Palliative Care Conversations for Heart Failure Nurses: A Pilot Education Intervention

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Abstract

Introduction: Heart failure is a progressive condition affecting 6.2 million Americans. The use of palliative and supportive care for symptom management and improved quality of life is recommended for persons with heart failure. However, 91% of nurses believe they need further training to have palliative care conversations. The purpose of this pilot education intervention was to determine if providing nurses with education on the timing and content of palliative care conversations would improve their perceived skill and knowledge.

Methods: This was a pilot study of an online educational intervention. Data were electronically collected from 13 participants using validated questionnaires delivered via Qualtrics. Participants completed a demographic survey and End-of-Life Professional Caregiver Survey (EPCS) before and after completing an online, asynchronous education module.

Results: Mean scores were higher on all posttest measures. Independent samples t-tests revealed statistically significant differences on the Effective Care Delivery (ECD) scale ($t[32] = -2$, $p = .05$) and total EPCS scale scores ($t[32] = -2.2$, $p = .03$) from pre- to posttest.

Conclusion: Scores increased on all dimensions pretest to posttest with statistically significant differences in ECD and total scores. Providing asynchronous online education on timing and content of palliative care conversations to nurses caring for people with heart failure is a feasible and effective way to improve perceived knowledge and skill of palliative care conversations.

Keywords

palliative care, education, heart failure, timing

Introduction

Approximately 6.2 million American adults have heart failure (HF); with a projected 46% increase in prevalence by 2030 due to an aging population, an additional 1.5 million people will be affected (Benjamin et al., 2019). HF symptoms include weakness, fatigue, and dyspnea that impairs quality of life (QOL) and worsens over time. The prognosis is not encouraging; 40% of HF patients will die within one year of their first hospital visit; 50% of people with HF die within five years of diagnosis (Schallmo et al., 2019). HF has an unpredictable disease trajectory, and this has been reported as a barrier to providing patients with HF appropriate, timely, palliative, and end-of-life care (del

Pozo et al., 2018). Guidelines from the American College of Cardiology, American Heart Association, and European Society of Cardiology recommend palliative and supportive care for symptom management and improved QOL for

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patients with HF (Hill et al., 2020; Maddox et al., 2021; Ponikowski et al., 2016; Yancy et al., 2013).

Brief Review

Palliative Care in HF. Palliative care is a patient and family-centered approach to promote physical, psychosocial, and spiritual health regardless of a diagnosis or prognosis (Klinedinst et al., 2019). Palliative care emphasizes the relief of suffering, improving QOL, providing needed support for a family (Klinedinst et al., 2019), and can be provided in conjunction with curative treatment. Some nurses associate palliative care with end-of-life/hospice care, and the terms, when used interchangeably, cause confusion (Mahon & McAuley, 2010; Singh et al., 2019; Weil et al., 2015). Hospice care incorporates palliation of symptoms, but hospice care recipients are not receiving curative treatment or cure is not possible. Palliative care can and should be introduced at an initial diagnosis and offered along with active treatment throughout disease progression until the end-of-life (Schallmo et al., 2019). In some instances, patients with HF and their family members have reported little communication with health care providers about what to expect from an unpredictable HF disease trajectory (Schallmo et al., 2019). However, in one study, after a definition of services provided by palliative care teams was given to spouses of people with HF, all thought the services were valuable and would be helpful to their loved ones (Hupcey et al., 2009).

HF nurses communicating about palliative care. Unfortunately, people with HF do not receive the same access to invaluable palliative care services as other patients with life-limiting diseases (del Pozo et al., 2018). Evidence indicates palliative care is widely underused in people with HF, and when used, it is often late in the illness after a patient's QOL and treatment efficacy has already significantly diminished (Fitzsimons et al., 2019). This results in patients and their families having unmet physical, emotional, spiritual, and social needs (Klinedinst et al., 2019). One reason for this is nurses believe that while they are competent to conduct discussions about palliative care, they lack knowledge about the timing and content of palliative care conversations with people who have HF and their families because of the unpredictable disease trajectory (Crimmins et al., 2021; Dunlay & Roger, 2013; Hjelmfors et al., 2014; Kavalieratos et al., 2014; Schichtel et al., 2019). Therefore, nurses do not want to give patients the impression they are nearing death (Schallmo et al., 2019).

