



#### **ISHLT CONSENSUS**

# The 2018 ISHLT/APM/AST/ICCAC/STSW recommendations for the psychosocial evaluation of adult cardiothoracic transplant candidates and candidates for long-term mechanical circulatory support

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#### **KEYWORDS:**

heart transplantation; lung transplantation; mechanical circulatory support; psychosocial evaluation; psychosocial risk factors The psychosocial evaluation is well-recognized as an important component of the multifaceted assessment process to determine candidacy for heart transplantation, lung transplantation, and long-term mechanical circulatory support (MCS). However, there is no consensus-based set of recommendations for either the full range of psychosocial domains to be assessed during the evaluation, or the set of processes and procedures to be used to conduct the evaluation, report its findings, and monitor patients' receipt of and response to interventions for any problems identified. This document provides recommendations on both evaluation content and process. It represents a collaborative effort of the International Society for Heart and Lung Transplantation (ISHLT) and the Academy of Psychosomatic Medicine, American Society of Transplantation, International Consortium of Circulatory Assist Clinicians, and Society for Transplant Social Workers. The Nursing, Health Science and Allied Health Council of the ISHLT organized a Writing Committee composed of international experts representing the ISHLT and the collaborating societies. This Committee synthesized expert opinion and conducted a comprehensive literature review to support the psychosocial evaluation content and process recommendations that were developed. The recommendations are intended to dovetail with current ISHLT guidelines and consensus statements for the selection of candidates for cardiothoracic transplantation and MCS implantation. Moreover, the recommendations are designed to promote consistency across programs in the performance of the psychosocial evaluation by proposing a core set of content domains and processes that can be expanded as needed to meet programs' unique needs and

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Candidates for heart transplantation, lung transplantation, and long-term mechanical circulatory support (MCS) undergo a multifaceted assessment process. The psychosocial evaluation is integral to this process for several reasons. First, it provides information relevant for the selection of patients for transplantation and MCS. Second, it enables care planning and the provision of interventions to improve patients' viability as transplant and/or MCS candidates. Third, it facilitates referrals for care for patients deemed ineligible for transplantation or MCS. Fourth, for patients who undergo transplantation or device implantation (either as a bridge to transplantation or as permanent, "destination," therapy), information from the psychosocial evaluation facilitates post-transplantation/post-implantation care to support optimal psychosocial and medical outcomes.

The International Society for Heart and Lung Transplantation (ISHLT), leading a collaboration with the Academy of Psychosomatic Medicine (APM), American Society of Transplantation (AST), International Consortium of Circulatory Assist Clinicians (ICCAC), and Society for Transplant Social Workers (STSW), convened a Writing Committee of international experts to produce this consensus document, which provides recommendations for: (a) the content of the psychosocial evaluation; and (b) the process of evaluation performance, reporting, and use by transplantation and MCS programs. The primary aim of the recommendations is to aid programs to construct evaluation protocols that comprehensively gather information on psychosocial factors recognized in ISHLT guidelines and consensus statements, <sup>1–3</sup> and/or in the empirical literature as relevant to patient selection for transplantation or long-term MCS implantation. In addition, when psychosocial contraindications for selection are identified, the recommendations outline the implementation of referrals for treatments or interventions that may improve patients' well-being and suitability as transplantation or MCS candidates.

#### **Need for recommendations**

Pre-transplant psychosocial factors, including patients' history of medical adherence, mental health, substance use, and social support, predict outcomes after cardiothoracic transplantation. As reviewed herein, these outcomes include post-transplant medical adherence and quality of life (QOL), as well as transplant-related morbidities and mortality. Although there are fewer studies, similar effects are observed in patients receiving long-term MCS. Transplantation and MCS programs perform evaluations to assess psychosocial factors as part of the patient selection process. However, despite recognition of the value of the psychosocial evaluation by ISHLT guidelines and consensus statements, 1-3 these documents have not delineated the full range of psychosocial domains that should be assessed, or the set of processes and procedures to be used to conduct the evaluation, report its findings, and monitor patients' receipt of interventions for any identified problems. To the best of our knowledge, these issues have not been fully delineated in any other published professional society guidelines or recommendations.

The clinical literature developed over the past 30 years has included extensive expert advice and commentary on rationale, ethical underpinnings, and essential content of the psychosocial evaluation. This literature has also offered some heuristic tools to guide and summarize the evaluation. In addition, there is an empirical literature that identifies psychosocial risk factors for patient outcomes, suggesting that the evaluation should include such factors. In the absence of any previous synthesis of both expert opinion and the empirical literature into a consensus-based, comprehensive set of recommendations for practice, cardiothoracic transplantation and MCS

programs have been left to determine their own approach to the psychosocial evaluation. Anecdotal evidence indicates that programs—and individual psychosocial evaluators—vary in the range of psychosocial domains examined; the breadth of elements considered within each domain; and the processes used to report evaluation findings and implement evaluation recommendations. <sup>4,9,14,19,21,22,25,33–35</sup> Variability in content and process may contribute to inequities in care and treatment options offered to patients. Conversely, greater consistency in the psychosocial evaluation both within and across programs may promote greater equity in both candidate selection and overall patient care.

#### How to use this document

This report represents a consensus of expert opinion and does not meet the criteria of "guidelines" as defined by the ISHLT. The Writing Committee judged that development of consensus-based recommendations was most appropriate for several reasons. First, guidance for decisions about the content and processes involved in psychosocial evaluation comes only in part from empirical literature; it also re ects expert experience. However, we note areas supported by robust empirical data in our discussion of the recommendations offered herein.

