Chapter 22: Palliative care and TAVR

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- Palliative care should begin early, as part of pre-TAVR planning if not prior
- Discussions should address patient values/preferences, goals of care, and advance care planning
- For patients who are not appropriate candidates for TAVR, palliative care should provide aggressive symptom mitigation and facilitate transition to hospice

Introduction

In addition to life prolongation, a major goal of TAVR is restoration of a satisfactory quality of life. While anatomy heavily influences procedural success, other patient characteristics such as comorbidities, frailty, and patient goals of care play critical roles in the likelihood of accomplishing this objective. Palliative care is therefore an important factor in the care of patients under consideration for TAVR. In the absence of intervention, aortic valve disease is well known to be a life-limiting condition, with a reported 40-50% 1-year mortality that increases to 80% by 3 years for aortic stenosis (1). In addition to mortality, morbidity can pose a significant burden, as reduced physical capacity in advanced disease limits a patient's ability to participate in activities that make life meaningful (2). In cancer, palliative care has been shown to improve quality of life and even prolong life (3, 4). Palliative care in heart failure has been linked to improved quality of life and symptoms, with decreased hospitalizations and in-hospital deaths (5).

TAVR is not for everyone

Patients under consideration for TAVR in the original PARTNER I studies were, by definition, elderly and at high or prohibitive surgical risk. Although TAVR is now approved for patients at intermediate risk and is being studied in low risk patients, current, mainstream use of this technology continues to center largely around elderly or frail patients. For some patients who are either too sick (referred to in PARTNER I as "Cohort C" patients) or for whom valve disease is not the primary driver of symptoms, TAVR may not offer much improvement in quality of life, despite procedural success (6, 7). Up to 30% of TAVR recipients in PARTNER I Cohort B either died or experienced persistent heart failure symptoms at 1 year (2, 8), with only small improvements in psychological and general health measures (9). Renal dysfunction, advanced lung disease, coronary artery disease, and reduced ejection fraction have all been reported to limit the benefit of TAVR, highlighting the importance of comorbid conditions in considering the appropriateness of TAVR (2, 9, 10). Finally, frailty was associated with both higher mortality and higher rates of poor functional outcome in PARTNER I (11, 12).

Multiple tools are needed to investigate the burden of symptoms and comorbidity during the pre-procedure multidisciplinary assessment. As no single model has been developed and validated in the TAVR population, data compiled from multiple tools can supply a more complete sense of impact. Models used include the European System for Cardiac Operative Risk Evaluation (EUROSCORE), the

Society of Thoracic Surgeons (STS) Score, the Charlson Comorbidity Index, the Kansas City Cardiomyopathy Questionnaire, the Minnesota Living with Heart Failure Questionnaire, and the Vancouver Functional Assessment (2, 7, 9). Use of these models also creates opportunity for shared decision making that goes beyond the procedural aspects at hand, delving into emotional and functional capacity issues that may guide patients' decisions surrounding TAVR.

Palliative Care as a component of pre-TAVR planning

Palliative Care is "patient and family centered care that optimizes health related quality of life by anticipating, preventing and treating suffering" (14). In recent years, palliative care has been recognized as a critical component of medical care that should be integrated into the care plan for patients with advanced illness, including aortic valve disease. It is important for both physicians and family members to understand that palliative care does not imply hospice, "palliative procedures," or withdrawal of care. Rather, palliative care is a collection of methods to help define goals of care, manage symptoms, and manage expectations that can and should be instituted alongside life-prolonging and disease-modifying interventions (15, 16).

Advance care planning is a component of palliative care that helps a patient define their wishes in the event of an adverse outcome or for the end of life. It helps impart a sense of control for the patient and reduces anxiety during a time that can be frightening. It affords the opportunity for patients to calmly and thoroughly explore different possible pathways. This exploration should include consideration of the different outcomes of a procedure guided by clinicians that can answer their questions and offer perspective. Ideally, this exercise is best performed outside of critical moments, when decisions need not be rushed and thinking is not clouded by distress or delirium (5, 15, 16). If TAVR is planned, the patient should work together with others on the Heart Team to construct a "valve preparedness plan," outlining their wishes for the multiple possible outcomes during and after the procedure (17).

If a patient is turned down for TAVR, timely advance care planning is just as, if not more, important. Even if some palliative care was provided prior to the assessment, feelings of hopelessness and abandonment are not uncommon as these patients face approaching mortality without valve treatment options. To allay these concerns and maximize quality of life, it is important to reassure patients that other medical care will continue to be provided. In addition, patients and family members may have questions and concerns about what the next months to years may hold for them, specifically the potential for suffering in terminal stages of diseases and the nature, timing and, locations of palliative interventions. Providing information about a patient's likely prognostic trajectory and developing a treatment plan in advance can help decrease anxiety. Volume overload and respiratory insufficiency may become prominent. Diuretics can be used to manage volume, supplemental oxygen can combat hypoxia, and low doses of morphine can be used, even in the home setting, to address air hunger. Benzodiazepines may be appropriate in cases of significant anxiety. In rare cases, balloon valvuloplasty can be considered to address symptoms refractory to medical management, recognizing that this is only a short-term solution. Appointing a provider to help the patient and family navigate the end of life is also important, whether that is a primary care provider, geriatrician, cardiologist or palliative medicine specialist. In some, perhaps many, cases, a multidisciplinary care team should be assembled to address specific and varied needs. When appropriate, clinicians should introduce the concept of hospice and start the process of

connecting patients to hospice resources, whether in the home or institutional setting. Hospice is likely underutilized in the population of patients with valvular disease, and many more patients are likely to benefit from the focus on symptoms relief, meaningful death and bereavement support