Nurses working with cardiac patients have acknowledged the importance of palliative care services for HF patients (Schallmo et al., 2019). In one study, 91% of nurses believed they would need further training to be prepared to have palliative care conversations with patients who have HF (Hjelmfors et al., 2014). Similarly in a study of 275 Dutch and Swedish nurses discussing prognosis with HF patients, the majority of nurses (70%) reported a need for more education in this area with no differences found in a number of years in health care or years in HF care (van der Wal et al., 2018). In related research Schichtel et al. (2019) in a systematic literature review and qualitative synthesis of 17 studies aimed to identify barriers and facilitators to engaging in advanced care planning (ACP) in HF. Two of the main barriers were a lack of disease-specific knowledge about HF-specific palliative care and a lack of multidisciplinary collaboration among health care professionals to reach a consensus on when ACP is indicated, mirroring the uncertainty in the trajectory of the disease. The main facilitators to engaging in ACP were being competent to provide holistic care when using ACP in HF, patients initiating the ACP discussions, and having the resources to deliver ACP at a time and place appropriate for the patient. Additionally, palliative care may be poorly addressed in some health care institutions, resulting in nurses being ill-prepared to discuss this service (Achora & Labrague, 2019).

Nurses are critical advocates for needed services for patients in their care and must have the knowledge and skills to have conversations with people who have HF in a sensitive and meaningful way (Achora & Labrague, 2019). Palliative care education is needed to improve nurses' knowledge, attitudes, and preparedness when caring for patients with cardiac disease in need of palliative care services (Hjelmfors et al., 2014). Therefore, the purpose of this pilot education intervention study was to determine the feasibility of an online, asynchronous module on the timing and content of palliative care conversations on nurses' perceived knowledge and skill in having these conversations with people who have HF and their families.

Methods

Design

This pretest, posttest pilot study used an online survey methodology delivered via Qualtrics. The pre- and posttests evaluated self-reported knowledge and skill related to palliative care and end-of-life conversations. The study site Institutional Review Board approved this study.

Sample and Setting

This study's target population was nurses providing direct care to people with HF across southeastern North Carolina. To be included in the study, participants must be nurses, at all degree levels, working with people who have HF, age 18 and older, read English, and have access to a computer or mobile device to complete the survey and education module. Individuals were excluded if they did not provide direct care in any setting (inpatient, outpatient, acute care, doctor's office, etc.) to people with HF.

Procedures

Subject recruitment and data collection occurred over eight weeks, from November 2018 through January 2019. A local health education center sent an email flyer to 2,995 nurses on their LISTSERV, advertising the research study. Recruitment was broad, not all of the 2,995 nurses cared for HF patients and the owner of the LISTSERV did not have data on subscribers to narrow solicitation. As an incentive, a continuing education credit was offered to nurses who completed the module. The module's link was provided in the invitation email flyer, and participants could access the module only once. Key stakeholders such as telemetry unit nurse managers and the HF telephonic case manager at the regional medical center, were also sent the flyer and asked to share it with their staff. The first question on the survey was to confirm eligibility by asking if the nurse provided direct care to patients with HF. If a nurse answered *no*, a thank you message appeared, and a participant was directed to the education module. If a nurse answered *yes* and met the inclusion criteria, the participant was directed to the demographic questionnaire and pretest with the End-of-Life Professional Caregiver Survey (EPCS) (Lazenby et al., 2012) and then routed to the education module. Once the module was completed, the EPCS was then completed postwebinar. To increase the response rate, reminder emails were sent at four weeks and then a week before the education module closed. There was an increase in access and completion after the first reminder email, but not the second.

Educational Intervention

The education need about communication on palliative and end-of-life care in HF was determined in consultation with practice professionals, including unit managers, educators at the study site and the area health education center, practicing nurses, researchers, and pharmacists. After completing the demographic questionnaire and EPCS pretest, participants listened to an 8-minute audiotaped testimonial. The testimony was from a family member of a person with HF who discussed how palliative care positively affected her and her mother when diagnosed with HF. Next, participants continued to watch and listen to a 42-minute long webinar from the American Association of Heart Failure Nurses (AAHFN) by Harleah G. Buck, *What do You Patients Need to Hear From You and When do They Need to Hear It?: Appropriate Communication Across the Trajectory of Heart Failure*. Permission from AAHFN was granted for the use of the webinar. To our knowledge, this webinar has not been used in prior research but has been used as a continuing education offering by AAHFN. The educational content described palliative care communication principles, phases of HF, communication about prognosis, and ACP appropriate for each phase and described communication topics specific to palliative care in people with HF.

