



Transition to palliative care when transcatheter aortic valve implantation is not an option: opportunities and recommendations

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Purpose of review

Transcatheter aortic valve implantation (TAVI) is the recommended treatment for most patients with symptomatic aortic stenosis at high surgical risk. However, TAVI may be clinically futile for patients who have multiple comorbidities and excessive frailty. This group benefits from transition to palliative care to maximize quality of life, improve symptoms, and ensure continuity of health services. We discuss the clinical determination of utility and futility, explore the current evidence guiding the integration of palliative care in procedure-focused cardiac programs, and outline recommendations for TAVI programs.

Recent findings

The determination of futility of treatment in elderly patients with aortic stenosis is challenging. There is a paucity of research available to guide best practices when TAVI is not an option. Opportunities exist to build on the evidence gained in the management of end of life and heart failure. TAVI programs and primary care providers can facilitate improved communication and processes of care to provide decision support and transition to palliative care.

Summary

The increased availability of transcatheter options for the management of valvular heart disease will increase the assessment of people with life-limiting conditions for whom treatment may not be an option. It is pivotal to bridge cardiac innovation and palliation to optimize patient outcomes.

Keywords

palliative care, transcatheter aortic valve implantation, transition of care

INTRODUCTION

The management of degenerative valvular heart disease represents the next epidemic wave of cardiovascular care in developed countries [1]. Severe aortic stenosis is primarily a disease of the elderly, causes debilitating symptoms, poor quality of life, repeat hospitalization, and it is the most lethal heart valve disease affecting adults [2[■]]. The prevalence of aortic stenosis is significant; it affects up to 7% of the population past the age of 75 [3]. Valve replacement is the only treatment that improves survival and quality of life [4].

In the past decade, transcatheter aortic valve implantation (TAVI) has rapidly transformed the treatment of symptomatic aortic stenosis and is now the recognized standard of care for higher surgical risk patients [5[■]]. Patients currently referred for TAVI are primarily older and have preexisting

frailty, concomitant complex comorbidities, and varying social and economic resources and needs; they also differ in their ability to access medical care that supports end-of-life decision making and the management of their cardiac and other conditions [6,7[■]]. TAVI programs are usually associated with

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KEY POINTS

- TAVI is the standard of care for higher surgical risk patients with severe symptomatic aortic stenosis.
- If treatment is deemed futile, patients referred to specialized TAVI programs require transition to palliative care to optimize outcomes and ensure continuity of health services.
- Guidelines developed for the management of end-of-life in heart failure can inform best practices in TAVI program.
- Continuity of communication between TAVI programs and referring/primary care physicians is essential.

specialized cardiac centers; most are modelled to determine patients' eligibility for the procedure, coordinate access to treatment if appropriate, and transition patients' care to their referring or most responsible physician whether TAVI is an option or not [8[■]]. Opportunities exist to better integrate palliative care transition pathways aimed at improving continuity of care and patient outcomes when invasive treatment is deemed futile.

The purpose of this review is to explore the opportunities and recommendations to transition patients to palliative care when TAVI is not an option. To this end, we will discuss the unique trajectory of patients with aortic stenosis and the determination of eligibility for TAVI, current evidence guiding the integration of palliative care in cardiac programs, and implications for TAVI programs seeking to adopt best end-of-life practices.

UTILITY AND FUTILITY OF TREATMENT OF AORTIC STENOSIS

Aortic stenosis is the most prevalent valvular heart disease and the third most common cardiovascular condition after coronary artery disease and hypertension [2[■]]. The progressive calcification and immobilization of the valve leaflets causes stiffening and narrowing of the aortic leaflets, scarring, impaired valve opening, and, eventually, heart failure. Patients usually remain asymptomatic for a long time; once they develop symptoms, disease progression accelerates and the prognosis becomes dramatically worse [9].

