Physicians Urged to Conduct Early and Ongoing Discussions of Preferences with Advanced Heart Failure Patients

‘Difficult discussions now will simplify difficult decisions in the future.’ — AHA statement

Due to the uncertain course of heart failure (HF) and the increasing complexity of treatment options available to patients with advanced disease, helping patients to make informed decisions is both crucial and challenging, and requires the patient-centered, ongoing process known as “shared decision making,” according to a scientific statement published by the American Heart Association (AHA) in its journal Circulation.

“Shared decision making extends beyond informed consent, requiring that health care providers and patients consider information together and work toward consensus,” states the AHA. “This process should focus on the outcomes that are most important to the patients, including not only survival, but also relief of symptoms, quality of life, and living at home.”

Because shared decision making requires more time than is usually available during a routine clinical visit, the statement calls for primary care physicians and cardiologists to schedule an annual HF review with the patient to discuss prognosis, consider reasonable therapies, and clarify the patient’s values, goals, and preferences. This review should be in addition to “milestone” discussions triggered by sudden changes in patient health or major life events, such as the death of a spouse.

“When triggered by a scheduled anniversary in the same way as well baby visits or periodic mammography, an automatic annual review can open a broad dialogue with patients and families without the unvoiced concern that it signifies bad news,” write the statement authors, led by Larry A. Allen, MD, MHS, assistant professor of medicine at the University of Colorado Anschutz Medical Center, Aurora.

PALLIATIVE AND HOSPICE CARE RECOMMENDED

The statement strongly recommends the integration of palliative care for all patients with advanced HF by all clinicians involved in their care. Referral to a palliative care team, write the authors, “should be considered for assistance with difficult decision making, symptom management in advanced disease, and caregiver support — even as patients continue to receive disease-modifying therapies.”

For those approaching the end of life, hospice care is an appropriate option; it allows most patients to die in their preferred setting while receiving expert symptom care and supportive services for themselves and their families. “As the end of life is anticipated, clinicians should take responsibility for initiating the development of a comprehensive plan for end-of-life care consistent with patient values, preferences, and goals,” state the authors.

Although currently fewer than half of all HF patients are enrolled in hospice care, this is a marked increase from the less than 20% of this population receiving hospice care just ten years ago, note the authors. Patients eligible for hospice services who feel they are “not ready for hospice” but who would benefit from expert symptom control and family support should be referred to palliative care, they suggest.

Meanwhile, “continued education about the benefits of hospice and the fact that families are often more satisfied with hospice care than care provided in the hospital may also help elucidate its benefits,” they write. “Appropriate timing of referral to hospice is important, because the family’s perception of being referred ‘too late’ is associated with greater dissatisfaction and unmet needs.”

Shared decision-making discussions initiated early and repeated regularly can help prepare patients to better understand their wishes when the time comes to discuss end-of-life care, note the authors, because helping patients to explore their values, goals, and preferences through shared decision making “is an iterative process that evolves...
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Approach to Shared Decision-Making Discussions with Advanced Heart Failure Patients

ESTABLISH THE CONTEXT. Determine whether the patient would like to invite others to the meeting and arrange for any appropriate clinicians to be present, consulting with all clinicians involved in the patient’s care beforehand. “In preparation for our meeting tomorrow, I’m going to ask [clinician] to be part of our conversation. In terms of your family or support network, who is it important that we ask to be there?”

DETERMINE WHAT THE PATIENT/FAMILY KNOWS AND WHAT THEY WANT TO KNOW. Use the “Ask-Tell-Ask” technique, which can be applied to different levels in the communication process, and is helpful over multiple encounters.

- **ASK** patients and their families what they know about their disease or the treatment being considered and how much information they would like.
  
  “Tell me about your heart disease; how have you been doing lately? What is your understanding of what is occurring now and why we are discussing this treatment? Sometimes patients want to know all the details, and other times they just want a general outline. How much information would you like? Would you want to know everything about your illness or this treatment even if it wasn’t good news?”

- **TELL**: Convey the information in a clear and thoughtful manner, focusing initially on the larger picture of the patient’s health. Use frequent pauses to assess the patient’s understanding. Address any misconceptions or unanswered questions.

- **ASK again**: Assess the patient’s and family’s understanding of the imparted information by asking them to repeat it back in their own words.