Instruments

The pretest instruments were a researcher-designed 12-item demographic questionnaire and the 28-item EPCS. The EPCS was administered again after the completion of the module.

Demographic Questionnaire

The demographic questionnaire collected data on age, gender, race, ethnicity, county of work, type of facility worked, level of nursing education, marital status, employment status, years working as a nurse, years caring for people with HF, and any additional certifications held.

End-of-Life Professional Caregiver Survey

The EPCS is a 28-item self-report scale to measure specific palliative and end-of-life care educational needs for health care professionals (Lazenby et al., 2012). This measure has been validated in health care professionals that included doctors, nurses, and social workers. Other researchers have used the EPCS, but none have reported additional psychometrics (Gannon et al., 2017; Moir et al., 2015; O'Shea et al., 2017). Permission was granted from the authors to use the EPCS. Items are rated on a Likert scale, from 0, indicating *not at all*, to 4, indicating *very much* about the nurses' confidence in response to a particular statement.

The EPCS has three subscales: patient- and family-centered communication (PFCC; 12 items); cultural and ethical values (CEV; 8 items); and effective care delivery (ECD; 8 items). Items are rated on a Likert scale, from 0, indicating *not at all*, to 4, indicating *very much* about confidence in response to a particular statement.

Cronbach's alpha reliability for the EPCS has been reported by Lazenby et al. (2012) as .96, and in the present study was .97. The total EPCS scale score was derived by adding the means of subscales. The eight domains of the national palliative care guidelines and all modules from the core curriculum and end-of-life education curriculum, both physician and nursing-specific, are measured in the total EPCS scale (Lazenby et al., 2012).

The PFCC subscale measures ones' perceived ability to collaborate effectively with patients, families, and health care teams about end-of-life care options. Examples of items on this scale include, "I am comfortable starting and participating in discussions about code status" and "I am comfortable talking with other healthcare professionals about the care of dying patients." Cronbach's alpha for this subscale has been reported as .95 (Lazenby et al., 2012) and in the present study was .96.

Table 1. Demographic Characteristics of Respondents and State Data.

Demographic variable	Sample $n = 21$ total (%)	State[a] (%)
Gender		
Female	$n = 21$ (100)	91
Race		
Caucasian	$n = 18$ (85.7)	80
Black/African American	$n = 2$ (9.5)	12
American Indian or Alaskan Native	$n = 1$ (4.8)	1
Age[a]		N/A
20–29	$n = 3$ (14.3)	
30–39	$n = 4$ (19)	
40–49	$n = 4$ (19)	
50–59	$n = 3$ (14.3)	
60–69	$n = 6$ (28.6)	
Only 20 reported for age[a]		
Level of education		
LPN	$n = 1$ (4.8)	6
ADN	$n = 8$ (38.1)	22
BSN	$n = 7$ (33.3)	28
MSN	$n = 3$ (14.3)	11
Doctorate	$n = 2$ (9.5)	10
Current employment status		
Full time	$n = 16$ (76.2)	
Part time	$n = 1$ (4.8)	
Unemployed, looking for work	$n = 1$ (4.8)	
Unemployed, not looking for work	$n = 1$ (4.8)	
Retired	$n = 2$ (9.5)	
Marital status		
Single (never married)	$n = 1$ (4.8)	
Married	$n = 14$ (66.7)	
Widowed	$n = 3$ (14.3)	
Divorced	$n = 2$ (9.5)	
Separated	$n = 1$ (4.8)	
County of work		
Brunswick	$n = 3$ (14.3)	
Columbus	$n = 3$ (14.3)	
Duplin	$n = 2$ (9.5)	
New Hanover	$n = 9$ (42.3)	
Pender	$n = 4$ (19)	
Other	$n = 7$ (33.3)	
Types of facilities		
Hospital	$n = 7$ (33.3)	
Long-term care	$n = 1$ (4.8)	
Outpatient setting	$n = 4$ (19)	
Other (health department, physician office, home health, home palliative care, and hospice)	$n = 11$ (52.4)	
Years working as a nurse		
0–9	$n = 6$ (28.6)	
10–19	$n = 6$ (28.6)	

(continued)

Table 1. Continued.

