

Concept Analysis of Symptom Disclosure in the Context of Cancer

Yiyuan Sun, DNSc, RN; M. Tish Knobf, PhD, RN, FAAN, AOCN

Although symptoms suggestive of cancer are the most common reason that people seek healthcare, the process undertaken to disclose the symptoms is unclear. The purpose of this article is to critically analyze the concept of symptom disclosure in the context of cancer. Rodgers' evolutionary approach was applied to analyze the concept of symptom disclosure. Concept analysis indicates that symptom disclosure is a decision-making process in which a person chooses to tell significant others and a healthcare provider about self-identified symptoms. Characteristics of the concept include symptom interpretation, weighing the risks and benefits of disclosure, and taking action. Influencing factors are knowledge, cancer risk perception, personal or family history of cancer, socioeconomic and cultural factors, and access to care. The concept analysis of symptom disclosure provides guidance for developing strategies to promote healthcare-seeking behavior in practice and suggest areas for future research.

Key words: *concept analysis, decision making, neoplasm, symptom disclosure*

IN 2007, more than 1.44 million people are expected to be diagnosed as having invasive cancer in the United States, corresponding to nearly 4000 new cases per day.¹ Early detection through screening and prompt symptom reporting is essential to reduce associated morbidity and mortality.² *Symptoms* used in this article refers to subjective experiences reflecting changes in the biopsychosocial function, sensation, or cognition of an individual, including signs.³ Symptoms are the most common reason that persons seek healthcare, and these presenting symptoms guide healthcare

providers in their diagnostic decision making. Symptoms from breast self-examination that led to a diagnosis of breast cancer have been reported in 71% of women 20 to 44 years old and 48% of women 50 years or older.^{4,5} Similarly, 69% of men with prostate cancer presented to their healthcare provider with lower urinary tract infection or systemic symptoms prior to the diagnosis.⁶

Delay in disclosing symptoms suggestive of cancer has been associated with late-stage disease, increased tumor sizes, and a greater number of positive nodes, which are associated with poorer quality of life and lower 5-year survival rates.^{7,8} Some symptomatic cancers have been reported to be biologically more aggressive, with a higher grading and a higher proliferative index, than screening-detected asymptomatic cancer.^{9,10} Thus, disclosure of symptoms suggestive of cancer earlier has advantages for early detection of many, although not all, cancer types. Yet, at least one third of the cancer patients did not disclose their symptoms to healthcare providers for 3 or more months after discovering the symptom(s).^{8,11} Despite the importance of disclosing symptoms in a timely

Author Affiliations: State University of New York at Stony Brook, Syosset (Dr Sun); and Yale University School of Nursing, New Haven, Connecticut (Dr Knobf).

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Corresponding Author: Yiyuan Sun, DNSc, RN, State University of New York at Stony Brook, 34 Nassau St, Syosset, NY 11791 (yiyusun@notes.cc.sunysb.edu).

manner, less attention has been paid to how patients decide to disclose their symptoms. Therefore, the purpose of this article is to critically analyze the concept of symptom disclosure in the context of cancer to help understand the decision-making process for clinical practice and enhance theoretical nursing knowledge.

METHODS

Rodgers' evolutionary approach was applied to analyze the concept of symptom disclosure. This approach is chosen because it involves doing a systematic review of the literature to collect the relevant data and allows the characteristics of the concept to emerge from the data.¹² Through an inductive procedure, the goal of evolutionary approach is to identify characteristics common to a class of objects or phenomena and the abstraction and clustering of these characteristics, along with some means of expression.¹³ Furthermore, the idea (concept) expressed using the identified word is of prime importance, not the word (expression) itself.¹²

Sample selection

Articles from CINAHL, Proquest, PsychINFO, Web of Science, and MEDLINE databases were examined by using key words "symptom disclosure," "symptom reporting," "presenting symptom," "neoplasm," "decision making," "help seeking," "care seeking," and "adults." Research articles and doctoral dissertations in English that met the following characteristics were chosen: (1) process of seeking diagnosis for symptoms suggestive of cancer; (2) factors influencing the process of seeking medical attention for symptoms suggestive of cancer; (3) decision outcomes for disclosing symptoms; and (4) adults (≥ 18 years). To trace the origin and use of symptom disclosure, a total of 35 articles published from 1958 and 2007 were identified as the final sample, which represented 4 disciplines (Table 1).

