider noted that in his experience among patients who had undergone LCS-LDCT there was a higher rate of smoking cessation, regardless of results. One patient found a nodule as a result of screening and “went into panic” leading them to quit smoking. A common concern among providers was

how to do smoking cessation counseling and LCS-LDCT SDM in the same time-constrained clinical visit. Providers felt that getting patient to quit smoking was the first priority, but that can be a long-term, difficult process for many patients.

Shared Decision Making (SDM)

A SDM visit is a Medicare requirement for coverage, yet no physician said they conducted a stand-alone SDM discussion. All 10 physicians said they do all LCS counseling as part of the regular patient visit and that it was typically a fairly short discussion: “it doesn’t take a long time” and “around, you know, 5 minutes or something like that.” A Family Medicine provider admitted that patients “probably [did] not” understand all the pros and cons of screening.

Matching provider responses, no patient said they had a separate SDM visit with a provider, and most patients said there was very little discussion with the provider about risks and benefits. Some patients were not aware of the benefits of LCS-LDCT screening when asymptomatic:

For people that don't have any symptoms and they smoke?...Hmm, no, I don't think so. Nuh-uh...Because they say it takes a year to have your lungs go back to normal after smoking. And if they're—you know, not coughing, nothing like that? No. I wouldn't. Uh-uh.

Half of patient respondents felt strongly that the most important factor influencing their decision to do the screening was a physician recommendation. One patient expressed – “Who more are you going to have confidence in if it’s not your doctor...just the authority that she says, ‘You’re eligible for this, you should have it done.’” This trust in physicians was also mentioned by another patient: “Well, definitely having it suggested by your doctor. Because the doctors generally know what’s the right thing to do.” A third patient suggested that this type of screening is only likely to happen if the physician mentions it: “...the doctor talking to them...because that’s usually what causes people to have tests and that sort of thing...because an ordinary person just doesn’t on their own say, ‘Oh, gee, I think I should go get my lungs scanned.’”

Improving LCS-LDCT

When asked about the possibility of integrating a nurse navigator into the LCS-LDCT process, all patients were enthusiastic and open to additional help. Patients noted that until LCS-LDCT truly becomes “a real standard of care,” a navigator might be necessary to push patients to complete the screening. Furthermore, having someone to confirm eligibility, provide smoking cessation counseling, schedule the initial scan and follow up, help patients understand the results, and ensure there will be no significant out-of-pocket cost were also felt to be benefits of navigator assistance. Providers similarly were mostly positive about integrating a navigator into the process. For the two providers who were less supportive of a navigator, one was more focused on patient responsibility for follow through (“I put the order in, and I feel that now it’s the patient’s responsibility...I don’t spoon feed my patients”) and the other thought patients would be more interested in having a pulmonologist than a nurse (“I don’t think they’re going to want to talk to a coordinator that they’ve got a possible positive test.”).

Providers and patients all felt regular use of a decision aid in LCS-LDCT would be beneficial for both parties. They suggested that the decision aid could explain the screening CT process and differences from an MRI could help those patients who are concerned with being “stuck in a little tube.” Additional information on risks and benefits, expectations (that it is a yearly screening), insurance coverage, eligibility criteria, and effective smoking cessation resources should also be included. Graphics could help greater understanding, particularly for those with lower education. Providers tended to think a handout that could either be provided during the visit or to take home was preferable, while patients thought receiving a pamphlet ahead of an upcoming visit may provide more time to review and reflect before talking with their doctor.

Discussion

Given that uptake of LCS-LDCT remains low, it is important to understand both provider and patient perceptions of LCS to identify modifiable components and create more targeted interventions to increase utilization rates to detect lung cancer early. In this interview study regarding perceptions of LCS-LDCT among patients and providers at a large healthcare system in northern California, we found near universal awareness of and support for LCS-LDCT among all participants. Unique to this study, we recruited patients based on 3 criteria (completed LCS-LDCT, ordered but did not complete, and eligible but no order) and we did not see many significant differences across these groups in the expressed perceptions of LCS-LDCT screening or ease of the process among those who had completed a screening. Both providers and patients mostly shared the same main benefits and perceived risks about LCS-LDCT. Timing of when to bring up the scan varied, with half of patients and most providers agreeing that the annual physical was appropriate, while less than a third of patients felt it could be discussed at any visit. When discussions of LCS-LDCT are happening, patients and providers both said they happen briefly during the visit and not as a separate SDM visit, as recommended. One of the major barriers with screening for providers is difficulties with the EHR, particularly not knowing about an existing SmartSet. Providers and patients also suggested adding a nurse navigator and regular use of a decision aid as potential improvements to LCS-LDCT.