Demographic variable	Sample $n = 21$ total (%)	State[a] (%)
20–29	$n = 2$ (9.5)	
30–39	$n = 6$ (28.6)	
40–49	$n = 1$ (4.8)	
Years working with HF patients		
0–9	$n = 11$ (52.4)	
10–19	$n = 7$ (33.3)	
20–29	$n = 1$ (4.8)	
30–39	$n = 1$ (4.8)	
40–49	$n = 1$ (4.8)	

Note. N/A = not available; LPN = Licensed Practical Nurse; ADN = Associate Degree Nurse; BSN = Bachelor of Science in Nursing; MSN = Master of Science in Nursing; HF = heart failure.
[a]State data obtained from the North Carolina Board of Nursing.

The CEV subscale measures ones' perceived competence in managing end-of-life concerns related to the patient and family's spiritual needs and comfort in the presence of a dying patient. Sample items included "I am comfortable dealing with patients' and families' religious and cultural perspective" and "I am able to be present with dying patients." Cronbach's alpha has been reported at .89 (Lazenby et al., 2012) and in the present study was .92.

The ECD subscale measures ones' perceived knowledge about health care options available for dying patients and resources available for nurses working with dying patients. Examples of items on the scale are "I am familiar with palliative care principles and national guidelines" and "I feel that my workplace provides resources to support staff who care for dying patients." Cronbach's alpha reliability has been reported as .87 (Lazenby et al., 2012) and in the present study was .92.

Data Management and Analysis

Data were collected via Qualtrics, a downloadable, password-protected software. Data were downloaded and anonymized; participants were assigned a randomly generated identification number. A separate master Excel file was created. Once data were deidentified, variables from the demographic questionnaire and EPCS were recoded as needed, uploaded, and analyzed using IBM SPSS statistics version 24. Data analysis included descriptive statistics and independent *t*-tests to determine differences in pre and posttest scores. The results were determined using a mean difference confidence interval of 95% and a *p*-value of <.05 to indicate statistical significance.

Results

Sample Characteristics and Descriptive Statistics

A convenience sample of 28 nurses started the pretest; seven surveys were discarded because participants did not complete the presurvey, answering only one to three of the demographic questions and none of the EPCS questions. Twenty participants viewed the educational webinar. Thirteen participants completed the posttest and downloaded the CE certificate; therefore, pre- and posttest scores could not be matched, and data were analyzed in aggregate. This method compares the means of the groups, whereas a paired *t*-test would compare each subject's scores, reducing intersubject variability and increasing the strength of the test. As shown in Table 1, all participants were female ($n = 21$, 100%), a majority of participants were Caucasian ($n = 18$, 85.7%), age 60–69 years ($n = 6$, 28.6%), married ($n = 14$, 66.7%), associate degree in nursing (ADN) prepared ($n = 8$, 38.1%), employed full time ($n = 16$, 76.2%), and had cared for people with HF for 0–9 years ($n = 11$, 52.4%). The demographics of this sample are comparable to the demographics of nurses in North Carolina (see Table 1). Years' working as a nurse was equally divided across 0–9 years, 10–19 years, and 30–39 years ($n = 6$, 28.6%). An important observation about the study sample was that demographically, one-third of the sample was aged 60–69 years, and the majority had been practicing for 10 years or more. A majority of participants reported *other* as the facility type referring to county health departments, physicians' offices, home health, home palliative care, or hospice.

End-of-Life Professional Caregiver Survey Table 2 presents the pre- and posteducational intervention means, standard deviations, and ranges for the EPCS and each subscale. Mean scores were higher on all posttest measures.

A series of independent samples *t*-tests were conducted to determine differences between EPCS total score, and scores on the PFCC, CEV, and ECD subscales pre- and posteducational intervention. Results are listed in Table 2. The ECD scale ($t[32] = -2$, $p = .05$) and total EPCS scale scores ($t[32] = -2.2$, $p = .03$) were statistically significantly different between pre- and posttest.