Second, the psychosocial evaluation of cardiothoracic transplantation and MCS candidates is complex because many domains of functioning and well-being are relevant for candidate selection and patient care. Moreover, the process of conducting the evaluation requires tailoring based on patients' ability to provide requested information, given such factors as their medical status and capacity to participate actively in the evaluation. Thus, it would not be appropriate to list strict, prescriptive guidelines for universal application. Likewise, and similar to other consensus-based recommendations in the field of cardiothoracic transplantation,<sup>2</sup> the Writing Committee asserts that the recommendations offered should not be interpreted as standard of care by health-care providers, patients, or third-party payers, or in legal proceedings. Instead, the recommendations were developed to be exible enough to accommodate the unique aspects of each patient, and each transplantation and MCS program across a wide spectrum of health-care delivery systems. The recommendations should be used to support programs' efforts to conduct and utilize the results of comprehensive psychosocial evaluations.

Finally, it is noteworthy that the recommendations focus on psychosocial evaluation content and process issues that are independent of any psychometric instruments or measures that evaluators may choose to administer to patients as part of the evaluation. Psychometric instrumentation is an evolving field, with measures routinely undergoing revision and/or being discarded in favor of superior tools. However, the content areas that should be assessed, and basic procedures to be used in the evaluation process transcend specific psychometric instrumentation and thus are the focus of the recommendations.

#### Methods

At the 2015 annual scientific meeting of the ISHLT, the Nursing, Health Science and Allied Health (NHSAH) Council of the ISHLT agreed on the importance of developing consensus recommendations for the psychosocial evaluation of cardiothoracic transplantation and long-term MCS candidates. The Council solicited interest in this work from the ISHLT Standards and Guidelines Committee, and invited a Writing Committee chair who worked with the Council to propose a slate of Committee members. The Committee composition and plan of work were approved by the ISHLT Standards and Guidelines Committee in April 2016. The Writing Committee re ected diverse constituencies. It included NHSAH Council members as well as members of the ISHLT Heart Failure and Transplantation, MCS, and Pulmonary Transplantation Councils. Participation was also sought from 4 key organizations with relevant expertise: the APM, AST, ICCAC, and STSW. These organizations each approved the plan of work in April-May 2016 and contributed at least 2 representatives to the Writing Committee. In total, the Writing Committee consisted of 27 expert members and was diverse in disciplines represented (including psychology, psychiatry, nursing, social work, pharmacy, cardiology and pulmonology) and geography (with members from 23 programs across eight countries). The ISHLT Board of Directors approved the final consensus document in February 2018; each of the 4 participating organizations approved it in February-March 2018.

The Writing Committee adhered to the ISHLT Standards and Guidelines Document Development Protocol (September 2015 update). The Committee was organized into a leadership group, composed of the Committee chair and co-chairs of each of 3 Subcommittees. The Subcommittees were assigned areas of work, including: (a) synthesis of expert opinion on the *content* of the psychosocial evaluation; and (b) synthesis of expert opinion on the *processes and procedures* for conducting the evaluation, reporting its results, and implementing any additional testing or treatment; and (c) literature reviews of empirical evidence to support the Committee's recommendations regarding *both* evaluation content and process.

The main strategy for the literature searches, reviewed by a medical librarian, was designed to identify empirical articles focused on psychosocial risk or protective factors for adverse post-transplantation/post-implantation clinical and behavioral outcomes (Table 1). In addition, the Committee consulted published expert reviews and commentaries. Because the consensus document provides recommendations and not guidelines, grading of levels of evidence for recommendations was not undertaken as per ISHLT Standards and Guidelines Protocol specifications.

The Writing Committee chair, working with Subcommittee cochairs, was responsible for organizing monthly discussions of assigned work within each Subcommittee and for evaluating the literature searches' completeness. Each Writing Committee member reviewed and provided input on multiple drafts of all recommendations and drafts of the entire consensus document.

#### Recommendations for the Content of the Psychosocial Evaluation

The broad rationale for the recommended domains to be assessed in the evaluation stems from the need to:

- (a) Assess risk factors for poor post-transplantation/post-implantation outcomes.
- (b) Collect information on factors related to patients' knowledge, understanding, and capacity to engage in decision-making about transplantation and/or MCS.

#### Table 1 Inclusion Criteria and Search Strategy for Empirical Evidence Supporting Consensus Recommendations<sup>a</sup>

#### Inclusion criteria

- 1. Peer-reviewed articles<sup>b</sup>
- 2. Articles published in Englishb
- 3. Articles focused on adults aged 18 and older
- 4. Publication dates between 2000 through mid-2017, inclusive
- 5. Seminal articles published before 2000 known to the Writing Committee members

#### Search term strategy

#### 1. Combination of:

(a) Terms to identify the relevant patient populations ([title words: heart transplant\* or lung transplant\* or heart-lung transplant\* or mechanical circulatory\* or ventricular assist\* or circulatory support or destination therapy] OR [key words: heart transplantation or lung transplantation or heart-lung transplantation or heart-assist devices or assisted circulation or heart, artificial]).

