CE

Geriatrics and Palliative Care

Collaboration for Quality of Life Until Death

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❖ Nurses specializing in geriatrics and palliative care share a common goal: Above all else they will help the patient to experience the best quality of life. However, nurses specializing in palliative care may not be aware of the numerous ways that the aging process alters health problems. This review article addresses ways that symptoms of illness and altered presentation of disease may occur in the very old or frail adult. Appropriate assessment instruments for screening or evaluating older adults are shared. Psychosocial issues for both dying older adults and their caregivers are discussed. Finally, evidence-based health promotion recommendations for the end of life are given.

K E Y W O R D S

aging
quality of life
screening
health promotion
assessment

Gerontology takes its origins from the Greek word *geront*, meaning "old man." Geriatrics is a health discipline "encompassing psychosocial, economic, historical, and physiological factors"[1] for adults 65 and older. With its origins in the United Kingdom credited to Dr. Marjorie Warren, geriatrics focuses on two principal goals: fostering independence or control over life and preserving quality of life. It achieves these goals through a collaborative care model involving health and social service disciplines. Not surprisingly, the palliative care movement also arose in Britain through the pioneering work of another woman, Dame Cicely Saunders, a nurse, physician, and social worker, who focused on comfort care. Palliative care is defined by the World Health Organization as "the active total

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treatment of patients whose disease is not responsive to curative treatment."[2] Both of these care models share similar goals and accomplish them through an interdisciplinary team effort.

Health professionals caring for older persons at the end of life may have preparation either in the field of palliative care or geriatrics, but usually not in both fields. This article presents a perspective of caregiving unique to older adults: geriatrics. It discusses how both symptoms of illness and dying may be different in the very old or frail adult, and melds geriatrics and palliative care to discuss health problems that may occur toward the end of life.

❖ DEMOGRAPHY OF AGING

All living things die, but with old age, the chance of survival narrows with each passing year. Using Hayflick's classic work that defined the number of times a cell can divide before it dies, current estimates are that a human should be able to live to 120 years.[3] Although few live to that age, the number of persons reaching their 100th birthday is rising exponentially, and the fastest growing cohort today includes those 85 years of age and older.[4] In the United States currently, the rate of death forms a classic "J curve," starting with a higher number of neonates, then showing a downward trend during the first 4 years of life, followed by a period of stabilization, and finally a rise to the highest rate of death in the old. According to the National Center for Vital Statistics,[5] the current death rate is an average of 873.6 per 100,000 persons for the entire populace, ranging from 18.5 per 100,000 in the 5- to 14-year-old age range (lowest) to 5190.8 per 100,000 in those 65 years of age and older (highest).

The most common causes of death for this oldest group include, in order, diseases of the heart, malignant neoplasms, cardiovascular disease, chronic lower respiratory disease, influenza and pneumonia, diabetes, Alzheimer's disease, nephritis, accidents, and septicemia.[5] In other age groups, accidents, homicide, suicide, and human immunodeficiency virus (HIV) are more prominent, and septicemia is seen only in children 4 years of age and younger, whereas Alzheimer's disease is not present.[5] Problems that cause death in older adults are exacerbations of chronic disease, not events that are unexpected or acute as seen in younger persons. These unexpected deaths caused by violence, war, trauma, accidents, and diseases such as HIV/acquired immunodeficiency syndrome (AIDS), which at one time were found principally among young adults, often are seen as the most tragic, whereas dying in old age is expected.

❖ HOW IS DYING OLD DIFFERENT?

Because dying may be a more lingering process in older adults (eg, progression of heart failure vs acute myocardial infarction), they actually may be dying for a much longer time, and thus may experience a plethora of symptoms. This may make prognostication of death very difficult, impeding other types of care. Rather than the steady and predictable "downhill" decline, a "roller-coaster" effect is observed. The older person experiences numerous trips to the hospital with miraculous recoveries, but each time, a small decrement in capacity occurs. Physiologic reserve, the capacity to bounce back from illness, wanes later in life. Loss of reserve culminates a final insult from which the individual can no longer recover, and death occurs. Lack of reserve and loss of resiliency may cause some older adults to welcome death as a way to join loved ones who have passed on, or as fulfillment of a wish to enter a better life or be reincarnated to a higher state, or even just to be free of suffering.