Discussion

It is essential patients with HF receive time-appropriate palliative care to maximize its benefits (Fitzsimons et al., 2019). With an unpredictable trajectory, initiating palliative care therapies concurrently with medical treatment at the time of diagnosis will improve symptoms and QOL (Fitzsimons et al., 2019). The present study examined if an educational intervention would improve nurses' perceived knowledge and skill to have palliative care conversations with people who have HF and their families.

The results demonstrated increased scores on all dimensions of the EPCS from pretest to posttest, though the increase was not statistically significant in all domains. The statistically significant increases were on the ECD subscale and total EPCS scores suggesting the module effectively improved nurses' knowledge and perceived skills in these areas. Although scores on the CEV subscale and PFCC domains did not achieve statistical significance, mean scores increased after the intervention.

Two common barriers to palliative care conversations identified by nurses are lack of training and education (Ugur et al., 2017). This study suggests that providing nurses with education about communication techniques that address how and when to conduct palliative care and end-of-life conversations increases their perceived knowledge and ability to have these conversations with people who have HF and their families. Currently, the American Association of Colleges of Nursing offers End-of-Life Nursing Education Consortium training courses, including communication. The National Hospice and Palliative Care Organization offers continuing education on many topics. While these are not HF specific, they do provide foundational information for nurses. Cost may be a factor in nurses accessing these resources. Additionally, in the United States, all individuals admitted to hospitals and other institutions are required to document the existence of an advanced directive and offer information on completing one. This is an opportune time to introduce the concept of palliative care and end-of-life decisions.

Nurses in the present study had the lowest total scores on the ECD scale, preintervention. In a similar study, nurses also scored the lowest in the ECD domain, indicating this is an area where nurses would benefit from focused education on palliative care conversations to improve their ability to effectively care for people with HF (Moir et al., 2015). In turn, the increased confidence and skill in palliative and end-of-life care may increase nurses' ability to provide effective care for patients at the end-of-life and have conversations when a patient is diagnosed with a life-limiting illness (Moir et al., 2015).

There were no statistically significant differences in the PFCC domain. Mean PFCC scores were high at baseline, similar to other findings with nurses working in oncology, intensive care, or telemetry (Moir et al., 2015). The nurses in the present study had similar levels of confidence and skill preintervention to nurses working in the intensive care unit. This could reflect the number of years worked as a nurse, as most of the sample had more than 10 years' nursing experience. Additionally, communication is a core nursing function and is embedded in basic nursing education and continuing education. So much so that in most nursing standards, such as the American Association of Colleges of Nursing (AACN) Baccalaureate Essentials, the Quality and Safety Education for Nurses (QSEN) competencies, and The Joint Commission (TJC) Standards, communication competency is included.

Table 2. Independent *t*-Test.

EPCS domains	Preintervention (*n* = 21) M (SD) Range	Postintervention (*n* = 13) M (SD) Range	Mean difference (95% CI)	t-Statistic (df)	P value
PFCC	47.4 (9.6) 20–60	52.1 (8.7) 30–60	−4.6 (−11.1, 1.8)	−1.4 (32)	.17
CEV	30 (6.2) 16–38	31.8 (6.9) 16–40	−1.8 (.6.3, 2.7)	−.7(32)	.44
(ECD)	28.4 (7.9) 9–40	33.5 (6.1) 17–40	−5.2 (−10.2, −.1)	−2 (32)	**.05****
Total EPCS score	105.8 (22.6) 45–138	21.3 (13.2) 63–138	−15.5 (−29.1, −1.9)	−2.2 (32)	**.03****

Note: Boldface entries indicate statistically significant results at the .05 level (two-tailed). EPCS = End-of-Life Professional Caregiver Survey; PFCC = patient- and family-centered communication; CEV = cultural and ethical values; ECD = effective care delivery; M = mean; SD = standard deviation; CI = confidence interval.

The posttest scores on the CEV scale were not significantly different from the pretest. This may be attributed to the webinar's focus on the content and timing of end-of-life and palliative care in HF, not on cultural and ethical aspects. The mean from pretest to posttest in this sample increased the least on this dimension, while the postintervention mean was also the lowest on this scale. Cultural competence, cultural respect, and person-centered care continue to be an area of improvement needed in health care (Campinha-Bacote, 2011). While more recently cultural congruence and competence have been required in nursing curricula, the age, and years in HF care in this sample indicate a gap and reinforce the necessity of continuing education in this area. CEV of patients and families must be attended to and content incorporated in continuing education generally, and specifically related to palliative and end-of-life care.