ESTABLISH THE PATIENT’S GOALS AND PREFERENCES. Use open-ended questions to elicit the patient’s values and hopes. This approach does not begin with questions about treatments, but rather is intended to help the patient weigh outcomes and consider trade-offs in light of hopes that can often be contradictory. “What is important to you in terms of your health care? What are you hoping for? What is your biggest concern right now? When you think about the future, what would you want to avoid?”

In the acute care setting, physicians can better understand patients’ priorities and values in their day-to-day lives by asking, “What is important to you in your life outside the hospital?” Seriously ill patients are often concerned with how well they will live, as well as how long they will live. It is important to summarize the hopes and preferences the patient has expressed. This ensures that these desires have been correctly heard and understood, and demonstrates care for the patient’s needs.

WORK WITH THE PATIENT/FAMILY TO TAILOR DECISIONS TO THEIR GOALS. Summarize the range of medically reasonable options for this patient at this time, explaining the risks and benefits of each in relation to the patient’s expressed values. Then offer a recommendation based on the patient’s stated goals. “Given what you have told me about what is important to you, I think the treatment that makes the most sense to get to the desired goal is...”

ACKNOWLEDGE THE UNCERTAINTY INHERENT IN THE COURSE OF HEART FAILURE. “One of the most difficult things about heart disease is that we can never know for sure exactly what will happen in the next [time frame]. We must make our best guess and decide what to do based on that information. If things change, we can always readress this discussion at any time.”

— Adapted from Allen et al, Circulation

Over time as a patient’s disease and quality of life change.”

These recurrent discussions are also important preparation for episodes of health spikes, they note. “On the day of hospital admission, it is far better to review rather than introduce advanced care decisions, which requires that patient preferences have been discussed previously and documented in the ambulatory setting.”

CURRENT BARRIERS TO NEEDED CONVERSATIONS

Barriers to shared decision-making discussions include time, training, resources, and reimbursement. For now, caution the authors, implementing shared decision making will be limited by the existing health care system’s current emphasis on reimbursement for specific therapies rather than for meaningful conversations about individually tailored choices. Also, training and mentoring in these communication skills for clinicians are still sadly lacking.

Meanwhile, to assist clinicians in conducting these important discussions, the authors offer an “idealized version,” a stepwise approach to complex conversations regarding medical decisions for advanced HF patients, in which the physician and patient/family unit work together to decide. [See sidebar.]

“This is, in fact, the core of shared decision making,” state the authors. “The clinician does not dictate treatments, nor does the burden of the decision rest solely with the patient and family. Instead, the two parties work together to determine which options or treatments make the most sense given the patient/family’s desired outcomes in the context of the current clinical scenario.”

Open, clear, and accurate communication is important because:
Inadequate treatment of pain remains a pressing health concern of modern society, yet pain education at North American medical schools — when it is not completely lacking — has been found to be “limited, variable, and often fragmentary,” a study by researchers from the Johns Hopkins School of Medicine, Baltimore, has found.

“This study provides an important benchmark for the current state of pain education in North America. Given the recent advances in pain science, it is perplexing that pain education in medical schools remains so limited,” write the authors of a report published in the Journal of Pain, the official journal of the American Pain Society.

Using an instrument they developed for a more in-depth analysis than that of the historical presence-or-absence criterion, the researchers conducted a systematic review of current pain education in medical schools whose curricula were maintained in the repository of the Association of the American Medical Colleges from August 2009 to March 2010.

**KEY FINDINGS**

- Only 3.8% of U.S. medical schools reported having a required pain course.
- 16.3% of U.S. schools offered a designated pain elective, with about half of these offering more than one elective in pain education.
- While 79.8% of U.S. medical schools included one or more pain sessions (range, 1 to 28 sessions) within required general courses, the median total number of these pain sessions taught at a single school was only 7.
- The cumulative number of U.S. pain teaching hours per school ranged from 1 to 31, with a median of 9 hours.
- By comparison, 92.3% of Canadian medical schools included pain sessions within at least one required general course, with a median of 12.9 sessions, and a median number of cumulative pain teaching hours of 19.5 (range, 3 to 76 hours).