A recent report on the health of older Americans showed that 70% of those older than 80 years had one chronic disability, that 53% in this group had one severe disability, and that 36% had moderate to severe cognitive impairments.[6] The top five chronic diseases affecting individuals older than 75 years are arthritis, hypertension, hearing impairment, heart disease, and cataracts.[7] Consequently, health professionals need to address not only issues associated with the dying process, but also fundamental problems associated with joint pain, loss of hearing and vision, and perhaps fatigue.

The paucity of providers who have specialized in geriatrics can place the older patient at risk for numerous problems. The rate of hospitalization for individuals 65 years of age and older rose 23% from 1990 to 2000, the only age group to increase. This age group made up 40% of all hospital discharges and used 50% of all hospital days.[8] Inability to recognize normal aging changes and the potential to treat these changes as illness raises the chances of iatrogenic illness. Additionally, the alternate presentation of symptoms and disease in older adults may allow the exacerbation of problems to critical stages before they are treated. With only 9500 certified geriatricians[9] and 4200 advanced practice nurses certified as either geriatric nurse practitioners or clinical nurse specialists,[10] not only may palliative care

providers not appreciate the health problems of older adults, but they also may not understand how dying might be handled differently in this population. Thus, a blending of geriatrics and palliative care is ideal.

❖ ALTERED PRESENTATION OF HEALTH PROBLEMS

As humans age, the presentation of symptoms change. However, from lack of knowledge, healthcare providers may either misinterpret or not recognize subtle symptom changes in older adults that indicate progression of an existing illness or an intervening transient illness. For the older individual receiving palliative care, not recognizing conditions that could be treated, with consequent improvement in the quality of life even at the end of life, would be tragic. A summary of altered presentations is given in Table 1.

Classic examples of changes that often are overlooked include the following:

Mental status may be altered, with a change from baseline and a fluctuating level of consciousness. Although a large number of older adults may have some degree of cognitive impairment, a rather rapid change in mental status—days to weeks—should be regarded as delirium and treated as such. The most common cause is drug toxicity, followed by cerebrovascular disease; systemic illness, especially heart failure, infection, or poorly controlled blood glucose; and finally withdrawal from substances of addiction.[11] Other common causes include untreated thyroid disease; vitamin deficiency, especially of vitamin B12; and decreased sensory input.[11]

TABLE 1
Altered Presentation of Illness in Older Persons

Change in mental status
Altered pain sensation; inability to localize
Vague symptoms
Inability to perform activities
Falls
Dehydration
Loss of appetite
Unusual medication reactions

Appreciation of painful sensation may be altered. Older adults may experience pain in different ways, related to living with lifelong pain, and therefore not notice the incremental increase in pain,[12] for example, pain from ischemia. Individuals with diabetes also may have altered pain pathways related to sensorimotor neuropathy. Additionally, older adults may experience less intense pain, and thus may have more difficulty identifying the exact origin of pain. Finally, pain is more difficult to localize below the waist and may be reported as "crampy."

Vague symptoms are more common than acute symptoms. Such symptoms are harder to isolate using a classic symptom analysis.[12] Caregivers may report vague changes, with such statements as "Mom just isn't right." Nursing home staff or caregivers also may appreciate subtle changes that are difficult to articulate.

Inability to perform usual activities can be a significant finding in both active persons and individuals with very limited mobility. A sense of fatigue may signal anemia, thyroid disease, cardiovascular or pulmonary insufficiency, or infection.[13]

Onset of falls often belies other problems. Falls should be considered a syndrome, and the workup should include cardiac, musculosketelal, neurologic, sensory (vision and hearing) functioning, continence, and pharmacologic review.[14] Fallers will fall again until the problem is diagnosed and corrected.

Dehydration is common in older persons because of decreased muscle mass and a consequent lack of intracellular water. Additionally, older people have a blunted thirst response and may not concentrate urine even in the face of dehydration.[15] This condition is exacerbated in a stressed or increased metabolic state, and would occur quickly with vomiting or diarrhea.