As noted earlier, one-third of the sample was aged 60–69 years, and the majority had been practicing for 10 years or more. This sample was a mature sample, with longevity in practice caring for people with HF. This could have contributed to, and may explain, the lack of statistical difference, and high baseline scores in the PFCC domain. These findings of no differences are consistent with van der Wal et al. (2018) but seem to be counter to what one would expect, that more nursing experience and more time working with people with HF would result in better knowledge and skill in having palliative care conversations. Thus, further research to examine factors and the importance of education on outcomes is warranted.

A limitation of the present study was its small sample size from a single region in southeastern North Carolina and analyzing data in aggregate. This method of analysis only detects differences in group means rather than differences in individual scores. Thus, while there is a difference in the group scores from pre- to postintervention, we could not determine that each participant had a significant increase in scores. This limits the generalizability of the findings. Another limitation is the possible testing effect. The EPCS is a fairly new scale

and only has one form. Subjects may have become sensitized to what information to pay attention to in the module because the same tool was used for pretest and posttest. The study was conducted when the region was recovering from a major hurricane that caused significant property damage and during the winter holidays, which likely affected recruitment, enrollment, and the poor response rate because continuing education and research participation was not a priority. This could contribute to nonresponse bias. A majority (52.4%) of nurses in this sample were from a wide variety of settings with potential differences in mission, philosophy, scope, and resources that may have impacted the nurses' preparedness to identify patient readiness cues for palliative care conversations. Another limitation was the inability to determine who qualified to participate when using a listserv, and thus the response rate. A generic nursing listserv did not allow for the researchers to target HF practitioners and determine the response rate for those qualified to participate.

Methodological considerations were that the module was developed so that individuals had to complete it in one sitting and could not access the postsurvey without completing the educational intervention. This could be a time burden for participants, and intervention delivery should be evaluated. An additional limitation is the intervention was delivered via webinar. This venue may not fit all learners' preferred learning styles and is an essential consideration for nursing professional development specialists. However, even with these limitations, the results are supported by others' research (Hjelmfors et al., 2014), indicating an educational intervention via an asynchronous online module can increase nurses' perceived knowledge and skill to conduct end-of-life and palliative care conversations with people who have HF and their families.

An asynchronous online module to reach individuals across the region for an educational offering was feasible. It has been reported that people engaged in webinar education on finances increased their knowledge and implemented positive financial behaviors (Johnson & Schumacher, 2016).

Implications for future research include replicating this study with a larger sample at multiple sites and evaluating if nurses put this improved knowledge and perceived skill into practice. Roleplay or simulation could be a part of the educational intervention on communication to apply and practice what participants have learned. Evaluation of learning and transfer of knowledge could be assessed through chart reviews to audit documentation of these palliative care conversations, assess actual referrals made to palliative care services by nurses who have received education, and design a simulation study where nurses must apply their new skills in simulated settings. A longitudinal component could be designed to determine the retention of knowledge over time.

Implications for Practice

Practice recommendations include mandatory continuing education requirements for all nurses to understand palliative care, an institutional policy that defines the nurse's role clearly, and recognition and reinforcement that palliative care and palliative nursing is an evidence-based specialty area that cuts across all illness types and populations. Implications for practice include the need for continued training on palliative care in general and disease-specific palliative care interventions, as well as culturally congruent palliative care. The implementation of palliative care teams to support both the health care providers and patients and families may produce optimal care and outcomes.

Conclusion

Providing asynchronous education on the timing and content of palliative care conversations with people who have HF improved nurse's knowledge, perceived skill, and comfort to have these discussions. The timing of palliative care conversations is an essential element. When nurses are knowledgeable and can identify family and patient readiness cues, it can impact the success of the palliative care conversations. Nurses who are better equipped to discuss palliative care with people with HF may result in palliative care services delivered earlier in the illness trajectory. Educating nurses on HF specific palliative care is crucial so people with HF and their families receive care before symptoms progress and QOL is diminished.

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