Careful case selection for TAVI is pivotal. A rigorous multimodality assessment that includes cardiac diagnostic testing and multidisciplinary consultations is required [8[■]]. International guidelines recommend a multidisciplinary Heart Team approach to determine patients' surgical risk and likelihood to derive benefit from treatment [10–12].

The goal of eligibility assessment is to answer two clinical questions: 'Can TAVI be done?' and 'Should TAVI be done?'

Clinical trials have demonstrated tremendous survival advantage, symptom benefit, and improved quality of life for many TAVI patients. In contrast, the treatment of patients who are dying 'with' aortic stenosis but not 'from' aortic stenosis does little to modify the poor prognosis associated with comorbidities, excessive frailty, and disability [5[■]]. For example, in the Placement of Aortic Transcatheter Valve trial, 30% of patients at prohibitive surgical risk treated with TAVI did not survive past the first year or experienced only limited improvement in their quality of life or New York Heart Association functional class [13[■]]. Predictors of poor outcomes after TAVI include impaired renal function, severe pulmonary disease, severity of aortic stenosis, and frailty indicators including impaired cognition and slow gait [14[■]].

The quantitative interplay of existing risk models and indicators of frailty, disability, and functional status has not been defined [5[■]]. Early studies demonstrated that frail TAVI patients are three to five times less likely to survive up to 1 year, but do not necessarily experience increased 30-day mortality or morbidity [15,16]. The development of multidimensional geriatric TAVI risk scores will clarify the impact of frailty and other indicators of decreased function on short and long-term outcomes to guide treatment decisions in this higher risk patient population [13[■]].

When TAVI is not a treatment option, programs ought to provide an alternative care plan for the group of patients for whom TAVI has been deemed clinically futile. For example, 410 patients completed the eligibility assessment at the Centre for Heart Valve Innovation at St. Paul's Hospital (Vancouver Canada) in 2014. In this cohort, 58% ($n=237$) were eligible for TAVI, 14% ($n=58$) were reevaluated for surgical aortic valve replacement, and 13% ($n=52$) were scheduled for on-going medical management and reassessment for TAVI. In 61 patients (15%), the Heart Team's recommendation was to consider symptom management and palliative care. The decision to not offer TAVI 'should not equate to abandoning care' [13[■]] [13, p. 173]; rather, TAVI programs could promote the transition from a procedure-focused program to palliative care to manage a poor prognosis and limited life expectancy associated with end-stage valvular heart disease [7[■]].

PALLIATIVE CARE PRACTICES IN CARDIAC PROGRAMS

The integration of palliative care and other end-of-life practices in the treatment decision of procedure-

focused cardiac programs, such as heart surgery, coronary revascularization, implantable cardioverter-defibrillator, and transcatheter heart valve is not well documented. Research focused on cardiac patients' needs at end of life is primarily informed by the experience of heart failure [17]. Heart failure is the life-limiting end stage of multiple cardiovascular diseases, including coronary heart disease, myocardial infarction, hypertension, arrhythmias, cardiomyopathy, congenital heart disease, and valvular heart diseases [18]. Although aortic stenosis may initially present with angina, syncope, and severe fatigue in addition to congestion, the disease trajectory ultimately progresses to severe heart failure and death [9]. Thus, informing the integration of palliative care in TAVI program benefits from an examination of recommendations and consensus statements pertaining to heart failure.

Algorithms and predictive scoring tools that use commonly available clinical information have been established to predict heart failure survival [19²²,20]. For example, the Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization Effectiveness risk model and discharge score established that 10 variables, including advanced age, impaired renal function, elevated brain natriuretic peptide, short 6-min walk distance, and high diuretic dose had good discriminatory capacity to predict the timing of death [21]. In the Seattle Heart Failure Model, predictors of disease progression and mortality included increased New York Heart Association functional class, lower left ventricular function, cardiac implantable electronic device, impaired renal and pulmonary function, and depression [22]. These markers of disease severity are scrutinized during the eligibility assessment for TAVI.