and

(b) Terms to identify relevant post-transplant/post-implantation clinical and behavioral outcomes that could be affected by psychosocial factors ([title words: survival or morbidity or mortality or graft rejection or infection or hospitalization or cancer or adheren\* or complian\* or medicat\* or self-manage\* or self-care or health-manage\* or smok\* or alcohol or tobacco or substance] OR [key words: health or survival or morbidity or mortality or neoplasms or graft rejection or infection or hospitalization or arrhythmias, cardiac or hemorrhage or stroke or patient compliance or medication adherence or self-care or alcohol drinking or substance-related disorders or tobacco use or smoking or smoking cessation]).

and

- (c) Additional terms iteratively identified by Writing Committee members charged with examining the literature on specific psychosocial risk factors (e.g., medical adherence history, mental health history, substance use/abuse history). The work was iterative because Committee members simultaneously discussed what domains of psychosocial factors were essential to include in the psychosocial evaluation, drawing on their own expertise and review of existing ISHLT quidelines and consensus recommendations.
- 2. Additional articles either found in the bibliographies of identified publications or authored by or known to Committee members. Included (especially when little to no literature was identified in cardiothoracic transplantation or in MCS) were seminal empirical articles from other areas of organ transplantation and from literature on advanced heart disease and advanced lung disease populations.

<sup>a</sup>Although a formal systematic review or meta-analysis<sup>36</sup> for each recommended domain of the psychosocial evaluation was not feasible within the scope of the consensus document development process, the Writing Committee performed literature searches using a consistent approach to inclusion criteria and search-term strategies for each psychosocial domain considered, as per the ISHLT Standards and Guidelines Document Development Protocol. Published systematic reviews and meta-analyses are cited where available.

<sup>b</sup>Required by the ISHLT Standards and Guidelines Document Development Protocol.

- (c) Collect information to characterize patients' personal, social, and environmental resources and circumstances, including factors that may mitigate the impact of any psychosocial risk factors on post-transplantation/postimplantation outcomes.
- (d) Unique to MCS candidates, evaluate patients' knowledge about and capacity to operate the device.

Table 2 lists the recommendations for evaluation content, including 10 domains and the components comprising each. Although the Committee viewed these domains and their components as essential, transplantation and MCS programs may determine that additional elements require assessment, according to local protocols and/or regulatory bodies. Table 3 summarizes the empirical evidence supporting each recommended content domain. 30,33,37-247

#### A. Assessment of risk factors for poor posttransplantation/post-implantation outcomes

#### 1. Treatment adherence and health behaviors

Background and recommendation. Repeated non-adherence to medications and other medical directives is a recognized

contraindication to cardiothoracic transplantation and MCS implantation  $^{1-3}$  Thus, the psychosocial evaluation should assess patients' past and current medical adherence, knowledge about their regimen, and willingness to adhere to the regimen after transplantation/implantation.

Evidence.<sup>37–51</sup> Extensive data (Table 3) show that non-adherence to medications and other medical regimen components, either before or after cardiothoracic transplantation, increases risks for post-transplant morbidities and mortality. More limited evidence suggests similar effects for MCS patients.

#### 2. Mental health history

Background and recommendation. Per ISHLT guidelines and consensus statements, psychiatric conditions are contraindications to transplantation/implantation insofar as they are uncontrolled, affect patients' ability to adhere to the medical regimen, and are not mitigated by factors such as social support. Therefore, the evaluation must assess patients' mental health history and current status, as well as treatment history.

Evidence. 15,27,34,39,45,47,48,52–79 Depressive and anxiety-

*Evidence*. <sup>15,27,34,39,45,47,48,52–79</sup> Depressive and anxiety-related conditions are relatively common in transplant and MCS candidates and recipients. Depression predicts post-

**Table 2** Consensus Recommendations on the Content of Psychosocial Evaluation of Adult Cardiothoracic Transplant Candidates and Long-term MCS Candidates: Domains to Be Assessed and Components to be Included Within Each Domain<sup>a</sup>

#### Evaluation domain

#### Components within each domain

A. Risk factors for poor outcomes after transplantation/implantation

- 1. Treatment adherence and health behaviors
- Past and current level of adherence to the required medical regimen.
- Knowledge and understanding of rationale and specific requirements of the current medical regimen (e.g., medication dosing; other self-management requirements; required clinical appointments and tests, etc.).
- Willingness and intent to modify self-management and lifestyle behaviors to meet any changing regimen requirements.
- 2. Mental health history
- Past and current mood, anxiety, or other disorders including personality disorders.
- Symptom severity and course, chronicity of symptoms.
- Receipt, adherence, and response to psychiatric treatment; willingness to seek treatment.
- Current or past suicidal ideation or self-injurious behaviors.
- · Mental health history of immediate family.
- 3. Substance use history
- Tobacco/alcohol/drug (licit and illicit) frequency, amount, duration of use, and length of abstinence.
- Diagnosable disorder, level of impairment to health/work/relationships, legal issues.
- Insight into any substance use problem, commitment to remain abstinent including prior attempts and periods of abstinence.
- Prior and any current treatment for substance use, willingness to seek treatment, skills and supports for abstinence.
- Substance use/abuse history of immediate family.
- B. Factors related to patients' knowledge, understanding, and capacity to engage in decision-making
- 4. Cognitive status and capacity to give informed consent
- Evidence of cognitive impairment that would compromise capacity to comprehend information and engage in decision-making about treatment options.
- Capacity to make judgments and decisions voluntarily without undue pressure from others.
- 5. Knowledge and understanding of current illness
- Knowledge and understanding of the causes and course of the organ disease to date and its impact on daily functioning and outcomes.
- Understanding of rationale for treatments received and inadequacy of treatments to manage symptoms/disease progression.
- Understanding of reasons for referral for transplant and/or MCS.
- 6. Knowledge and understanding of current treatment options
- Knowledge and understanding of risks and benefits of the surgical intervention under consideration (i.e., transplant, MCS).
- Understanding of post-intervention medical regimen, self-care and lifestyle requirements.
- Attitudes about the intervention (e.g., receptiveness, expectations, concerns/fears, reservations, values, preferences, and goals).
- C. Factors specific to patients' personal, social, and environmental resources, and circumstances
- 7. Coping with illness