While the majority of North American medical schools covered certain specific major topics in pain education (e.g., pain neurobiology, clinical assessment, chronic pain, and pharmacological management), most schools completely neglected other important pain topics, the study found. However, researchers found no correlations between the types of pain education offered and medical school characteristics.

**UNADDRESSED PAIN TOPICS**

- Geriatric pain was covered by 12% of U.S. medical schools and no Canadian schools.
- Pediatric pain coverage was reported by about 14% of U.S. schools, but by nearly 70% of Canadian schools.
- Medico-legal aspects of pain care (substance abuse and addiction) were covered by only 9% of U.S. schools and 23% of Canadian schools.

“Given that the twin dangers of pain undertreatment and the abuse of pain-active medications are among our society’s deepest public health concerns, pain medicine does not receive the attention that it deserves in medical education,” the authors conclude. “A more organized and formal delivery of pain education is likely to be a principal catalyst in the sea change required to rectify the current shortcomings of pain care.”

Source: “Pain Education in North American Medical Schools,” The Journal of Pain; December 2011; 12(12):1199-1208. Mezei L, Murinson BB, and the Johns Hopkins Pain Curriculum Development Team; Department of Neurology, Johns Hopkins School of Medicine, Baltimore, Maryland.

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**Advanced Heart Failure Patients (from Page 2)**

- Patients want to be informed about their illness, and to be included in decision making.
- Patient care is more likely to be aligned with individual goals and preferences.
- The relationship between the patient and physician is improved.
- Bereaved families have better psychological and bereavement outcomes.

“The importance of shared decision making in advanced heart failure cannot be overstated, given the complex myriad of treatment options that confront patients, families, and caregivers,” the authors conclude. “Our statement is a ‘call to action,’ not only to clinicians within our community directly responsible for facilitating shared decision making, but also to those on a national level who would reform and restructure the health care medical system to truly support patient-centered care.”

Palliative Care Concurrent with Oncologic Care Recommended for All Patients with Metastatic Cancer and/or High Symptom Burden

Following a review of what it considers “practice-changing data” published in several recent major studies, the American Society of Clinical Oncology (ASCO) has issued guidance for clinicians recommending that palliative care services be integrated into standard oncology practice for all patients with metastatic or advanced cancer — from the time of diagnosis.

“Palliative care is about maintaining quality of life throughout the cancer journey,” says Jamie Von Roenn, MD, co-author of ASCO’s provisional clinical opinion, entitled “The Integration of Palliative Care into Standard Oncology Care,” which was published in the Journal of Clinical Oncology.

“For patients with advanced cancer, the data are increasingly showing us that palliative care can be incredibly valuable for patients and their caregivers from the time they are diagnosed, not just at the end of life,” continues Von Roenn, who is professor of medicine, Division of Hematology/Oncology, at the Feinberg School of Medicine, Northwestern University, Chicago.

Findings from seven recently published randomized controlled trials were analyzed by a panel of oncology and palliative experts convened by ASCO. Each trial compared outcomes for patients with advanced cancer receiving either standard oncology care, or “concurrent care,” i.e., palliative care integrated into standard care.

**BENEFITS**

The concurrent care approach is associated with the following benefits:

• Comparable or improved survival
• Better symptom management
• Reduced depression
• Improved quality of life for patient and caregiver
• Increased satisfaction for patient and caregiver
• Lower overall resource use and cost
• More appropriate referrals to hospice

Concurrent care was found to be associated with earlier and more frequent hospice use, “which in turn relieves symptoms, caregiver burden, and may improve survival,” notes ASCO.

“Although the use of hospice and other palliative care services at the end of life has increased, many patients are enrolled in hospice less than three weeks before their death, which limits the benefit they may gain from these services,” state the authors.

The addition of palliative care interventions, including end-of-life care discussions, to standard oncology care demonstrated benefits in all studies analyzed. “No harm to any patient was observed in any trial, even with discussions of end-of-life planning, such as hospice and advance directives,” write the authors.

Practical challenges to implementing early integration of palliative care in the clinical setting currently exist, acknowledge the authors. These include reimbursement issues, as well as insufficient numbers of palliative care specialists to meet a growing demand.

The clinical opinion expands upon ASCO recommendations for ensuring patient access to high-quality palliative care contained in its 2011 policy statement, “Towards Individualized Care for Patients with Advanced Cancer.” The earlier statement recommended the initiation of candid discussion of all palliative and treatment options with patients newly diagnosed with advanced cancer, with the aim of improving quality of life for patients and their caregivers throughout the course of the disease.