Loss of appetite or early satiety is not always classic anorexia, but may mean other problems are fomenting. Worsening of heart failure and early-onset pneumonia often present with this symptom before any other.[16]

Adverse drug reactions (ADRs) occur at a high rate in this population, and often present with altered mental or functional status. With 12% of the population taking 28% of all prescription medications, with 66% of all older adults taking over-the-counter medication, and with the absorption, distribution, metabolism, and elimination of medications altered by physiologic changes in the liver and kidney, the chances of ADR increase.[17] Adverse drug reactions can be caused by

"polypharmacy," which is the use of multiple drugs or more drugs than indicated clinically. Although residents of skilled nursing facilities are required to have their medications reviewed by a pharmacist for the presence of polypharmacy, the average nursing home resident takes eight medications daily.[17] Because of a lack in professional staffing, the long-term care nurse may be administering medications to 25 to 40 residents, with little time to monitor for polypharmacy or ADRs. In a recent study of 282 patients 65 years of age or older admitted to an emergency department, 10.6% had recognized ADRs, and that number rose to 16.9% among those taking six or more medications.[18]

The provider may find exemplar problems that have altered presentations in old age useful for identifying issues unique to symptom presentation in the older adult who may be dying. Assessment instruments used and normed with an older population are helpful for discriminating the origin of symptoms, and thus for focusing treatment. A list of commonly used assessment instruments is found in Table 2.

TABLE 2
Age-appropriate Assessment Instruments

Pain
- Faces Pain Scale[39]

Confusion versus dementia
- Confusion—Confusion Assessment Method[40]
- Dementia—Mini-Mental Status Examination[41]

Fatigue
- Symptom Distress Scale[42]
- Sleep—Pittsburgh Sleep Quality Index[43]

Dyspnea
- Chronic Respiratory Disease Questionnaire[44]
- Modified Borg Scale[45]

Function
- Person living independently—5-item Instrumental Activities of Daily Living Screening Questionnaire[46]
- Person needing assistance—Katz Index of ADLs[47]

Nutritional status
- Mini-Nutritional Analysis[48]

Depression
- Geriatric Depression Scale[32]

Anxiety
- Hamilton Rating Scale for Anxiety[49]

Caregiver Burden
- Assessment of Caregiver Burden[50]

ADLs, activities of daily living.

❖ PAIN

Pain often is undertreated in older adults, particularly in those with cognitive impairments. In fact, cognitive impairments may limit the ability of the older individual to participate actively in nonpharmacologic methods of pain control such as relaxation techniques.[19] Because of the ADR risk associated with possible drug-drug interactions, choosing pain medication may be challenging. Decreased hepatic and renal functioning also may make the use of certain agents unwise. The American Geriatric Association recommends the following guidelines: "Use least invasive route; use short-acting analgesia for episodic pain and around-the-clock regimens for continuous pain; use long-acting or sustained release formulations for continuous pain only; `start low and go slow'; and anticipation, prevention, and treatment of side effects."[19(p30)] Treatment of chronic pain sometimes is overshadowed by other problems that appear to be more pressing. The American Pain Society's recent guidelines for treatment of arthritic pain, a condition that occurs in 8 of 10 older adults, offer the nurse evidence-based recommendations for the use of pharmacologic agents and lifestyle changes.[20]

A review of drug actions of particular concern in older adults identified the following: Older adults are more likely to suffer from a gastrointestinal bleed related to the use of nonsteroidal antiinflammatory drugs (NSAIDs) or impaired renal function; edema or altered potassium may develop in hypertensive patients; side effects of opioids may be particularly worrisome because older adults are predisposed to constipation and dehydration; opioids to be avoided in older adults include meperidine and methadone because of their long half-life and propoxyphene because it may have no more effect than acetaminophen, making the older adult

more prone to sedation, dizziness, falls, and delirium; short-acting opioids that are effective in older adults include acetaminophen or aspirin in combination with oxycodone or oral transmucosal fentanyl citrate; longer-acting opioids (sustained-release morphine or oxycodone or transdermal fentanyl) work well in older adults; adjuvant therapies in the form of tricyclic antidepressants, especially Elavil, have potent anticholinergic properties that may cause other problems in individuals with glaucoma or benign prostatic hypertrophy, or in those who are confused.[19,21] The "baby-boomer" generation uses complementary and alternative medicines more frequently than previous generations, and may be at risk for ADRs with prescription drugs if over-the-counter supplements are not reported.[22]

Assessment of pain in older adults should be performed regularly using tools that have been demonstrated as effective in this population, for example, the Verbal Descriptor Scale, the Numeric Rating Scale, the Pain Thermometer, and the Faces Pain Scale.[21] Whether cognitive impairment is caused by delirium (transient pathologic causes) or dementia (primary alteration in brain physiology), the health professional loses the primary technique for assessing the patient: asking questions and expecting reliable answers. However, an attempt always should be made to ask the patient directly and simply whether he or she is in pain.