- Emotional response to illness; acceptance or denial about severity of illness, prognosis and treatment options.
- Coping strategies used to manage illness and its impact on daily life (e.g., problem solving strategies used, reliance on others, avoidance coping).

8. Social support

- Availability, stability, and capacity of family and other sources to provide support.
- Understanding and knowledge among family and other supports of treatment options and current care needs.
- Expectations of family and other supports about care needs after intervention (i.e., transplant, MCS).

9. Social history

- Demographics, including religion/faith practices, education, literacy and health literacy.
- Relationship history (e.g., marital status, other significant relationships, stability of relationships with others).
- Employment experience and occupation.
- Financial status, including insurance status or options for medical cost coverage, and living arrangements and number of dependents.

Continued on page 808

Table 2 (Continued)

#### Evaluation domain

#### Components within each domain

- History of legal issues.
- Concurrent life stressors and history of exposure to traumatic events.

#### D. Factors specific to patients under consideration for MCS

### 10. Knowledge about and capacity to operate MCS device

- Knowledge and understanding of basic device operation, including signs of device
- Evidence of cognitive limitations, or physical limitations or disabilities (including sensory loss), that would compromise capacity to operate the device or to perceive and respond to device alarms.
- Safety of the home environment for device operation, including access to a reliable source of electricity and accessibility of the home by health-care or emergency personnel.

transplant mortality, likely due in part to its impact on behavioral outcomes, including medical adherence and coping strategies. It is unclear whether anxiety increases mortality risk. Neither condition has been examined relative to MCS recipient mortality.

Less common mental disorders such as psychosis and bipolar disorder may, but do not inevitably, lead to poor post-transplant clinical outcomes. This may re ect both careful candidate selection and close management of these conditions. Personality disorders do not appear to directly increase risk for poor post-transplant outcomes. Rather, they may have indirect effects by increasing risks for non-adherence, substance use, poor coping strategies, and poor social support. Psychosis and bipolar and personality disorders have not been studied in MCS recipients.

Finally, family history of mental disorder is relevant for evaluation because it is a known risk factor for patient psychiatric disorder, and it predicts disorder course and treatment efficacy. It can also affect family capacity to provide social support and caregiving.

#### 3. Substance use history

Background and recommendation. Active alcohol abuse and drug abuse are contraindications to cardiothoracic transplantation and MCS implantation. 1-3 Active tobacco is a contraindication to cardiothoracic transplantation.<sup>1,2</sup> While smoking cessation before MCS implantation is recommended,<sup>3</sup> guidelines state that if this cannot be accomplished before implantation due to patients' medical urgency, abstinence is required afterward if patients are to be considered for transplantation.<sup>3</sup> ISHLT guidelines and consensus statements<sup>1-3</sup> address some aspects of marijuana use, which is now legal for medical and/or recreational purposes in some regions but remains controversial for patient selection. 1,103,248,249 However, as for any substance, abuse is a contraindication for transplantation/implantation. 1-3 The psychosocial evaluation should assess history of use of all substances, current status, any treatments received, periods of abstinence, and insight and willingness to receive treatment.

*Evidence*. <sup>33,38,45,50,64,80–116</sup> Tobacco use and alcohol/drug abuse before transplantation/implantation increase risks for

poor post-surgical clinical outcomes and mortality, primarily mediated by relapse to use after transplantation/implantation. Longer durations of abstinence before transplantation/implantation can reduce relapse risk. There is little evidence on marijuana use. Family substance use/abuse history is an important risk factor for patient substance use and for relapse after organ transplantation.

## B. Assessment of factors related to patients' knowledge, understanding, and capacity to engage in decision-making

## 4. Cognitive status and capacity to give informed consent

Background and recommendation. Informed decision-making is predicated on patients' cognitive capacity to comprehend information and engage in decision-making discussions with health-care providers. 16,21,126,250,251 Patients should be capable of understanding treatment requirements, risks, and benefits. 1-3 Dementia is a contraindication for transplantation/implantation. Although the informed consent process goes beyond the psychosocial evaluation, the evaluation should identify any evidence that cognitive status may compromise patients' ability to make decisions and give informed consent.

Evidence. 51,52,117-146 Although dementia generally precludes informed consent, patients with milder degrees of cognitive impairment or with transient impairments that improve may have the capacity to give informed consent. In some other situations where patients cannot consent (e. g., due to intellectual disabilities), transplant outcomes may not be adversely affected. No studies have examined the impact of intellectual disabilities on outcomes after MCS. Beyond informed consent issues, patients' level of cognitive impairment before transplantation/implantation and residual impairments after surgery can increase risks for mortality and poor behavioral outcomes such as regimen non-adherence.