“Preserving quality of life is of utmost importance for all patients,” says lead author of the clinical opinion Tom Smith, MD, professor of oncology and director of palliative care, Johns Hopkins, Baltimore. “We now have strong evidence in metastatic cancer that combining palliative care with standard cancer treatment improves our patients’ lives in many ways, and, in some cases, can help extend their lives. Patients deserve to have access to palliative care services and specialists throughout the course of their care.”

U.S. Minorities with Dementia May Be at ‘Double Disadvantage’ for Receiving Optimum End-of-Life Care

Care for patients with dementia at the end of life in this country is associated with unique challenges, and belonging to an ethnic minority group may constitute an additional barrier to high-quality end-of-life care for this population, according to a literature review conducted by British researchers.

“Disparities in end-of-life care for people with dementia from ethnic minority groups appear to exist and may be due to the double disadvantage of dementia and ethnic minority status,” write the authors of a study published in the Journal of the American Geriatrics Society.

The team analyzed the findings of 20 U.S. studies among patients, or their caregivers, from various ethnic groups who had dementia or severe cognitive impairment. The setting for the majority of studies was nursing homes or long-term care facilities.

OVERALL FINDINGS
- The use of artificial nutrition and other life-sustaining treatments was more frequent among African-Americans and Asians than among Caucasians.
- Decisions to withhold treatment were less common in the African-American and Asian groups than in the Caucasian group.
- Caregiver decisions near the end of life varied by ethnicity, with African Americans and Hispanics less likely to make decisions, or to have a loved one with an advance directive in place.
- While caregivers’ experiences differed between ethnic groups, the levels of strain experienced while caring for a relative with dementia at the end of life were similar.

ARTIFICIAL NUTRITION
- All studies found higher rates of artificial nutrition used among ethnic minority groups than among Caucasians.
- In all studies, African-Americans had a higher rate of artificial nutrition than Caucasians (range, 1.55 to 9.43 times as likely). Following adjustment, the Asian group had a similar likelihood.
- Artificial nutrition was more likely to occur in facilities with higher proportions of ethnic minority residents.
- African-American and Asian physicians were more likely to recommend artificial nutrition than were Caucasian physicians.

“[F]uture studies might need to examine whether end-stage dementia is perceived as a terminal illness, which would affect use of palliative care and hospice services,” conclude the authors.

Source: “End-of-Life Care for People with Dementia from Ethnic Minority Groups: A Systematic Review,” Journal of the American Geriatrics Society; February 2012; 60(2):351-360. Connolly A, et al; The Mental Health and Neurodegeneration Research Group, School of Community-Based Medicine, Manchester Academic Health Science Centre, University of Manchester, Manchester, United Kingdom.

Non-Pharmacological Care Provision at the End of Life Is Complex and Personalized, International Study Finds

Caring for patients close to death includes non-pharmacological activities that alleviate suffering and promote well-being and comfort in a myriad of separate yet interwoven ways, an international research team reports in an article published in PLoS Medicine, an open-access, peer-reviewed medical journal.

Researchers analyzed data collected by specialized palliative care staff (registered nurses, 80%; physicians, 15%) from 16 facilities in seven European countries, plus Argentina and New Zealand. The study was conducted under the auspices of OPCARE9, a European Commission Seventh Framework Programme project whose aim is to optimize research and clinical care for cancer patients in the last days of life.

Despite the variety of activities reported, a common underlying theme was identified: most palliative care staffs’ efforts were directed at personalizing care and fostering connections with the patient’s everyday life.

The most common caregiving activities provided included:
- Having contact with the patient’s body, through caring for needs while maintaining comfort and dignity
- Listening to, talking with, and understanding the patient and/or family members
- Creating an aesthetically pleasing, personalized, and safe environment
- Performing rituals surrounding death and dying
- Being present and enabling the presence of others (described as increasingly important as death neared)

Guiding and facilitating, which encompassed providing compassionate support “Our findings show that providing for fundamental human needs close to death is complex and sophisticated, but ultimately integrated into a common theme of caregiving,” the authors conclude. “It is necessary to better distinguish nuances in such caregiving to acknowledge, respect, and further develop end-of-life care.”