Three types of behavior have been associated with pain in persons with dementia: aggressiveness, resistance against care, and vocalizations including increased volume of existing vocalizations.[23] Caregivers need to be educated to observe for patterns of behavior around certain activities that may be provoking pain (movement, transferring, bathing), and to treat the individual proactively. The use of a pain journal might be helpful for identifying trigger events.

❖ CONFUSION

Confusion poses a special set of problems for older adults who are dying. Delirium or acute confusion, which occurs in 20% to 50% of all hospitalized older patients, is manifested in three patterns: cognitive restriction, physiologic instability, and metabolic instability.[24] It is more likely to occur after emergency admission or admission from another institution in patients 80 years of age or older, in men, in patients with preexisting dementia, in those with limited social contacts, and in patients with two or more chronic illnesses.[24] Delirium has a high rate of mortality if not detected and treated early. The *Diagnostic and Statistical Manual,* 4th edition (DSM-IV) defines delirium as

> disturbance of consciousness with reduced ability to focus, sustain or shift attention; a change in cognition or the development of a perceptual disturbance that is not better accounted for by a preexisting, established, or evolving dementia; develops over a short period of time and tends to fluctuate during the course of the day; there is [objective evidence] that the disturbance is caused by direct physiological consequences of a general medical condition.[25(129)]

Vision and hearing impairment affect almost all older adults, limiting sensory input. Communication can become challenging, and the older adult may appear not to understand or may not be understood. This eventually can create a sensory deprivation environment, generating cognitive changes. Therefore, assessment of visual and hearing acuity is warranted, and provision of adaptive equipment is necessary at the end of life. New-onset confusion in the individual with diabetes needs to be explored. Hypoglycemia may not be readily recognized until blood glucose is dangerously low. The usual adrenergic symptoms of tachycardia and diaphoresis may be blunted in older adults, and an increasing confusion may be the only apparent symptom.

Currently, more than 4 million Americans have a diagnosis of Alzheimer's disease, the most frequently occurring form of dementia, and the risk of this disease developing rises with old age.[5] Thus, confusion superimposed on preexisting dementia may develop in an older person. Older individuals with dementia may become more confused or display new or extreme behaviors related to the affects of medication, infection, hypoxia, or neurologic events. Thus, for this group also, examination of increased confusion is always warranted.

Dementia is also a terminal illness,[26] although it has not always been conceptualized as such. Dementia has a steady downward course that varies in length, largely related to the confounding factor of brain pathology associated with poorly controlled hypertension and cardiovascular disease.[27] Because it is more difficult to project 6-month survival in patients with dementia, enrollment in hospice may not be timely. Quality-of-life issues need to be recognized among individuals with dementia. For example, "excess disability" or performance of tasks by caregivers that the patient has mastered but may perform less efficiently often is evident in this

group. Behavior needs to be recognized as having meaning and as often signaling a change that may be amenable to comfort measures. To relieve pain and aid in performance, a variety of palliative and rehabilitation approaches should be investigated by members of an interdisciplinary team.

For Alzheimer's disease and vascular dementia, the average time from diagnosis to death is 3.3 years.[28] As such, the caregiver or partner often becomes socially isolated for years because friends and family, unable to tolerate the unpredictable behavior of a person with dementia, may avoid social encounters. These caregivers may have limited access to social service or respite care. Thus, palliative care services may be a real lifeline for these caregivers. Often, individuals with middle- to late-stage dementia are placed in institutions wherein the need for palliative care may not be recognized.[29]

❖ DYSPNEA AND FATIGUE

More than chest pain or diaphoresis, the classic presentation of myocardial infarction in older adults is new-onset dyspnea and fatigue. In an older person without underlying pulmonary disease, even in the absence of cough, fever, or pleural pain, an increased respiratory rate, exceeding 24 breaths per minute, is recognized as an altered presentation of pneumonia. A sensation of fatigue and inability to perform one activity of daily living is seen additionally as an early indicator of pneumonia. For the older person who has very limited mobility, inability to retain a sitting posture independently also is indicative of pneumonia. Fatigue accompanies the worsening of heart failure.