<sup>&</sup>lt;sup>a</sup>The order of listing of the domains to be assessed in the psychosocial evaluation is based on conceptual distinctions (see subheadings in the table) and is not meant to imply any recommendation that the domains should be assessed in this order.

MCS, mechanical circulatory support.

#### Table 3 Empirical Evidence Supporting the Inclusion of Each Domain of the Psychosocial Evaluation

A. Risk factors for poor outcomes after transplantation/implantation

- 1. Treatment adherence and health behaviors
  - Medication non-adherence before cardiothoracic and other solid-organ transplantation increases risk for post-transplant medication non-adherence,<sup>37,38</sup> which, in turn, increases risks for acute and chronic graft rejection, and mortality.<sup>38-44</sup>
  - Non-adherence to other components of the pre- or post-transplant regimen affects health outcomes.
    - Heart candidates with a history of general non-adherence to medical management have poorer survival post-transplant.
    - Heart recipients less adherent to clinical follow-up or to the general medical regimen post-transplant are at elevated risk for graft rejection<sup>46,47</sup> and mortality.<sup>47,48</sup>
    - Lung recipients less adherent to home spirometry requirements are at higher risk for bronchiolitis obliterans syndrome. 49
    - MCS patients with a history of non-adherence to medical directives are at higher risk for complications such as pump thrombosis.<sup>50</sup>
    - Poorer adherence to care requirements after MCS implantation is associated with poorer QOL.<sup>51</sup>

#### 2. Mental health history

- Depression and anxiety (both diagnosable disorders and clinically significant symptomatology) are the most common psychiatric conditions in transplant and MCS candidates and recipients.<sup>15,34,52</sup>
- Pre-transplant depression predicts mortality after cardiothoracic transplantation, as does post-transplant depression<sup>45,53–56</sup>; these effects are seen in other types of solid-organ transplantation as well.<sup>57</sup> Pre-transplant depression is a strong predictor of post-transplant depression.<sup>34,58</sup>
- Anxiety may predict post-transplant mortality, but the evidence base is small and not definitive.
- Depression likely affects mortality in part through behavioral pathways. 57,59 In cardiothoracic transplant and MCS patients:
  - Depression is associated with poorer medical adherence, poorer coping strategies, and higher risks for complications, such as infections.<sup>45,58,60-63</sup>
  - Such intermediate outcomes, in turn, increase risks for rehospitalization, graft rejection and loss, and mortality. 39,47,48,54,55,64
- A small literature on epidemiologically rare psychiatric disorders (psychosis, bipolar disorder), including some reports on
  cardiothoracic transplant recipients, finds that these disorders do not commonly have any impact on risk for graft rejection, other
  morbidities, or mortality.<sup>65–69</sup>
  - Such findings may be due to careful screening of such patients for transplantation, and close management thereafter.
  - However, if management cannot be optimized, transplant outcomes can be adversely affected: risks for graft loss and mortality were increased in kidney recipients who required hospitalization for psychosis.<sup>70</sup>
- A small literature suggests that personality disorders do not directly increase risk for post-transplant mortality, 71,72 but may have indirect effects.
  - Personality disorders can increase the likelihood of maladaptive coping patterns and non-adherence, including return to substance use, in organ recipients.
  - Transplant recipients with personality disorders can have poor interpersonal relationships, thus decreasing the likelihood that they will have stable social support.<sup>76</sup>
- Family mental health history is rarely studied in transplant populations but is an established risk factor for many psychiatric disorders. The family history can predict disorder course and what treatment is likely to be most effective. Mental health problems and distress among family members may impair their ability to provide care and social support to the patient.

#### 3. Substance use history

- Tobacco use and alcohol/drug abuse before cardiothoracic transplantation or MCS implantation increases the risk for use of these substances after transplantation/implantation. 64,80-86
- Smoking tobacco increases the risks for post-transplant/post-implantation morbidities and mortality, including:
  - Cardiac allograft disease, cancers, hypertension, and acute kidney injury in heart recipients. 87-93
  - Cancers and kidney disease in lung recipients. 85,89,94-98
  - Pump thrombosis and gastrointestinal bleeding in MCS recipients. 50,97
  - Mortality in transplant and MCS recipients. 90,98-102
- Alcohol abuse and drug abuse increase the risks for post-transplant/post-implantation morbidities and mortality, including:
  - Drive-line infections and hospital readmissions in MCS recipients.<sup>64,81</sup>
  - Mortality in transplant and MCS recipients. 45,83
- Heavy inhaled cannabis use in organ transplant recipients has been linked to increased post-transplant infection risks in case reports; 103,104 inhaled/vaporized marijuana may be the source of fungal lung infections. 105 Cannabis may alter the metabolism of immunosuppressive medications but insufficient in vivo data exist to confirm this effect. 106 Cohort studies in kidney recipients and liver recipients have not demonstrated associations between marijuana use pre- or post-transplant and survival rates or (in kidney recipients) indices of graft function. 103,107,108
- Some studies did not find substance use/abuse to be associated with clinical outcomes after transplantation/ implantation. 38,109-113 This may reflect programs' selection criteria and requirements regarding abstinence from use. 33,38,110 Continued on page 810