Rethinking the Presentation of Cardiopulmonary Resuscitation as the ‘Default’ Option

Experts suggest tailoring the approach to the relative benefits and burdens of each situation

By presenting cardiopulmonary resuscitation (CPR) as the de facto default whenever there is a risk of cardiac arrest, the health care system is encouraging an “ethically unjustifiable practice” of exposing too many patients to substantial harms, asserts a team of experts in an article published in the Journal of the American Medical Association.

“Physicians are responsible for recommending the medical means to honor their patients’ values and for helping them to identify and achieve their health care goals,” write the authors. “This responsibility becomes crucial in the setting of life-threatening illness, in which patients are especially vulnerable and may be exposed to potentially harmful life-sustaining interventions.”

Presenting CPR in a default framework — that is, requiring that patients opt out of the intervention — can lead to a misinterpretation of its potential for both harm and benefit, a misunderstanding of the clinical situation and the physician’s recommendations, and patient choices that mistakenly go against their own wishes and best interests.

“[D]efault options are often interpreted as recommendations or guidelines, or as the path of least resistance,” note the authors, and when presented as such can bias patients and families toward choosing full resuscitation status, even when there is little chance of benefit and great risk for harm.

The authors propose three different approaches to discussing the advisability of CPR with patients and/or surrogates, based on the relative benefits and harms.

APPROACH 1: DISCUSS CPR AS A PLAUSIBLE OPTION

When the relative benefits and harms of CPR are uncertain (as in patients with chronic but not end-stage illness), physicians can:

• Explore the patient’s understanding of the disease and clarify any misperceptions.
• Discuss the likelihood of successful resuscitation and the possible harms of attempted CPR.
• Understand the patient’s values, and accept that medically similar patients may make different choices.
• Document the discussion and status in the medical record, along with the patient’s values, goals, and preferences.

APPROACH 2: RECOMMEND AGAINST CPR

When there is a low likelihood of benefit and a high likelihood of harm from CPR (as in patients with advanced incurable cancer, advanced dementia, or end-stage liver disease), physicians can:

• Prepare to advise against CPR while remaining open to unique patient/family values, beliefs and/or cultural factors that may make a resuscitation attempt valuable to them.
• Recommend against CPR (in most cases), explaining that it would potentially expose the patient to significant harm while providing little benefit. “Patients in this category who survive resuscitation are likely to spend their last hours or days in an intensive care unit or have an anoxic brain injury,” the authors point out.
• Affirm that this decision is intended to protect the patient. Take care not to give an impression that the best care will be withheld or that the patient will be abandoned.

In some situations, a patient or surrogate will nevertheless insist upon choosing CPR. “It is ethically acceptable for the physician to acquiesce to such a request, as long as it is grounded in the patient’s values and goals and there is a potential for a modicum of medical benefit,” advise the authors.

APPROACH 3: DO NOT OFFER CPR

When a patient is imminently dying or has no chance of surviving CPR to hospital discharge, “absent extraordinary but reasonable patient values or goals that might make the harms of CPR in this situation worth risking, it is, in our opinion, not only ethical, but also imperative, that CPR not be offered,” the authors declare.

Physicians can:

• Disclose the decision not to offer CPR to the patient/surrogate.
• Affirm that the intent is to protect the patient and maximize comfort, and does not mean giving up, or that the patient will be ignored or abandoned.
• Request an ethics consultation if, despite the medical circumstances, the patient or surrogate insists that CPR be attempted. Support from a social worker, chaplain, or patient advocate can also be made available to the patient and family.
• “The physician’s primary responsibility is to protect the patient from harm,” conclude the authors. “While promotion of patient autonomy is a fundamental responsibility of physicians, protecting the patient from harm becomes increasingly important as the patient becomes more vulnerable. Sometimes, it should be preeminent.”