Table 1. Disciplines of selected sample literature

Discipline	Reference number
Medicine ($n = 9$)	11, 18, 20-22, 36, 37, 40, 47
Psychology ($n = 9$)	16, 17, 25, 31, 34, 35, 38, 39, 46
Public health ($n = 8$)	24, 26, 41, 43-45, 48, 49
Nursing ($n = 9$)	19, 23, 27-30, 32, 33, 42

Data analysis and management

The actual process of evolutionary approach emphasizes the collection and analysis of raw data by reviewing the literature.¹² A data sheet was developed for each article by using a template corresponding to the Rodgers and Knafli guideline.¹² The data sheet included name of authors and date of study, setting, and sample, theoretical approach/methods, uses of the concept, attributes (characteristics of the concept), antecedents (events or phenomena preceding the concept), and consequences (what happens after disclosing symptoms suggestive of cancer) (Table 2).

Each article was read through several times to obtain a sense of the whole. Initial codes were developed by retrieving findings from the sample articles. Similarities and differences between codes were compared and grouped together to create themes. For example, 3 themes were identified for attributes of

Table 2. Key elements of the evolutionary approach to concept analysis

Rodgers' evolutionary approach	
Attributes	The characteristics of the concept including dimensions or categories of the concept
Antecedents	Events or phenomena that precede the concept, that is, the factors influence and exist preceding the concept of symptom disclosure
Consequences	What happens after or as a result of the concept

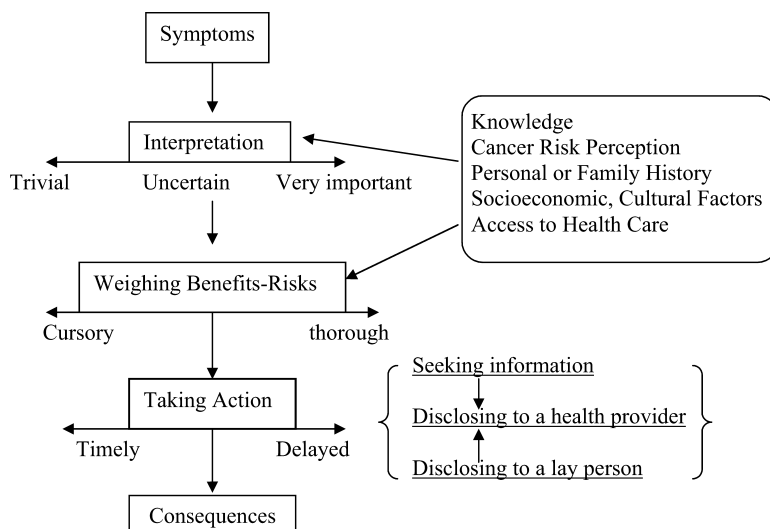


Figure 1. Understanding symptom disclosure.

symptom disclosure: symptom interpretation, weighing the risks and benefits of disclosure, and taking action. Through linking emerging themes together, a model of symptom disclosure is presented in Figure 1.

FINDINGS

Origins of symptom disclosure

The concept of symptom disclosure is strongly associated with self-disclosure. Jourard and Lasakow defined *self-disclosure* as “the process of making the self known to other persons.”^{14(p91)} Culbert later integrated the theory of interpersonal process into the concept of self-disclosure: “Self-disclosure refers to an individual’s explicitly communicating to one or more others some personal information that he believes these others would be unlikely to acquire unless he himself disclose it. Moreover, this information must be ‘personally private’ . . .”^{15(p2)}

The concept of symptom disclosure was first introduced by Young¹⁶ to identify factors influencing an individual’s willingness to disclose various types of symptoms to a physician. However, no definition for symptom disclosure was found in the literature. In the context of cancer, symptom disclosure

includes the time interval from the initial discovery of a suspicious cancer symptom to first healthcare consultation.

Attributes

According to Rodgers, the attributes are the characteristics of the concept and include dimensions or categories of the concept. Attributes of symptom disclosure are symptom interpretation, weighing the risks and benefits of disclosure, and taking action.