While patients and providers in our study reported the same three top benefits of LCS-LDCT found previously – early detection, supporting smoking cessation, and patient peace of mind¹⁰ – they noted a number of risks. It was as anticipated that participating providers expressed concerns over the high rate of false positives when 96.4% of positive LCD-LDCT screening results were false positives in the NLCST.¹⁵ We found it more surprising that “false positives” were not among the top perceived risks expressed by patients, indicating that patients may be less aware of this possibility or that they believed the positives of early detection and peace of mind outweighed this concern. The patient perceived risks mentioned by both our patient and provider participants, such as radiation and psychological distress, echo findings found previously.¹⁶ That peace of mind and psychological distress were noted by all participants as a benefit and concern highlights the double-edged nature of LCS, and may impact screening rates. While it is understandable that patients would want to know their cancer status, LCS-

LDCT is based on a high-risk behavior and may be adversely affected by the stigma attached to smokers from their choice to smoke. So, unlike other preventive cancer screening tests where patients are mainly screened based on age, LCS-LDCT may bring feelings like guilt and regret of possibly causing the cancer, thus creating additional psychological distress.

While both patient and provider participants noted that a separate SDM visit does not occur, this is similar to other very low reported rates.^{17,18} Despite being a requirement for Medicare coverage, these results suggest that SDM has still not been well-integrated into the LCS process. LCS-LDCT screening is considered a “preference-sensitive” decision in which SDM should be used to help patients better understand the pros and cons of screening. However, patient participants expressed that the most influential factor in their decision was a provider recommendation. Still, all participants did note the benefit of incorporating a decision aid, which is another Medicare requirement, into the process. Interestingly, patients were more open to receiving the decision aid ahead of a visit to review information and formulate questions, while providers preferred incorporating the decision aid into the visit or use as part of an after visit summary. It may be that providing information on LCS-LDCT in advance could change the patient-provider interaction dynamic during the visit and providers may be worried about patients engaging in endless internet searching or coming to hold false beliefs about LCS-LDCT before the clinical visit.¹⁹

Provider participants reported difficulties in determining eligibility based on pack years despite an existing SmartSet within the organization’s EHR. This suggests that regular reminders for eligible patients could be incorporated into the EHR like other preventive screening tests such as colonoscopy or mammogram.^{20–23} With ever increasing demands on provider time,²⁴ these EHR alerts could reduce some of their mental burden by indicating a patient is eligible for screening.²⁵ Since these interviews, an EHR reminder was implemented at our organization to help with LCS-LDCT, though the impact has yet to be evaluated. Creating alerts and reminders within the EHR for physicians to regularly discuss LCS-LDCT may alone significantly increase LCS-LDCT uptake, especially given that provider recommendation and patient-provider communication have been shown to be strongly influential in screening uptake for other types of preventive cancer screenings.^{26–30}

Participants suggested having a nurse navigator in the clinical setting to provide more assistance to patients going through the LCS-LDCT process. Nurse navigators could confirm eligibility and coverage, schedule initial scan and follow-up, and provide thorough counseling and smoking cessation support. Previous research showed that community health center-based LCS patient navigators increased patient screening rates (24%) versus usual care (8.6%).³¹ Since the time of the interviews, Sutter Health has implemented a nurse navigator at one site with plans to expand this service to additional locations across the system. Further investigation is needed to fully understand the impact of nurse navigation on LCS-LDCT.

We recognize several limitations with the current study. First, all participants came from one healthcare system in northern California, were primarily non-Hispanic white, and patients were well-insured, which

may not be representative of providers and patients in other areas of the U.S. Second, all interviews were conducted in English; it may be that non-English speakers have significant and different perceptions from those presented in this interview study. Additionally, most patients interviewed were former smokers who had completed at least one scan. Current smokers and patients who opt out after a referral from a provider may have differing perspectives on the value or importance of LCS-LDCT. Future studies should include a more diverse population of respondents to confirm that our results are consistent across provider and patient groups.

Conclusion

In March 2021, the USPSTF updated LCS-LDCT guidance by lowering screening start age to 50 years and smoking history to 20 pack-years, increasing screening eligibility by 87% compared with the 2013 criteria and making millions more smokers in need of LCS-LDCT.³² Given that it can take up to 17 years to translate clinical evidence into practice,³³ it is not surprising that SDM has still not been well-integrated into the LCS process; however, these expanded guidelines may be covered by Medicare or other insurers in the near future and working now to integrate LCS and SDM into clinical practice will prepare healthcare systems for a future influx of patients eligible for and seeking screening. Thus, it is critical for healthcare systems to understand provider and patient perceptions to further increase LCS-LDCT.

Declarations

Ethics approval and consent to participate: All methods were carried out in accordance with relevant guidelines and regulations. Informed consent was obtained from all subjects. This study was approved by the Sutter Health Institutional Review Board.

Consent for Publication: Not applicable

Availability of data and materials: The datasets analyzed during the current study may be available from the corresponding author on reasonable request.

Competing Interests: Authors have no competing interests to disclose.

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