Palliative care can be described in terms of "primary" and "specialty"(18). Specialty palliative care is provided by a clinician with advanced training. Specialty palliative care is appropriate in the setting of refractory symptoms, symptoms related to multiple comorbidities, and difficult or complex decision making. Exploration of goals of care may benefit from specialty assistance, particularly if there is underlying psychosocial distress (15). There is substantial interest in involving palliative care specialists in illnesses other than cancer, particularly as the population lives longer and develops cardiac disease, dementia, and other illnesses of the elderly. However there is an acute shortage of specialty palliative care providers, and while palliative care programs exist at most large medical centers, these resources often remain focused on cancer care.

Primary palliative care can be performed by any clinician, including the primary care provider, cardiovascular specialist or member of the structural heart team. Palliative care of this sort is front line and complimentary to specialist palliative care. At its root, palliative care is connecting with the patient on a human level, something all clinicians have been trained to do, even if it was not explicitly called palliative care at the time of training. Helping patients understand the benefits and limits of potential interventions and how they may or may not improve their lives is well within the sphere of practice of cardiovascular specialists referring to or performing TAVR. Clinicians providing primary palliative care often have better familiarity with the disease process and prognosis, and may have an established relationship with the patient which can facilitate identification of patient values and goals. Ideally, advance care planning discussions should be part of informed consent. Key elements include exploration of patients' values and preferences, identification of a surrogate decision-maker, discussion of all treatment options (including palliative medical management), and discussion of the patient's wishes for the different potential outcome scenarios. A commonly-reported barrier to primary palliative care is a lack of training, or a provider's fear that he or she does not have the skills to "do it well." Cardiovascular specialty societies are increasingly including palliative care sessions in their annual meetings and are developing on-line palliative care resources for patients and clinicians. Examples include the American College of Cardiology's "CardioSource".

Specific Tips for Primary Palliative Care Implementation

Palliative care practices can be routinely incorporated into protocols without large-scale changes or extensive training. Standardized tools within and across institutions such as patient-directed literature that clearly and simply explains the principles and importance of palliative care, symptom assessment tools that aim to identify prominent cardiac and non-cardiac symptoms, and advance directive forms that address relevant potential scenarios can effectively accomplish this task (19). The "Ask-Tell-Ask" framework (20) is commonly referenced as a way to explore patients' understanding of their situation, raise concerns, and to address those issues in an iterative manner. Listening is an integral component of this framework, which in reality should be framed as "Ask-Listen-Tell, Repeat." Asking whether patients prefer "big picture" explanations or detailed ones, and knowing about the patient's support structure can help avoid overwhelming the patient. Noticing and responding respectfully to emotions and nonverbal

patient and family cues is another important component of this exercise, for which the NURSE mnemonic can be utilized (See FIGURE) (20).

Though there is limited formal research in this area, real-world experience has suggested significant benefits to advance care planning and end-of-life discussions prior to making the decision to pursue TAVR. Sometimes these discussions take place with the primary care physician prior to TAVR referral, and sometimes these discussions occur during the TAVR evaluation by members of the Heart Team. Recognition that these patients remain at high short-term risk of death even after successful intervention and that, without intervention, the patient certainly faces short-term death, argues for the early and ongoing inclusion of palliative care in the care of patients referred for TAVR. For those who are turned down for TAVR, palliative care can help guide more imminent end-of-life decision making. Much of this can be done in the setting of primary palliative care, but secondary palliative care options may be employed for more challenging cases. Thorough exploration of these topics will help both patients and providers be more fully prepared to move forward in the treatment of the valve disease at hand.

Fostering Communication (Ask-Tell-Ask)	
Ask	• Patient's concerns • Current understanding of disease/procedure
Tell	• Prognostic information • Procedural Description • Provider's concerns
Ask	• Restate main points in own words • Outstanding questions/concerns

Responding to Patient Emotions (NURSE)	
Naming	Call out a possible emotion: "It sounds like you are worried."
Understanding	"My understanding of what you're saying is…"
Respecting	Respectful verbal or nonverbal acknowledgement of patient emotions
Supporting	Supportive statements: "Our team will help you navigate this process."
Exploring	Further explore patient's concerns or needs, using focused questions or conversation

Figure: Tools to facilitate advance care planning and end of life discussions.

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