The needs of patients and their families who are dying from cardiac diseases and other serious illnesses are well described. The care priorities include treating pain, other symptoms, and psychological and spiritual distress, using advanced communication skills to establish goals of care and help match treatment options to individualized goals, and provide coordinated care to ensure continuity and seamless transition [23²⁴]. These interventions enable patients to retain a degree of control, have opportunities to strengthen or resolve interpersonal relationships, and opportunities to prepare for death [19²⁵].

Given the established course of the cardiac end stage disease trajectory, there is increasing emphasis on the pressing need to improve end-of-life care – both preparations for, and the delivery of – for patients and families with heart disease [24]. This increased scrutiny is arising out of observations that patients and families' experiences with dying from

heart disease is poor compared with patients who die from similar life-limiting illnesses, including many malignancies [25]. For instance, in the final month of life, most patients dying from heart failure reportedly experience poorly controlled pain [26] and inadequate control of other symptoms commonly associated with dying such as anxiety, shortness of breath, and delirium [24,27].

There is a misalignment between the perceptions of care providers and patients and families in acknowledging the end stage of cardiac illnesses [28²⁹]. Cardiac patients and families are often poorly informed, underinvolved in decision making, goal setting, and care planning, and have minimal insight about their illness and prognosis [29]. Similarly, most physicians and other healthcare providers have often had limited or no formal training in the conduct of end-of-life communication and other palliative care practices [23³⁰]. These gaps present barriers to strengthen the continuity of health services and provide opportunity to improve collaboration along the continuum of the patient's disease trajectory [30].

One of the significant challenges of the innovative management of aortic stenosis is the balancing and transitioning between treatment-focused (i.e., life-prolonging) and supportive, palliative-oriented care. A patient's decision to undergo TAVI eligibility assessment is multifaceted and complex [31³²]. It is essential that TAVI not be viewed as 'one more thing to try' but rather a treatment decision expected to result in considerable life extension, improved symptoms, and quality of life, which may be clinically futile in the presence of excessive risks. Though considerably complex and difficult, careful examination of this challenge is critical because insufficient treatment-focused care and/or inadequate palliative-oriented care in the final stages of life can have adverse impacts on patients and families [32].

CURRENT GAPS AND OPPORTUNITIES TO SUPPORT PALLIATIVE CARE IN TRANSCATHETER AORTIC VALVE IMPLANTATION PROGRAMS

The survival success of TAVI has created new challenges in the continuum of care for patients with severe heart valve disease for whom invasive treatment was previously not an option. The appreciable gains in life expectancy, quality of life, and functional capacity associated with TAVI, combined with the complexity of parsing patients who may or may not benefit from the procedure has sparked increased interest in palliative care as a pertinent issue in TAVI programs [7³³,33³⁴]. As arbiters of

healthcare planning, regional jurisdictions have established indications based on current guidelines [2⁷]. For example, in British Columbia, Canada, TAVI is indicated for patients who are likely to derive at least 2 years of quantity and quality of life [34]. To identify and support those who do not meet the required criteria, recommendations for the inclusion of geriatric medicine and palliative care specialists in the multidisciplinary TAVI Heart Teams have been made to strengthen continuity of care, chronic disease management, and integration of palliative care [8⁷].

The integration of palliative care along patients' journey from referral to follow-up is not necessarily tied to prognosis [33⁷]. The adoption of a dual strategy that incorporates a predominantly curative focus (i.e., treatment/procedure-focused) bridged to a primarily supportive (i.e., palliative-oriented) focus when TAVI is futile may address potential gaps in care. The tenets of palliative care mirror the TAVI Heart Team approach; both rely on a multidisciplinary and coordinated team, emphasize symptom management and improved quality of life, and consider all medical therapies that help meet the objectives of care. In this context, all healthcare providers, in all healthcare settings, should provide basic palliative care [35⁷]. This convergence differs from specialized palliative or hospice care which may be required to assess, treat, or guide the care and management of complex symptoms and other issues related to dying 'with' aortic stenosis.