Symptom interpretation

Noticing a change from the way one usually feels prompts one to assess the meaning of this change. Assigning meaning to the change, specifically symptoms, is an interpretive process that includes knowledge and reasoning.¹⁷ The interpretation of the symptom(s) is based on the nature of the symptom(s) and its effect on everyday life.^{18,19} The nature of symptoms may influence the meaning of the perceived changes. People are less likely to interpret the perceived changes as a serious health threat when the symptoms are ambiguous or do not match the person’s expectation of cancer presentation.^{20,21} For example, symptoms of colon cancer may be

vague, nonspecific, and diffuse (such as tiredness, loss of weight, and decreased appetite), making it hard to attribute them to cancer.^{19,22} In contrast, specific symptoms (such as a breast lump) or symptoms having destructive impact on one's life are more likely to be attributed to cancer.^{21,23} Studies found that people were more likely to disclose the self-discovered symptoms promptly to a physician when they interpreted the symptoms as something serious.^{20,24} In contrast, individuals may postpone their decision of disclosing if they interpret their symptoms as not important or serious or were uncertain over whether symptoms required medical attention.^{25,26} The participants were prompted to disclose their symptoms when the symptoms progressed to interruption of their daily activities.²⁶

Weighing the risks and benefits of disclosure

The decision regarding whether and when to disclose symptoms suggestive of cancer is a process involving cognitive assessment, which can be a cursory or a very deliberate thorough process.^{27,28} Persons with symptoms suggestive of cancer weigh the need to disclose symptoms on the basis of the perceived seriousness of the symptoms and the perceived benefits and risks of disclosing.^{21,28,29} This process is also associated with contextual factors, including the degree and nature of fear related to consequences of disclosing, knowledge, and socioeconomic and cultural factors (such as access to healthcare and perceived risk for cancer). Few studies have been conducted to investigate the cognitive process of weighing the benefits and risks of disclosing. Reasons to report symptoms to a healthcare provider are numerous and none clearly identify or explain those who delay versus those who seek immediate healthcare consultation. Perceived benefits of disclosing symptom(s) are what the person anticipates to gain, which motivates individuals to disclose their symptoms.^{28,30} The benefits of disclosing include relieving uncertainty, fear, and worry; obtaining sup-

port, advice, and consultation; identifying the cause of the symptom; managing the symptom; and getting treatment if indicated.^{28,31} If individuals fear that delay in disclosing the symptom may worsen the disease or lead to unnecessary suffering and death, they will take action quickly.^{21,28}

Studies reported that individuals who delayed disclosure to a healthcare provider were more likely to have poorly reasoned arguments to support their delay, report more perceived risks of disclosing, and ignore or abandon the potential benefits of seeking healthcare.^{27,29} The perceived risks of disclosing are the probability of suffering harm or loss, which include unpleasant diagnostic procedures, out-of-pocket payment, being labeled hypochondriac or symptoms being dismissed by healthcare providers, and feeling embarrassed because of symptoms associated with sexual areas of the body.^{21,30,32} For individuals who suspect cancer, the perceived risks of disclosing include the probability of being diagnosed with cancer, need for cancer treatment, fear of being discredited, losing control, likelihood of hospitalization, and potential loss of femininity or masculinity.^{7,21,33,34}

Perceived risks of disclosing can often lead to emotional distress and stigma. Fear may relate to a knowledge deficit about the efficacy of cancer treatment, personal experience, or fear of loss of function, employment, and ultimately life. Conscious or unconscious denial may be used as a coping mechanism to allay fear, minimize the significance or urgency of the symptom, and substitute a less-threatening form of the rejected meaning.^{35,36} Appropriate denial can help people cope with threatening information, perceptions, or thoughts as a new, less-threatening, and more acceptable interpretation of experience replaces anxiety-provoking truth. Yet, denial can be maladaptive when it prevents people from disclosing symptoms to healthcare providers.

Cancer is often considered as a stigmatized illness, representative of death and suffering. Goffman described stigma as an

“attribute that is deeply discrediting” and that reduces the person “from a whole and usual person to a tainted, discounted one.”^{37(p3)} Sontag³⁸ argued that any disease for which causality is unclear, as well as treatment is ineffectual, tends to become a stigmatized condition. Negative terms such as *terrifying*, *ugly*, and *extremely frightening* are used to describe cancer.²⁷ People with cancer often confront a set of subtle, unwarranted prejudices that assign ultimate responsibility for the disease to the afflicted individual. Chapple and colleagues³⁴ found that lung cancer patients in particular felt prejudice because the disease is so strongly associated with smoking. As a result of awareness of society’s perspectives, some individuals may be reluctant to disclose their symptoms. Failure to disclose symptoms to a healthcare provider can result in progressive disease with more limited treatment options and poorer outcomes.

