A Telephone-Linked Computer System for COPD Care*

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The current revolution in communications technology provides an opportunity for novel approaches to management of medical illness. As economic imperatives lead to a progressive reduction in the time that health-care providers spend with their patients, computerized, telephone-linked communication systems offer an inexpensive, widely available alternative with which patients and providers can maintain contact. Such systems may be particularly useful for providing ongoing monitoring and education of patients with chronic illnesses such as COPD. In this article, we describe the general application of telephone-linked communication systems in the health-care setting. We then present in detail one such system, which provides telephone-linked care for COPD (TLC-COPD). The operation of the system is described, as are its theoretical underpinnings in social learning theory. A randomized clinical trial currently is being performed to study the effects of the TLC-COPD system. The rationale for expected improvements in disease control and quality of life, and for a reduction in acute health-care utilization, is discussed.

Key words: chronic bronchitis; chronic disease; computer; COPD; emphysema; telecommunications; telephone

Abbreviations: QOL = quality of life; SLT = social learning theory; TLC = Telephone-Linked Care

The US health-care system has demonstrated repeatedly its ability to adapt to new technologies and economic pressures and to change how health care is delivered. The growth of cities in the early part of the 20th century, combined with technologic advancements such as the telephone, automobile, and improved medical equipment, led to a steady decline in the use of house calls in health-care delivery.1 Setting up medical appointments in one central location became more cost efficient for physicians, who could then see more patients, and for patients, who no longer had to travel to a physician’s house to request an appointment. While the majority of physician-patient encounters took place in the home in the early 1900s, this practice had decreased to 40% of all physician-patient encounters in 1930 and to 10% by 1950.1 This number continued to drop to 0.6% by 1980.2 This sharp decrease in house calls paralleled a dramatic increase in the number of physician office visits. Office visits are still the most common forum for physician-patient encounters, with an estimated 734 million occurring in 1996.3 However, the transition to managed care in recent decades has caused physicians to drastically reduce the time allotments for patient appointments in order to see more patients.4 This pressure on the health-care system to be more efficient has resulted in a great deal of concern regarding the quality of health care being delivered.5 One solution to the dilemma of delivering high-quality care at lower costs may lie in automation, specifically by using modern information and telecommunication systems technology to carry out some of the routine patient monitoring between expensive, time-consuming of-

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office visits. This article will describe an innovative computer-based telecommunications system that educates and monitors patients in their homes and promotes their self-care through frequent, totally automated telephone encounters (or visits) that complement office visits with physicians.

This approach to the delivery of medical care was applied to the care of patients with COPD, one of the most common chronic illnesses in the adult population and one that is responsible for 13% of hospitalizations nationally. These hospitalizations are usually for COPD exacerbations that are characterized by increased dyspnea (92%), cough (82%), wheezing (79%), and sputum production (65%), which usually are preceded by a gradual worsening in the patient’s pulmonary status. Appropriate long-term management of COPD, including pharmacotherapy, patient education, and pulmonary rehabilitation, combined with early recognition of exacerbations and timely treatment, can reduce morbidity and acute health-service utilization in patients with COPD. Unfortunately, inadequate patient education, patient nonadherence to medication regimens, and the failure to detect early symptoms of exacerbation before the patient requires emergency care and/or hospitalization are common problems in the management of patients with COPD. It has been recognized that interventions that enhance symptom self-monitoring by COPD patients and increase their understanding of COPD therapy may reduce the occurrence of COPD-related hospitalizations and other acute health-care services. To this point, such interventions have involved the use of time-intensive education and patient monitoring by nurses and other personnel and have been expensive and inconvenient for patients, as they typically require patients to go to a medical facility on a regular basis. A novel alternative means of providing such an educational and monitoring intervention would use computer and telecommunications technology to monitor, educate, and counsel COPD patients through regular automated encounters in their homes. We designed and constructed such a system, called Telephone-Linked Care (TLC) for COPD, which we describe in this article. We anticipate that the application of this system to COPD patients will lead to the earlier detection of clinical deterioration, which will permit more timely intervention by health-care providers, as well as improved self-care by COPD patients, including their adherence to medication regimens. This, in turn, is likely to result in fewer emergency department visits and hospitalizations and to improved quality of life (QOL). The TLC-COPD intervention is being evaluated formally in a randomized controlled clinical trial that will be concluded in the year 2001. Before describing this intervention in more detail, a general description of the TLC technology that underpins the intervention is provided.