#### Table 3 (Continued)

- Abstinence affects risks:
  - The shorter the period of abstinence from tobacco use before heart, lung or other types of transplantation, the higher the risk of relapse post-transplant.<sup>84–86,114,115</sup>
  - While duration of abstinence from alcohol/drug use has received little empirical attention in cardiothoracic transplantation or MCS, it is a strong predictor of relapse to use in other types of solid-organ transplantation.
- Alcohol and drug abuse run in families, <sup>116</sup> and increase the risk for relapse to substance use in transplant populations. <sup>82</sup>
- B. Factors related to patients' knowledge, understanding, and capacity to engage in decision-making
- 4. Cognitive status and capacity to give informed consent
  - At least some cognitive impairment is common in patients being evaluated for cardiothoracic transplant and/or MCS. 117-130 However, absent moderate or severe dementia, other conditions including milder cognitive impairment and transient conditions (e.q., delirium/encephalopathy) that resolve do not necessarily preclude capacity to give informed consent. 131
  - A small literature suggests that patients with intellectual disabilities can achieve medical outcomes after solid-organ transplantation similar to other patients, provided they have the social support necessary for medical adherence. 52,132
  - Aside from its role in capacity to give consent, cognitive status can affect cardiothoracic transplant and MCS patient outcomes.
    - Cognitive functioning can improve with transplantation/implantation<sup>117,121,122,133-136</sup> and show continued gains over time. <sup>125,137,138</sup> However, some impairments may remain and/or worsen in the long term. <sup>118,122,133,139,140</sup>
    - Greater cognitive impairment increases mortality risk both before and after cardiothoracic transplantation. 134,141
    - Cognitive impairment increases risk for medication non-adherence in community samples;<sup>142</sup> and in patients undergoing
      evaluation for cardiothoracic transplantation, it is associated with impairments in activities of daily living, including
      medication management and treatment regimen adherence. <sup>143–146</sup>
    - In MCS patients, poorer cognitive function has been associated with reduced confidence in ability to manage the regimen and poorer QOL, but not with poorer medical adherence.<sup>51</sup> The latter result may have been due to related findings that more cognitively impaired patients relied more heavily on others for their care.<sup>51</sup>
- 5. Knowledge and understanding of current illness
  - Level of knowledge in patients with advanced heart or lung disease (some of whom are considering transplantation) has frequently been found to be deficient. 147-150 Patients often report uncertainty about disease course and prognosis. 150-152
  - Inadequate knowledge and understanding is associated with poorer self-care and medical adherence. 153-157
  - Higher levels of knowledge in advanced heart or lung disease patients, including MCS candidates, can lead to improved self-care and thereby to fewer hospital readmissions, reduced mortality, and better psychosocial and QOL outcomes. 30,158-163
- 6. Knowledge and understanding of current treatment options
  - Patients report gaps in understanding the range of treatment options and associated risks and benefits, <sup>164–166</sup> as well as required self-care responsibilities after cardiothoracic transplantation/MCS implantation. <sup>164,165,167–170</sup>
  - Understanding and decision-making about transplantation and/or MCS implantation can be driven more by attitudes and emotional factors (fears, expectations, and hopes) than by a systematic weighing of risks and benefits. 167,171-173
  - Patients may feel substantial decisional conflict (i.e., uncertainty about how to choose or what choice to make<sup>174</sup>) when faced with transplantation, MCS, or other medical options. 166,170,175
  - Similar to other patient populations choosing among treatment options, <sup>176</sup> when patients considering cardiothoracic transplantation and/or MCS understand their treatment options and have their decisional conflict reduced (e.g., through use of decision aids<sup>173,177,178</sup>), they feel more prepared to make treatment choices, and more involved and satisfied with the decision-making process. <sup>177,179</sup>
  - Although not examined in cardiothoracic transplant or MCS patients, studies in heart and lung disease populations show that greater understanding and lower decisional conflict can lead to improved medication adherence and health outcomes. 180,181
- C. Factors specific to patients' personal, social, and environmental resources and circumstances
- 7. Coping with illness
  - Patients' coping strategies are associated with outcomes before and after cardiothoracic transplantation.
    - Positive expectations, an optimistic outlook before transplant, feelings of self-efficacy, and a sense of control predict better subsequent mood, medical adherence, health status, and QOL in transplant recipients.
    - Use of passive or avoidant coping strategies to manage health problems, having a low sense of mastery or personal control, and focusing on and expressing negative emotions are associated with increased risk for mental health problems and impaired QOL after transplantation. 188–195
    - Denial, avoidant coping, and emotion-venting strategies are linked to higher fatigue, pain, anxiety, depression, difficulties in daily activities, and impaired QOL during the wait for transplant.<sup>196–200</sup>
  - Engaging in denial, failure to use available resources (medical, financial, family supports) to manage one's illness before transplantation, and feelings of little personal control over one's health increase post-transplant mortality risks. 185,201,202
  - Patients themselves describe optimism as an important resource for coping and recovery.<sup>20</sup>

#### Table 3 (Continued)

- In the smaller evidence base for MCS patients, coping after implantation is associated with other psychosocial outcomes.
  - A greater sense of self-efficacy—that is, feeling more capable of engaging in MCS self-care management—is linked to better adherence and better QOL during MCS support. <sup>51</sup>
  - Patients who have difficulties psychologically accepting the need for MCS or engaging in problem-solving in daily life, and patients who use denial and avoidant coping are more likely to have self-care difficulties and poorer QOL after MCS implantation.<sup>204</sup>