Taking action

When people make the decision to disclose the symptoms suggestive of cancer, they realize the need to do something about the symptoms. Taking action is characterized by the behaviors of seeking information, disclosing to a lay person, and disclosing to a healthcare provider. The dimension of taking action includes timing of the behaviors.

Persons with symptoms suggestive of cancer often seek information from lay persons, mass media (eg, Internet, newspaper, journals), or other resources regarding the meaning of the symptoms and the need of medical attention. They may also seek information related to healthcare providers and health insurance if they lack access to healthcare.^{20,28,29} Disclosing symptom to significant others before deciding to disclose to a healthcare provider can be both positive and negative. Family and significant others may influence the person’s decision by offering advice, lay diagnosis, or recommendations about taking action or not.^{25,32} Some studies found that participants who had not initially discussed the symptom with others or had ignored

other people’s advice postponed the decision to disclose to a healthcare provider for a longer period than patients who had talked with others about symptom.^{32,33} In contrast, another study found that there was no difference in time to disclosure for women who had talked to someone about their symptoms and those who had not talked to someone about their symptoms before seeing a healthcare provider.³⁹

Timing of disclosure refers to the decision regarding when to disclose the symptoms suggestive of cancer. Timing of disclosure is associated with the nature and the perceived significance of the symptoms, perceived benefits and risks of disclosing, disclosing to a lay person, access to healthcare, and sociocultural factors.^{21,29,30,33} People who decide to disclose their symptom(s) in a timely manner acknowledge the perception of having the symptom(s), the significance of the perceived symptom(s), and perceive that the benefits of disclosing outweigh any risks. Such acknowledgements result in a timely symptom disclosure.^{27,28} In contrast, others may perceive their symptoms as minor and not serious and postpone disclosure.²⁶

Delay in disclosing symptoms to a healthcare provider either may reflect denial as a coping response leading to a more late-stage diagnosis and poorer outcomes or may be related to a lack of knowledge of the seriousness of the symptom or lack of perceived health risk associated with the symptom(s). Unfortunately, timely reporting of symptoms does not guarantee early detection of cancer because some symptoms may not present until the cancer is in the advanced stage such as pancreatic or ovarian cancer.¹¹ In many cancers, such as ovarian cancer, symptoms may be vague and the site allows the tumor to grow to an advanced stage before the symptoms are manifested.

Antecedents

Antecedents refer to events or phenomena that precede the concept, that is, the factors influence and exist preceding the concept of symptom disclosure. Antecedents of

symptom disclosure in the context of cancer include knowledge, cancer risk perception, personal or family history of cancer, socioeconomic and cultural factors, and access to care.

Knowledge, cancer risk perception, and cancer experience

Knowledge, cancer risk perception, and personal or family history of similar symptoms influence symptom interpretation. Cancer knowledge is a necessary, but insufficient, condition for the decision of disclosing symptoms.^{22,24} Even persons with some knowledge about warning signs and symptoms of cancer waited 3 or more months to disclose the symptom because the majority of them did not suspect cancer.^{32,40} Some of those assessed their symptom as lacking characteristics of a warning sign of a cancer and did not perceive the symptom as a threat to their health. Others may either perceive themselves at low risk for cancer despite the presence of symptoms or unconsciously deny the potential threatening implication of a symptom or symptoms.³⁶

A personal or family experience of similar symptoms may influence an individual's interpretation of the symptom(s) and result in a positive or a negative influence on the decision to disclose the symptom(s). Prior personal or family history of cancer may help identify the potential symptom and prompt the decision of disclosing.⁴¹ However, for some, the fear of death associated with a cancer experience may hinder their decision to disclose to a healthcare provider.¹⁸ Similarly, people who have previously been treated for benign disease often wait to disclose a symptom, assuming that the symptom(s) is not significant on the basis of past experience.¹⁸ Studies revealed that women who perceived themselves at low risk for breast cancer were more likely to postpone their decision to disclose a breast symptom.⁴¹