TLC

Overview

TLC is a fully automated telecommunications system that functions as an at-home monitor, educator, and counselor for patients. TLC engages patients in regular automated telephone conversations (typically weekly) between their office visits to their physicians or other health-care providers. The system uses computer-controlled speech to ask patients questions similar to those a physician or other health professional would ask during an office visit. The patients respond to these questions via the touch-tone keypad of their telephones. Based on these responses, TLC provides appropriate feedback.

There are three major types of TLC interventions that can be used independently or in combination. Most commonly the system has been used in the management of patients with a chronic disease or disability. For example, in a randomized clinical trial of a TLC system for patients with hypertension, the TLC user monitored BP at home using a sphygmomanometer and called TLC weekly. They sustained an average decrease of 4.4 mm Hg in the diastolic BP after 3 months of TLC use, which was both statistically and clinically significant compared to control patients. Other examples of TLC use in chronic disease and disability include the care of patients with angina pectoris and chronic disability. A second type of TLC intervention aims to change or sustain important health-care behaviors. The technology has been used to promote smoking cessation, adherence to a medication regimen, regular physical activity, and healthy eating. The third type of TLC intervention aims to provide support to people who are caring for a patient with a serious health condition such as Alzheimer’s disease. The capabilities of the TLC system can be understood more fully with a general knowledge of its computer architecture. This information is included in the Appendix.

TLC Conversations

All TLC conversations follow a similar format. They begin with a greeting to the patient, followed by password verification to ensure security, and then by the clinical portion, concluding with a closing statement that tells the patient when the next call is scheduled. In order to personalize the calls and make
them more closely resemble a conversation with a real person. TLC refers to the patients by name and varies the content of the calls to make them clinically appropriate. Conversation content can be distributed among a series of calls if the total content is too much for a single call. The content of a conversation also changes over time, depending on patient status. For example, if a patient reports increased shortness of breath, TLC will ask whether shortness of breath is being experienced at rest or after walking down a flight of stairs. It will also ask the caller about the severity of his/her shortness of breath while performing five personally selected daily activities.

The chronic disease, health-care behavior, and caregiver support applications each follow specific formats in the clinical portion of the TLC. The chronic disease interventions aim to aid physicians by providing them with clinical updates on patients with a chronic disease between office visits, and to aid patients in improving their self-care through a variety of educational and counseling techniques. TLC collects information on patients’ clinical status through regularly scheduled calls, which generally occur once a week. Patients are questioned on the status of their symptoms and other findings that are relevant to the given chronic disease. The information collected can be displayed in the form of a monthly report that can be faxed or electronically sent to the patient’s physician. In certain medical situations, urgent reports can be sent to a physician in the same manner. This prompt transmission of information from patient to physician is likely to improve health outcomes by allowing the physician to make necessary adjustments in the management of the disease, preventing an acute deterioration from becoming a chronic setback.

A major focus in improving the self-care of patients with a chronic disease is medication adherence. TLC assesses whether patients understand which medications they should be taking and how to take them. It establishes agreement or disagreement between the patient’s understanding of what the physician prescribed and the physician’s actual prescription. It then assesses the patient’s adherence to the regimen. In the case of a patient who has not adhered to the prescribed medication regimen, inquiries are made to determine the reasons for the poor adherence. TLC then gives the patient advice on how to avoid that problem in the future.

TLC also provides periodic counseling on a variety of other behaviors that are important in improving self-care. For example, patients with COPD are advised on issues such as smoking cessation, exercise, and receiving influenza and pneumonia vaccinations.

**Potential Limitations of TLC Systems**

Several potential limitations of TLC systems should be mentioned. Although most adults are able to use TLC systems without difficulty, these systems may be inappropriate for some patients. Use of the TLC system requires the availability of touch-tone telephone service and thus would be inappropriate for patients without telephone service, or who are unable to use a telephone due to severe deafness or the inability to operate a telephone keypad. Patients with severe cognitive impairment may have difficulty utilizing a TLC system. In order for a TLC system to serve non-English-speaking patients, the dialogues would need to be translated into other languages.