In developing a strategy to integrate palliative care, issues pertinent to the partnership between TAVI programs and primary care providers must be addressed.

RECOMMENDATIONS FOR TRANSCATHETER AORTIC VALVE IMPLANTATION PROGRAMS

In 2014, the WHO resolved that palliative care should be integrated in all healthcare settings and by all healthcare specialties in its member countries [36]. Although widely adopted in multiple guidelines, this potentially complex intervention lacks evidence that it contributes to improved outcomes in the management of valvular heart disease [33⁷]. In the absence of such research, the scope of responsibility of TAVI programs and the question of whether the needs of the patient or the prognosis of severe aortic stenosis should trigger the identification of patients and the initiation of palliative care are unknown. TAVI clinicians may perceive that discussions about end of life may remove hope, cause increased

confusion, or be incongruent with previous discussions held with other healthcare providers [28⁷]. The complex drivers of case selection, prognostic uncertainty during the eligibility assessment phase, lack of knowledge about palliative care, and confidence to initiate or pursue discussions about end of life further contribute to a lack of clarity of the responsibility of TAVI programs [37]. In addition, the limited human resources, infrastructure, and mandate must be realistically appraised by TAVI programs in developing a strategy to integrate palliative care. To this end, the following recommendations may be pertinent to develop a road map for the Heart Team:

- (1) Recognize the importance of palliative care in the continuum of the management of aortic stenosis and increase the Heart Team's knowledge about best palliative care practices.
- (2) Consider establishing a partnership with a palliative care specialist to strengthen the TAVI Heart Team.
- (3) Provide realistic information to patients and families during the eligibility assessment to outline the process of treatment decision and highlight that TAVI is not an option for all patients.
- (4) Consider criteria-based early consultation with palliative care during the eligibility assessment to improve symptom management.
- (5) Consider using the 'Ask-Tell-Ask' recommended format of patient-centered communication to ascertain what patients know about their disease progression, the process of TAVI treatment decision-making, and their future care planning, followed by clarification of pertinent information and a chance to pursue arising questions [38].
- (6) Document patients' symptoms and communicate findings to the primary care provider and community teams.
- (7) Strengthen communication with the primary care provider; share expertise about disease progression and treatment options.
- (8) Adopt shared decision making approaches to incorporate patients' goals, values, and preferences in treatment decision, and bridge their understanding of the common goals of procedure-focused and palliative-oriented care.

RECOMMENDATIONS FOR PRIMARY CARE PROVIDERS

TAVI patients are often under the care of a web of specialists who manage the complexity of their health issues; this network has the potential to

mask patients' true disease progression and hinder the delivery of well coordinated care from the most responsible physician. The temporary treatment-focused care received at the TAVI program can further jeopardize continuity of care and end-of-life planning. It is essential to clarify who the patient's most responsible physician is, and who will centrally organize the patient's care [39]. The success of the integration of palliative care in TAVI programs hinges on the pivotal role of the primary care physician to ensure that patients for whom TAVI is not an option do not experience the negative outcome of their eligibility assessment as loss of hope, abandonment, and increased uncertainty. Uncertainty and concerns about judging prognosis, especially in light of the availability of innovative treatment options, can postpone the discussion about future care planning until the patient is very unwell or the TAVI Heart Team recommends initiating palliative care.

CONCLUSION

Palliative care has not traditionally been considered central in cardiac care, and cardiac patients receive proportionately less palliative care services. Systemic barriers increase the challenges of bridging innovative management of valvular heart disease and best end-of-life practices. However, this is changing as priorities shift to increase patient-centeredness and transition of care. The integration of best palliative care practices in TAVI programs will establish a gold standard of program development as new therapies for the transcatheter management of mitral valve and other valve diseases become increasingly available. Further research is essential to evaluate patients' perspectives and support cardiac and primary care clinicians in the adoption of best palliative care practices.

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