Older adults have an altered sleep-wake cycle, falling asleep earlier and rising earlier in the morning. Because they have less stage 4 sleep, they may arise feeling less rested. Daytime napping is not uncommon in older adults, but excessive napping may disrupt nighttime sleep. Regular use of alcohol or sleeping medications may further disorder sleep. A sleep history may be helpful. Nighttime hypoxia resulting in restless sleep, or at the extreme, paroxysmal nocturnal dyspnea, can be related to worsening obstructive lung disease or heart failure.

❖ SATIETY AND ANOREXIA

Individuals with heart disease, especially heart failure, often experience the sensation of early satiety with decreased appetite before the weight gain of extracellular fluid is noted. Pneumonia also presents in some individuals with diminished appetite. For individuals with late-stage dementia, a wasting phenomenon with limited intake does occur, but this can be mediated by contextual factors. For the person with dementia, minimal or negative interaction, assistance at meals, no adherence to prior mealtime routines, lack of adaptive equipment, and an overly stimulating dining area are notable for decreasing the ability to consume meals.[30] A diminished sense of smell and taste can cause a lack of interest in eating, a link often unexplored when an individual is disinterested in food. Additionally, when the sense of smell, the most evocative of all the senses and the most closely linked to memories, is lost, a portal to memories is lost.

❖ GASTROINTESTINAL DISTRESS

Altered gastrointestinal (GI) status caused by low-level dehydration, slower peristalsis, the presence of chronic neuromuscular disease such as Parkinson's disease, amyotrophic lateral sclerosis, muscular dystrophy, and even lack of mobility related to osteoarthritis predisposes the older adult to constipation. The standard treatment for osteoarthritis, NSAIDs, makes the individual with this diagnosis more prone to GI bleeding. Reliance on the patient's report of changes in stool color or blood in the stool may be meaningless without affirmation of visual acuity because the individual may not be able to see the toilet contents. Upper or lower GI bleeding may present insidiously with signs of dehydration and "crampy" abdominal pain that is difficult to localize. Gastrointestinal obstruction also presents without the usual boardlike abdomen, but instead with cramps, stringy stool or diarrhea, vague complaints of feeling "unwell," and dehydration. For older persons who are receiving opiates, monitoring of bowel sounds and stool history and treatment with laxatives is required.

❖ INFECTION AND FEVER

Individuals 60 years of age or older have 50% of the immunologic function observed in 20-year-olds, and thus should be treated as an immune-compromised population. Because of lower basal metabolic rates, older adults have lower core temperatures. Additionally, a sluggish thermal feedback loop makes temperature an

imprecise measure for the severity of infection. Because many older persons are self-treating with NSAIDs for painful musculoskeletal conditions, their inflammatory response is altered. The most common infections in the older population form the acronym PUS: *P*neumonia presenting with increased respiratory rate, decreased appetite, and functioning; *U*rinary tract infections presenting with increased confusion and falls; and *S*kin infections related to the increased incidence of vascular disease and increased risk for pressure ulcers.

❖ FEARS AND DEPRESSION

The great fear of dying alone or being abandoned is very real for older adults. The very old may lack an active support system because they often outlive family and friends. Profound problems with mobility, loss of ability to drive, and loss of financial independence may severely limit the ability of some individuals to maintain social networks. In retirement enclaves such as the Southeast, older adults may have moved away from families and friends, effectively limiting ties with a broader network. Because many older persons report not wanting to be a burden to others, they may minimize their problems or those of their spouse until the situation is desperate. Additionally, there are older persons who have been marginalized by society, those with mental illness, transients, or persons with a criminal history. These individuals may never have had an active support system, which was never an issue until they were facing serious illness or death. Now, they may be truly alone and unaware of avenues for seeking help.