TLC systems are generally well-accepted by both patients and physicians. Prior studies of TLC systems indicate that > 90% of patients found the systems easy to use and that overall satisfaction with the systems was high. Similarly, 85% of physicians participating in a study of TLC for the management of hypertension found the system to be useful. Nonetheless, there are some patients who are unwilling to make use of TLC systems.

One concern raised by the use of TLC systems is that patients might inappropriately rely on these systems in lieu of conventional medical care. For this reason, warnings to the effect that TLC is not designed to replace routine medical care are provided both verbally and in written form when patients are oriented to the TLC system. Moreover, during the greeting dialogue of each TLC call, the TLC system reminds users that if they need immediate medical attention, they should hang up and contact their physicians or an emergency department. Thus, care is taken to ensure that TLC systems are used to supplement, not supplant, routine medical care.

**Special Features of TLC System**

In order for TLC to benefit them, participants must make their scheduled calls, and for optimal chronic disease management, the physician must be made aware of important changes in a patient’s health status. For these reasons, TLC monitors when each patient is scheduled to make his/her call. If the call is not made, TLC will make a reminder call to the patient’s house. An alternative or additional means of encouraging regular calling to TLC by patients is being applied in the TLC-COPD study. Participants who do not skip their calls receive gifts such as phone cards and gift certificates.

Another important feature of TLC is that the reports can be sent to the patients or to their physicians. These reports can be transmitted via fax
or the Internet (ie, e-mail, file transfer protocol site, or Web site), or can be entered into a comprehensive electronic medical record. The reports serve multiple purposes. For example, in the monitoring of chronic diseases, the physician may want to see how the disease is progressing over time. TLC is able to display the information it collects in easily readable reports that can be sent to the physician or patient on a regular basis. These reports can convey the performance of a population of patients as well as that of individuals. In some instances, a patient may require prompt medical attention. In these cases, TLC can send out an immediate report to the physician that identifies the caller’s problem(s). An example of such a situation is the acute or subacute development of increased pulmonary symptoms in patients with COPD.

**TLC for COPD**

**Overview**

The TLC-COPD system assists in the management of patients with moderate-to-severe COPD by providing patient education and symptom surveillance between office visits. The TLC-COPD dialogues are designed to emulate the monitoring and counseling strategies and the conversational style of clinicians. The content and logic of the dialogues were developed on the basis of the recommendations of an expert panel that included Bartolome Celli, MD, chairman of the American Thoracic Society committee that developed the Standards for the Diagnosis and Care of Patients with COPD. The TLC-COPD system includes the following three types of conversations: routine calls; exacerbation calls; and exacerbation follow-up calls.

**Routine Calls**

The overall outline and sequence of a routine call are shown in Figure 1. Patients are asked to call weekly on a day of the week of their choosing. If the patient fails to call within 2 days of the scheduled day, then TLC-COPD calls the patient.

At the start of each TLC-COPD call, patients are asked to enter a personal password that is used to ensure security and confidentiality. Following the confirmed identification of the patient, routine calls start with an assessment of the patient’s clinical status, focusing on symptoms identified as important indicators of COPD exacerbation. First, patients are asked whether their dyspnea has worsened since their previous call. Those who report that their breathing is worse are asked whether they have experienced shortness of breath at rest or after walking down one flight of stairs. If their breathing is not so severe that they experience dyspnea at rest or after walking down one flight of stairs, then TLC asks questions regarding their involvement in five daily activities over the previous week and the corresponding level of breathlessness. The activities referenced...
are selected by each TLC user during the administration of the chronic respiratory questionnaire immediately prior to the first TLC call.

Following its assessment of dyspnea, TLC-COPD evaluates wheezing, cough, sputum production, change in sputum color, and fever. As in the dyspnea evaluation, patient responses to the lead question determine whether subsequent follow-up questions are required. For each symptom, TLC-COPD begins by asking whether the symptom is present. For each symptom that patients report, they are asked the number of days they have experienced that symptom and other specific questions relevant to it. For example, if patients report that they have a fever, TLC-COPD will ask whether they have taken their temperature. If so, they are instructed to use their telephone keypad to enter their most recent temperature.