#### 8. Social support

- No matter whether social support is defined in terms of social network size and availability, or by quality of practical and emotional support provided, large literatures in cardiothoracic and other solid-organ transplant recipients show that patients with poorer support are at increased risk for post-transplant medication non-adherence<sup>83</sup> and relapse to substance use.<sup>82,84</sup>
- Organ recipients themselves describe social support to be critical for their adherence and well-being. 203,205
- In cardiothoracic transplantation:
  - Stronger support is associated with better outcomes during the waiting period before heart transplantation, including longer survival time, lower likelihood of requiring MCS, and greater likelihood of stable or improving clinical status.<sup>206–208</sup>
  - Stronger social support before or shortly after heart or lung transplantation—particularly from the primary family support person—is associated with: better adherence to and perceived ability to manage the medical regimen<sup>38,183,209,210</sup>; lower risk of substance use relapse<sup>211</sup>; lower risk of graft failure<sup>38,212</sup>; longer survival time<sup>71,212,213</sup>; lower risk of mental health problems<sup>47,189,214,215</sup>; and increased satisfaction and QOL. <sup>182,184,188</sup>
- Mortality risk after MCS implantation is lower among patients with stronger social support before MCS.<sup>216</sup> MCS recipients whose primary family support person exited the caregiver role have a higher 30-day hospital readmission rate.<sup>217</sup>
- Social support can mitigate the impact of other risk factors for poor outcomes, including cognitive impairments and intellectual disability, <sup>132</sup> and mental health problems. <sup>206</sup> For example, depression symptoms have been found to increase both mortality risk on the waitlist and delisting due to clinical deterioration in heart transplant candidates with low social support. In contrast, depressive symptoms did not affect these risks in patients with higher support. <sup>206</sup>

#### 9. Social history

- Lower educational attainment, and poor literacy and health literacy (i.e., the capacity to obtain, process, and understand health information<sup>218</sup>):
  - Affect patients' degree of understanding of their current illness and treatment options. 219-221
  - May, but do not always, predict poorer outcomes after cardiothoracic and other types of organ transplantation, as well as MCS implantation. Such outcomes include reduced QOL, general health behaviors and medical adherence, <sup>222–227</sup> and increased morbidity and mortality risks. <sup>44,48,113,228–231</sup>
  - May show variable impact on outcomes due to differences between programs in the nature and degree of education and other care services provided to patients.<sup>113,229</sup>
- Lower SES and reliance on public (rather than private) health insurance:
  - Predict poorer outcomes after cardiothoracic transplantation in the United States, including medical non-adherence, hospital readmissions, morbidity, and mortality.
  - Show inconsistent effects on outcomes during MCS.<sup>230,232,237</sup>
- After transplantation, the impact of SES—particularly insurance status—on outcomes has been attributed in part to limitations in
  the organization and financing of health-care services in the United States, where health-care costs may not be reimbursed to
  patients and may be beyond their means.<sup>183,228</sup>
- However, even under the universal health care coverage in many other countries, patients with lower SES and fewer financial resources may be at risk for poorer outcomes.<sup>234</sup>
- Lifetime exposure to traumatic events, including adverse childhood experiences:
  - Is a known risk factor in the general population for physical morbidity and mortality, due in part to impact on risk for mental and substance use disorders.
  - Increases mortality risk in lung recipients.<sup>243</sup>

#### D. Factors specific to patients under consideration for MCS

- 10. Knowledge about and capacity to operate MCS device
  - Patients face complex care requirements for managing the device and their general medical regimen after implantation, and it is
    essential to have family members or other support persons available and willing to assist in this process.<sup>244–247</sup>
  - A small empirical literature indicates that:
    - MCS patients who perceive themselves to have more cognitive limitations and are less adherent to requirements for operation and monitoring of their device at home are at risk for poorer QOL.<sup>51</sup>
    - Assistance from family caregivers may help to mitigate patient limitations in capacity to operate the MCS device or adhere to related care requirements.<sup>216,217</sup>

#### 5. Knowledge and understanding of current illness

Background and recommendation. A determination of patients' level of knowledge regarding their illness helps to delineate educational needs, guide the informed consent process, and facilitate shared decision-making. 16,151,252,253 It can also lead to recommendations for supportive resources (e.g., greater involvement of family members with patient care) needed to promote optimal patient outcomes before and after transplantation/implantation. 16,17,254 Thus, the psychosocial evaluation should review patients' knowledge and understanding of their illness and why they were referred for evaluation.

Evidence. 30,147–163 In patients with advanced heart or lung disease, knowledge deficiencies about their condition are common and are associated with poorer self-care and medical adherence. Conversely, enhanced knowledge can lead to improved self-care and better health.

## 6. Knowledge and understanding of current treatment options

Background and recommendation. Shared decision-making between patients and transplantation/MCS teams depends on patients' understanding, values, and preferences regarding treatment options. 151,175,250,255 The psychosocial evaluation should assess patients' knowledge about risks and benefits of transplantation and/or MCS implantation; alternative treatments; and post-surgical medical regimen, self-care, and lifestyle requirements. Patients' attitudes about treatment options (e.g., receptiveness to transplantation/ MCS, expectations, fears) should be assessed.

Evidence. 164–181 When faced with possible cardiothoracic transplantation and/or MCS implantation, patients' knowledge of their options and responsibilities for self-care is often incomplete. Even with complete knowledge and understanding, attitudes and emotional factors can cloud decision-making about treatment options, and feelings of decisional con ict (i.e., uncertainty about how to choose between options) are common. Lower decisional con ict can lead patients to feel more prepared to make decisions and more satisfied with decisions.