Sociodemographic and cultural factors

Many studies have explored the influence of sociodemographic variables, including age,

gender, race, socioeconomic status (SES), marital status, and education level, on the decision of disclosing symptoms to a healthcare provider. Being married, older age, high SES, and more education have been associated with prompt decision of disclosing symptom in some studies^{7,11} but not others.^{19,39}

White Americans are more likely to disclose their symptoms to a healthcare provider in a timely manner than do black, Asian, and Hispanic Americans.^{11,18,23} Minority women are reported to have longer delays in disclosing symptoms suggestive of cancer to a healthcare provider than white women, and this appears to be influenced by lower SES and access to healthcare.^{11,42} Few studies have examined how cultural factors other than access to healthcare and SES contribute to the difference in the timing of symptom disclosure between non-Hispanic white and minority populations.

Access to healthcare

Access to healthcare refers to the opportunity and right to receive healthcare, which is associated with health policy, characteristics of the health delivery system, and characteristics of the population at risk. Penchansky and Thomas⁴³ suggested that the concept of access should reflect the "fit" between the characteristics and expectations of the system and the patient. They defined the fit to be measured across 5 aspects: affordability, availability, accessibility, accommodation, and acceptability.

Medical costs and indirect healthcare costs (such as costs of sick leave, transportation, and child care) may influence the decision making for symptom disclosure. The influence of insurance status on the decision of disclosing symptoms to a healthcare provider is well documented in the literature. Studies revealed that patients without insurance often wait to disclose their symptoms because of cost concern, especially when they did not consider the symptoms as a significant problem.^{7,44} No usual care source, previously encountered prejudice, perceived rude and

insensitive behaviors of healthcare providers, language barriers, difficulty obtaining an appointment, and lack of transportation have been associated with delay in disclosing symptoms to a healthcare provider.^{21,30}

Consequences

Consequences refer to what happens after or as a result of the concept. Two categories of consequences of symptom disclosure were discussed in the literature: patient-provider interaction during clinical encounter and diagnostic evaluation outcomes. Although the quality of the patient-provider interaction has a profound impact on the ability of patients to communicate symptoms to their provider and decrease the likelihood of malpractice, fewer empirical studies have investigated how individuals interact with their healthcare providers when representing cancer symptoms to the later.

Beach and colleagues⁴⁵ examined how patients raised, and how doctors responded to, their concerns with cancer symptoms by analyzing video excerpts from routine oncology interviews. The study found that patients often expressed their cancer suspicion and concerns “in the midst of volunteering narrative information about their medical history and experiences with symptoms,”^{45(p905)} for example, reports about family members being diagnosed with cancer. In response, the doctor tended to move away from rather than pursue patients’ psychosocial or emotional concerns by offering a textbook-like listing of symptoms or restrict patients’ further elaboration by shifting his or her focus away from patients.⁴⁵ Avoiding, failing to acknowledge, and constraining patients’ disclosure of significant events and concerns, particularly their cancer symptoms, contribute significantly to patient dissatisfaction, increase the likelihood of malpractice, and decrease the likelihood for early detection.⁴⁶

Disclosing symptoms to a healthcare provider usually leads to clinical and diagnostic evaluations. Not all symptoms designated as “warning signs” for cancer will result in a cancer diagnosis. A cohort study in the United

Kingdom reported that cancer was found in a small percentage of people with hematuria (11%), hemoptysis (38%), dysphagia (0.7%), and rectal bleeding (9%).⁴⁷ A population study reported that only 6% of women who presented to a primary healthcare provider with breast symptoms were diagnosed with breast cancer.⁴⁸

In contrast, for persons with symptoms that are diagnosed as cancerous, the timing of the disclosure of the symptoms may or may not be related to detection at an early stage or result in better survival outcomes.^{7,8} For breast cancer, a delay in a breast symptom (eg, breast lump) will more likely be associated with a higher cancer stage and poorer outcome.⁸ For some cancers, such as ovarian or pancreatic cancer, timely disclosure of symptoms may not improve outcomes because of the advanced stage when the symptoms become manifest. In addition to the timeliness of symptom disclosure by an individual, there are system-related delays that may influence survival outcomes.^{18,49} These delays may include prolonged evaluation of symptoms (multiple visits, tests), scheduling delays for diagnostic testing, and barriers to navigating the complex healthcare system (eg, insurance, transportation, competing life demands).