Next, TLC questions patients about their understanding of and adherence to their medication regimen. TLC begins by asking patients whether there have been any changes in their medication regimen since their last call. If a change has been made, TLC confirms that a physician recommended the adjustment. Any medication changes made without the physician’s permission are reported to the physician. When changes are not reported, TLC makes inquiries regarding the amount of each prescribed medication that the patient has used in the past 24 h. The dosages then are compared to the patient’s prescription, and appropriate feedback is provided.

The final part of a TLC-COPD conversation is the counseling component. This includes reminders about physician appointments, encouragement to exercise regularly, recommendations about influenza and pneumococcal vaccinations, and advice on how to stop cigarette smoking. Since the education and counseling take considerable time, they are divided up and delivered over a number of TLC-COPD conversations.

The duration of a TLC-COPD conversation depends on what the patient reported during previous conversations and on the patient’s responses during a given conversation. An average conversation takes 5 to 10 min. A small portion of the routine call script is shown in Figure 2 to illustrate the functioning of the TLC-COPD system. In this section of the script, the patient is being questioned about sputum production. Patients reporting new or increased sputum production are further questioned about sputum color and then are counseled to call their physician to report this finding of new or increased sputum production. In contrast, subjects who report no sputum or no change from baseline are not asked to call their physicians. All subjects then proceed to the next portion of the TLC-COPD conversation, which reviews recent COPD medication use with the patient.

The TLC system relays information from the conversations to the patient’s physician on a printed report similar to a computerized laboratory report. Routinely, these reports are sent to the physician’s office monthly. On the printed report, information that is abnormal or otherwise clinically significant is highlighted. If the information received during a given conversation is important for the physician to review in more timely manner, it is faxed to the physician immediately (further details to follow).

**Exacerbation Calls**

TLC-COPD focuses on identifying COPD exacerbations early and in facilitating early intervention. Patients are instructed to call the system whenever they feel that an episode of increasing respiratory symptoms may be starting. Patients are reminded that a TLC call should never be substituted for a call to their physician if they feel that is necessary. A TLC exacerbation call serves as an additional means of monitoring respiratory symptoms, not as a replacement for a call to a personal physician. TLC begins the exacerbation conversations by telling the patient to hang up and call the hospital if the situation is urgent. These unscheduled TLC-COPD exacerbation calls are important for two reasons. First, they provide a simple and convenient way for patients to report information about a worsening of symptoms to their physicians. Right after the TLC call, the system sends an immediate fax to the physician to alert him/her. This communication may make the physician aware of the need to modify patient management to abort an exacerbation before it leads to worse symptoms, untoward health outcomes, and short-term health-services utilization. Second, these exacerbation calls provide the best opportunity for TLC-COPD to affect patient behavior by providing educational and behavioral feedback at the time of worsening symptoms. It is important to get COPD patients in the habit of contacting their physician at the start of an exacerbation instead of waiting until it develops into a more serious episode.

During the exacerbation calls, TLC-COPD uses the same line of questioning as in routine calls to assess a patient’s clinical status. The medication adherence component of exacerbation calls is an abbreviated version of that used in routine calls. Exacerbation calls focus on medications consumed during the previous 24 h and place less emphasis on educating patients about COPD medications.
Exacerbation Follow-Up Calls

Following a report of increased respiratory symptoms, the patient is followed closely with daily calls. This applies also to patients who were treated for a COPD exacerbation (inpatient or outpatient) by a physician. Once patients report that their respiratory symptoms have returned to their baseline level, they are instructed to resume their weekly TLC-COPD calls. The purpose of these follow-up calls is to monitor the progress of the exacerbation and to prevent the rebound exacerbation that occurs about one quarter of the time. Like the exacerbation calls, relevant clinical information is sent to the patient’s physicians immediately. A small portion of the exacerbation follow-up call script is shown in Figure 3.

Behavioral Theoretical Underpinnings of TLC-COPD

As discussed above, TLC-COPD is designed to help both the physician and the patient improve patient adherence to medical treatment plans, particularly with regard to medication use. We expect that the effects on physicians would be mediated through TLC reports that provide current information on patients’ status as well as alerts regarding possible or actual COPD exacerbations. This information may influence physicians to make decisions regarding the patient’s management.