Source: “Time to Revise the Approach to Determining Cardiopulmonary Resuscitation Status,” Journal of the American Medical Association; March 7, 2012; 307(9):917-918. Blinderman CD, et al; Department of Anesthesiology, Columbia University Medical Center, New York City; Division of Medical Ethics, Departments of Medicine and Global Health and Social Medicine, Harvard Medical School, Boston; Palliative Care Service and Optimum Care Committee, Massachusetts General Hospital, Boston.
Primary Care Physicians Offered Clinical Overview of Palliative Care

A report from the American College of Physicians (ACP) presents an evidence review, discussion, and guidance for practicing physicians wishing to upgrade their knowledge of palliative medicine. Published in the *Annals of Internal Medicine* as part of its “In the Clinic” series, the report stresses the importance of providing better care to patients with serious illness.

Palliative care “is a fundamental component of the practice of medicine in all disciplines, and at all levels of health,” states the ACP. “When cure or life prolongation is no longer possible, palliative care becomes the central component of treatment.” Although hospice and palliative care are related but distinct forms of palliative medicine, the ACP emphasizes, they “should not be reserved for patients who are imminently dying.

“Palliative medicine focuses on quality of life and the alleviation of symptoms in patients with serious illness,” the ACP explains. “It aims to consider the physical, mental, spiritual, and social well-being of patients and their families in order to maintain hope while ensuring patient dignity and respecting autonomy.”

The clearly written, succinct review addresses such topics as prognostication, and the assessment and management of pain and other distressing symptoms — such as dyspnea, nausea, agitation, delirium, and depression. It also offers clinicians guidance on when it is appropriate to partner with a consultative palliative care team for patients with unmet needs.

**SECTION HEADINGS INCLUDE:**

- Palliative Care vs Hospice Care
- Management of Common Symptoms
- Communication, Psychosocial, and Ethical Issues
- Patient Education
- Practice Improvement

The article includes tables with data and guidelines, as well as “clinical bottom line” summaries of selected sections. A supplemental tool kit provides links to general information and palliative care tools from external sources, and a patient information page entitled, “Things You Should Know about Palliative Care,” can be downloaded and printed for use as a patient handout. The patient information page is available at [http://www.annals.org/site/intheclinic/itc-palliative-care-2012-patient-information.pdf](http://www.annals.org/site/intheclinic/itc-palliative-care-2012-patient-information.pdf).

Physicians are invited to complete the quiz accompanying the article for continuing medical education credit, which is free to journal subscribers and available as a pay-for-view option for non-subscribers.

10th Annual Sharp HospiceCare Benefit Regatta Supports Hospice Patients

All hands are on-deck as the community comes together with boating enthusiasts and health care professionals at the 10th Annual Sharp HospiceCare Benefit Regatta on Friday, Aug. 24 and Saturday, Aug. 25, 2012. Hosted by Sharp HospiceCare, Coronado Yacht Club, and Cortez Racing Association, the event will feature dinner, dancing, live entertainment, sailboat regatta, and hosted yacht parties for race spectators.

Proceeds from the regatta support Sharp HospiceCare, an organization that provides comprehensive care and compassionate support for patients and their families facing a life-limiting illness. This year’s event is expected to net $250,000 for Sharp HospiceCare’s Homes for Hospice campaign, an initiative to build hospice homes in San Diego. So far, the campaign has led to the completion of two homes. A third hospice home is in the planning stages for the Southbay.

The event kicks off Friday evening, Aug. 24 with a pre-race dinner, followed by all-day festivities on Saturday, Aug. 25, as guests board sponsored yachts and cruise along the race course for a breathtaking view of the regatta and the San Diego Bay.

In addition, the ever-popular Physicians’ Challenge takes place with a head-to-head competition among physicians from two Sharp-affiliated medical groups, Sharp Rees-Stealy and Sharp Community Medical Group. Attendees will cheer on their favorite crew of doctors as they race aboard legendary America’s Cup yachts, Stars & Stripes and Abracadabra.

For more information about the Sharp HospiceCare Benefit Regatta, call Bill Navrides at 619-740-4316. To learn more about Sharp HospiceCare, call 1-800-82-SHARP (1-800-827-4277) or visit www.sharp.com/hospice.

About Sharp HospiceCare:

Caring for patients since 1992, Sharp HospiceCare is a not-for-profit, Medicare-certified organization, dedicated to providing comprehensive care and compassionate support for patients and their families facing a life-limiting illness. Sharp HospiceCare is accredited by the Joint Commission (JCAHO), and is affiliated with the California Hospice and Palliative Care Association (CHAPCA) and the National Hospice and Palliative Care Organization (NHPCO).