CONCLUSIONS

The definition of symptom disclosure

Symptom disclosure is a process where the individual decides to share his or her symptom experience with others (lay persons and healthcare providers). Symptom disclosure is also an interpersonal process and occurs within an interactive, complex, psychosocial, situational, and cultural context of individual’s life. The decision to disclose symptoms suggestive of cancer is characterized by symptom interpretation, weighing the benefits and risks of disclosing, and taking action. The decision regarding why, to whom, and when to disclose reflects the individual’s interpretation about the causality, severity, and importance of the symptom and a belief

in the benefits of disclosing outweighing the risks of seeking care. This decision-making process is influenced by knowledge, cancer risk perception, personal or family history of cancer, socioeconomic and cultural factors, and access to healthcare (Fig 1).

Implication for practice

To provide competent care, healthcare providers need to understand important details about their patients care-seeking behaviors. Findings from current study suggest that the scope of practice for healthcare providers be more proactive and individualized because individuals vary significantly regarding symptom interpretation and the perceived benefits and risks of disclosing. For individuals who might downplay symptoms and illness, healthcare providers should help them recognize the importance and seriousness of the symptom; for individuals who fear cancer treatment, healthcare providers should emphasize many benefits of seeking care including relieving uncertainty, fear, and worry; obtaining advice and consultation; identifying the cause of the symptom; and having the symptom treated earlier if needed. These proactive and individualized interventions can be done by assessing their patients cancer knowledge, cancer risk perception, personal or family history of cancer, socioeconomic and cultural factors, and access to healthcare during clinical visits. Healthcare providers can also decrease the perceived risks of disclosing by being sensitive to verbal and body language and encourage their patients to ask questions and express concerns by creating an atmosphere of care, openness, and nonjudgment (Table 3).

Implication for research

It is important to understand how people make potential life-altering decisions regarding symptoms, especially those suggestive of cancer. Many studies have investigated facilitators for and barriers against disclosing symptoms to a healthcare provider. Yet, none prove to be reliable indicators to predict who will

Table 3. Themes emerged from concept analysis of symptom disclosure

Findings from the study	
Attributes	Symptom interpretation Weighing the risks and benefits of disclosure Taking action
Antecedents	Knowledge Cancer risk perception Personal or family history of cancer Socioeconomic and cultural factors Access to healthcare
Consequences	Patient-provider interaction Clinical and diagnostic evaluations

wait to disclose the symptom versus those who will seek healthcare in a timely manner. Factors that influence symptom disclosure (cancer knowledge, perceived risk, personal and family experience, socioeconomic and cultural factors, and access to healthcare) may either motivate a person to disclose a symptom or hinder a person's decision to disclose. Further research is needed to investigate why people do not suspect anything serious or important in the case that they have the knowledge about cancer symptom, as well as how people balance the perceived benefits and the perceived risks of disclosing when making the decision to disclose. Studies are needed to examine the combined influences of the attributes and antecedents of symptom disclosure. For example, these researches could address whether and how access to healthcare interacts with symptom interpretation and weighing perceived benefits and risks of disclosing.

Implication for cancer education

Findings from current study indicate that cancer knowledge is a necessary, but insufficient, condition for the decision to disclose symptoms. Thus, future cancer education should not only provide information

about how to recognize cancer symptoms but also help individuals weigh the benefits against the risks of seeking care earlier. Cancer information should also reassure public about the benefits of early treatment on prognosis and the advances in the management of the adverse effects of chemotherapy. In addition, educational message should strike a balance between scaring away people from healthcare providers and taking away their motivation to come forward. Financial and social resources for the diagnosis and treatment of cancer should also be included in health education messages.

Rodgers' evolutionary approach views concept analysis as a dynamic process; that is, concept analyses should not present their results as finished.¹² Further studies are needed to examine factors associated with symptom disclosure and cancer outcomes. There are significant gaps in our knowledge of symptom disclosure across ethnic groups. This gap is important to address in light of the rapidly changing demographics of the United States. Future intervention studies should aim to provide tailored educational information appropriate to the target population to promote early detection of cancer.

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