The behavioral theoretical underpinning of the TLC effects on patients can be understood by considering the key concepts of social learning the-
ory (SLT) including behavioral capability, self-efficacy, outcome expectation, and reinforcement. We will illustrate the application of these SLT concepts by considering the mechanisms by which TLC-COPD might affect patient behavior, particularly taking medication. With regard to medication-taking, behavioral capability entails the knowledge of what medications to take and how to take them. TLC-COPD covers these topics on a regular basis when it asks patients to look at their medications and to enter their prescribed dosages. This repetition makes patients familiar with the correct names and prescriptions of their medications. Behavioral capability is considered a necessary prerequisite for performing a behavior but is insufficient to guarantee performance. Self-efficacy expectation deals with a person's sense of personal capability to take action, and in the case of medications, to take medications regularly and appropriately. TLC-COPD helps to improve a person's self-efficacy by providing positive feedback each time the patient demonstrates a knowledge of and adherence to their medication regimen. Outcome expectations are a person's belief concerning the effects of following the behavior, in this case, the medical regimen. If patients believe that they will gain a health benefit by using medications as prescribed, they will be more likely to do so. TLC-COPD provides information to educate the caller on such health benefits. For example, patients who take less prophylactic medication when feeling healthy or take more when feeling sick are reminded that these medications need to be taken as prescribed, regardless of symptoms. Reinforcement refers to responses to a person's behavior that increase
or decrease the likelihood that the person will engage in the targeted behavior (eg, taking medication as prescribed). TLC-COPD provides direct reinforcement, for example, when patients demonstrate correct knowledge of the use of a given prescription and report good adherence, TLC responds, “Great!!! Keep up the good work.” The key concepts of SLT also are used by TLC-COPD to affect other important patient health behaviors. For example, when patients report increased respiratory symptoms, they are instructed to call their doctor, leading to an increased awareness of when to schedule medical appointments.

**TLC User Issues**

Participants are instructed to call a TLC “help line” about any problems that they may have with using the system. The help line is available to users to leave messages anytime. The participant leaves his or her name, telephone number, and the nature of his or her problem. A staff member is responsible for contacting the patient and resolving the problem. Participants are carefully instructed not to call the TLC help line for prescription refills, medical appointments, or issues related to their health.

**Confidentiality**

All information from TLC-COPD conversations is kept confidential. Information that could identify a patient is released only to a treating physician and his/her staff.

**Discussion**

With the dawn of the information age comes a variety of options for improving the delivery of health care. One such option, described for the care of patients with COPD, uses the telephone as its communication device. The widespread accessibility and low cost of telephone service make it a practical communication channel for linking health-care providers and their patients.26

In previous studies,19,21 we have demonstrated: (1) the applicability of TLC technology in the care of adults with chronic disease (eg, hypertension and hypercholesterolemia); and (2) the clinical efficacy of TLC in improving health outcomes (eg, for BP and serum lipid levels)19,21 and patient behavior (eg, medication-taking, diet, and exercise).21

Although a telecommunications system has not yet

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**Figure 4. Reporting participant information to the TLC.**
been employed in the management of patients with COPD, a few published trials have addressed the potential impact of interventions that improve the monitoring of patients with COPD and their adherence to their treatment regimen. Despite certain methodological limitations, including small sample sizes, these studies have shown that COPD monitoring interventions have appeared to reduce either health-care utilization or mortality rates in COPD patients. These trials are summarized below.

A randomized controlled trial evaluated an inpatient education program for patients admitted to the hospital for COPD that stressed the rationale for maintenance COPD therapy and how patients should manage their exacerbations. The 50 patients who received the intervention were less likely to require subsequent hospitalization over a 1-year period than the 50 control subjects (17% vs 35%, respectively; \( p = 0.06 \)).\(^{13}\) Moreover, the intervention group had approximately 50% lower costs for emergency services (\( p = 0.02 \)) and total expenses for general practice (\( p = 0.001 \)) than did the control group, during a 1-year follow-up period.