Depression is not uncommon in older adults, and suicide is not infrequent in late life.[31] Although health professionals might assume that depression is a natural outcome of losses experienced during the dying process, preexisting depression may complicate assessment and treatment. Among older adults, depression often is marked by increased disability beyond what would be expected from a given health problem. Screening for depression should be done with an instrument suited for older adults that does not focus on somatic symptoms, which could be associated easily with chronic illness. The Geriatric Depression Scale, an appropriate screening tool, is published in both 15- and 30-item versions that can assist in determining the degree of depression.[32] Depression in older adults is amenable to both pharmacologic and behavior therapies. Treatment should not be denied to depressed older adults, especially at the end of life.

❖ PLACES TO DIE

Like all individuals, older adults may encounter death in a variety of settings. However, with advanced age and infirmity, the chances of an institutional death markedly increase. Whereas hospital staff may be very proficient in caring for the physical needs, there often is a lack of emotional engagement with the dying older person, resulting in a lack of spiritual and emotional care.[33] In nursing homes, staff in a very real way become family, and they may be emotionally unprepared to deal with the resident's death. Unlike a family, with its history of a unified culture, nursing home staff can vary widely from persons who come from the same community to those who hail from all parts of the world. Therefore, honoring traditions associated with dying may be as diverse as the staff itself.[34]

Nursing homes may not want to project an image as "a place to die," and therefore may segregate dying patients as they segregate "low-functioning" patients. Facilities often transfer dying patients to a hospital. In a retrospective study investigating nursing home residents' patterns of hospital admission, investigators found that residents with dementia had a slightly higher rate of admission than persons without this disorder. Admissions for acute conditions were primarily for pneumonia, and exacerbations of chronic conditions were related to cardiopulmonary failure.[35]

In a review of records from a nested random sample of eight skilled nursing facilities for 1 year, Saliba et al[36] found that 44% of emergency department transfers and 45% of hospital admissions were inappropriate. A national review of records from all nursing home residents (n = 1,381,729) showed that 25% of these residents die within 24 hours of transfer to a hospital, that 50% die within 4 days, and that the estimated costs are $10,759 more if deaths occur in a hospital instead of a nursing home.[37]

Hospice may be a real benefit for nursing homes because payment is better than Medicaid. Federal survey data from all nursing homes receiving Medicare and Medicaid in the contiguous United States showed that with the arrival of the Prospective Payment System, some nursing homes were seeking out hospice patients.[38] Whereas 70% of the homes had no residents receiving the benefit, 4% of the homes had 5% or more residents

TABLE 3
Health Promotion Activities at the End of Life

Monitoring of vital signs including weight (if able)
Influenza and pneumovax vaccine
Aspirin if at risk for cardiovascular disease
Visual, hearing and oral health screening
Monitor potential for abuse
Evaluation of ADLs and Instrumental ADLs to provide appropriate assistance and referrals
Evaluation of etiology of incontinence
Monitoring of blood glucose if diabetic
Depression and cognitive screening
Pain assessment
Medication review
Review of advance directives
Caregiver support

Adapted with permission from St. Louis University Division of Geriatric Medicine.[51]

ADLs, activities of daily living.

receiving the hospice benefit, with the largest number in Florida. Of 16,716 homes, only 226 had a dedicated hospice unit. These homes tended to be larger, with more Medicare-certified beds, a higher occupancy rate, and lower staffing levels, and they attracted more private-pay residents. In general, nursing home residents may have fewer hospice-specific needs than community care patients, except for tube feeding.

❖ HEALTH PROMOTION ACTIVITIES IN RELATION TO DEATH

Finally, everyone has a right to the best health, even those who are dying. In the trajectory of chronic illness, as the individual comes closer to death, actions that advance health continue to promote a better quality of life, and finally a better death. Not to immunize an individual against influenza, not to evaluate and devise compensatory methods for dealing with poor hearing or vision, not to evaluate for and treat a urinary tract infection directly related to new-onset incontinence neglects the core of palliative care, yet may be overlooked without a geriatric perspective. Health promotion may allow the older person and the caregiver to be free of avoidable stress and suffering, and to have a more active role in treatment. Health promotion activities that promote quality of life at the end of life are included in Table 3.

Older adults and their caregivers need to be given choices in a context that allows them to be supported by a team, respected for their informed decisions, and assured of independence as long as it is desired. If concepts of geriatrics are interwoven with the principles of palliative care, the promise of a good death can be ensured for more older persons.

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