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An uncontrolled study\(^{14}\) of an intensive home-based nursing and respiratory-care intervention among 17 patients with very severe COPD showed that the intervention reduced hospitalization frequency (\( p = 0.022 \)), hospital days (\( p = 0.024 \)), and emergency department visits (\( p = 0.017 \)) by \( \geq 26.7 \) years compared to an equivalent period prior to the intervention. The patients in this study had particularly severe COPD, with a mean FEV\(_1\) of 0.68 L and an average preintervention hospitalization rate of five hospitalizations of \( > 19 \) months.

Littlejohns et al\(^{15}\) reported the results of a randomized controlled trial concerning the effectiveness of an outpatient respiratory-care worker who provided patient education, symptom monitoring, and treatment monitoring and who served as a liaison between primary-care providers and hospital services. The 65 subjects in the control group experienced a higher mortality rate during a 12-month follow-up period than did the 68 subjects in the intervention group. After controlling for FEV\(_1\) and age, the odds ratio of death among subjects in the control group was 5.5 (95% confidence limits, 1.2, 24.5) as compared to patients in the intervention group. The two groups did not differ in health-care utilization during the 1-year follow-up, but the higher fatality rate in the control group appears to have resulted in more severe disease among the surviving intervention group subjects than the surviving control group subjects. Evidence of this can be seen in the sickness impact profile scores and in the indexes of impairment.

Cockcroft et al\(^{16}\) conducted a randomized controlled trial in 75 patients with advanced COPD, evaluating the effectiveness of monthly home visits by a nurse who provided patients with education in adherence to their therapeutic regimens and the early self-detection of clinical deterioration. The intervention group experienced a slightly lower
fatality rate than did the control group (p = 0.11) (relative risk, 0.36; 90% confidence limits, 0.1, 1.0) over a 10-month follow-up period; however, the intervention group also had more frequent hospital days. As with the study by Littlejohns et al., the greater fatality rate of patients in the control group may have resulted in more severe disease among the intervention subjects surviving through the follow-up period.

Only two of these studies examined the impact of COPD care interventions on QOL. The intervention reported by Littlejohns et al. led to a significant improvement in the physical score of the sickness impact profile. The mean change in the intervention group was 5.53 (95% confidence limits, 3.70, 7.40) compared to a change in the nonintervention group of 1.65 (95% confidence limits, 0.18, 3.12). Cockcroft et al. observed no effect of their monthly visiting nurse intervention on responses to a QOL instrument designed for their study.

Although the interventions used in these studies vary and are multifaceted, on balance they suggest that COPD patients benefit from interventions that enhance patient education, symptom self-monitoring, adherence to treatment regimens, and early action in response to worsening symptoms. Based on these studies, we hypothesize that a TLC system for patients with COPD will lead to better health outcomes and reduced patient use of emergency healthcare services. This would be achieved through improved self-monitoring of symptoms and better patient adherence to prescribed treatment regimens.

TLC-COPD will result in the earlier detection of clinical deterioration by providing reports to the patients’ physicians at regular intervals as well as in response to patient-identified worsening of symptoms. This, in turn, also could lead to improved functional status and QOL, and to reduced short-term health-care utilization in patients with COPD.

APPENDIX: ARCHITECTURE OF THE TLC SYSTEM

The TLC computer system is designed as two computer subsystems (dual microprocessors) in order to allow for one subsystem to be altered or repaired without affecting the other. The two subsystems are referred to as the run-time subsystem, which retrieves information from the patient and provides appropriate feedback, and the database management subsystem, which stores the information provided by the patient and then outputs it to the physician and other providers.

Information on patients is sent to the TLC database via two sources. Either a data manager can enter information directly into the computer system or the participant can enter it through the touch-tone keypad of the telephone. Data such as the patient’s name, telephone number, and password are entered by the data manager. This information, which is entered before the participant’s first call, enables TLC to work with a particular patient. The rest of the information that TLC collects is entered by the participant during the TLC call (Fig 4).

TLC uses the information it collects from the data manager and the patient in two ways. It is either output in reports or it is used by TLC during the current and subsequent TLC conversations. The information that TLC collects is stored in a variety of data tables that are linked through a relational database. The information collected during a call is uploaded to two tables at the end of each conversation. These two tables also contain the information that the data manager enters directly into the computer. One table is available as a reference during the next call. This allows for the determination of changes in status from one call to the next. The second table is used to download information that is included in reports (Fig 5).

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