## C. Assessment of patients' personal, social, and environmental resources and circumstances

#### 7. Coping with illness

Background and recommendation. The possession of limited skills for coping with health issues and stressors is a recognized contraindication to MCS, given the complex care regimen and related lifestyle changes after device implantation.<sup>3</sup> Coping skills are not discussed in ISHLT guidelines and consensus statements for cardiothoracic transplant candidates.<sup>1,2</sup> However, their regimens are also complex, and adaptation to post-transplant life can be

demanding, thus necessitating a determination that patients possess adequate coping skills. 12,22,256

Evidence. 40,51,182-204 Patients' approach to coping with their illness and prognosis is linked to psychological and behavioral outcomes before and after cardiothoracic transplantation or MCS implantation. Coping characterized by optimism, active problem-solving, and having a strong sense of self-efficacy is associated with better psychological, behavioral, and clinical outcomes. Use of denial and avoidant coping can lead to poorer outcomes.

#### 8. Social support

Background and recommendation. Lack of sufficient social support is a contraindication to cardiothoracic transplantation and MCS implantation. The requirement that social supports be in place stems from the need to ensure that patients can adhere to the medical regimen after these procedures. The psychosocial evaluation should ascertain the availability, stability, and capacity of patients' support resources. The evaluation should also consider support persons' understanding of patients' treatment options and care requirements after transplantation/implantation.

Evidence. 38,47,71,82–84,132,182–184,188,189,203,205–217 Better social support predicts better behavioral, psychological, and clinical outcomes in cardiothoracic and other solidorgan transplant recipients; such effects are observed no matter whether support is defined by social network characteristics or by support quality. A small literature shows similar findings for MCS recipients. Social support can mitigate the impact of other risk factors (e.g., mental health problems, cognitive or intellectual disability), and thus play an important protective role.

#### 9. Social history

Background and recommendation. Obtaining a social history re ects the importance of understanding the personal and cultural context of patients' lives. 22,26 Assessment of education, literacy, and health literacy is relevant for optimizing teaching strategies, 126,219,222 and assessment of patients' key relationships can identify potential support resources. Occupational status and work history are relevant vocational rehabilitation.<sup>35</sup> Patients' post-surgical socioeconomic circumstances, including financial resources and health insurance coverage, require review, particularly to identify patients likely to need financial supports for long-term care.<sup>35</sup> The evaluation should assess past and current legal issues. Although candidacy decisions should not be based on social worth or characteristics such as conviction history, 257,258 legal history is pertinent for determining personal constraints or financial responsibilities due to parole requirements, pending charges, and possible imprisonment. 11,30 Assessment of exposures to traumatic events is important for determining patients' adaptations to major stressors, and whether current stressors are affecting—and perhaps amplifying—any distress they have regarding their health. 9,11,17,19

Evidence. <sup>39,44,48,113,183,218–243</sup> Aside from expert experience, empirical evidence exists for 3 broad areas. First,

lower educational attainment, poor literacy, and poor health literacy can affect patients' understanding of their current illness and treatment options, and can predict poorer outcomes after transplantation/implantation. Second, lower socioeconomic status and related financial constraints have been associated with poorer behavioral and clinical outcomes after cardiothoracic transplantation. Third, lifetime exposure to traumatic events increases morbidity and mortality risks in the general population; evidence in lung recipients suggests similar effects.

## D. Assessment specific to patients under consideration for MCS

## 10. Knowledge about and capacity to operate MCS device

Background and recommendation. Per ISHLT guidelines, MCS is contraindicated if patients have physical or cognitive limitations rendering them unable to operate the device, or if they live in unsafe environments. MCS teams' education and clinical monitoring MCS patients, 24,246,247,259 as required under ISHLT guidelines, 3 aim to minimize risks of adverse events resulting from patient and caregiver problems in managing the device. Although the full assessment and education of patients and their caregivers regarding device operation, patient capacity to operate it, and home safety extend beyond the psychosocial evaluation, the evaluation provides an opportunity to screen patients to identify permanent or remediable deficiencies in these areas.

Evidence. 51,216,217,244–247 Despite sparse empirical research, it is well-known that MCS patients have complex self-care requirements. A small evidence base indicates that social support and assistance are essential for promoting optimal device management and related care, especially if patients have limitations in their capacity to operate the device.

## Recommendations for psychosocial evaluation process

The broad rationale for recommendations for process and procedural issues associated with the psychosocial evaluation stems from the need to delineate a consistent approach to:

- (a) Identifying who should conduct the evaluation.
- (b) Conducting the evaluation and determining when additional testing or consultation is indicated.
- (c) Reporting evaluation findings to the transplantation or MCS teams.
- (d) Monitoring the receipt and impact of treatments or interventions to remove or mitigate contraindications to transplantation/implantation or other problems identified in the evaluation.

Table 4 lists the recommendations. As reviewed in what follows, they are based largely on the expert opinion and experience of the Writing Committee, as well as published expert reviews and commentaries. Little to no empirical work

exists on processes and procedures associated with the psychosocial evaluation. Such work is noted where available.

#### 1. Qualifications and experience of the evaluator

Patients undergoing psychosocial evaluation are medically complex and the evaluation can be psychologically stressful. 7,12,19,22 Evaluation findings and recommendations are relevant to programs' decisions about patient selection for transplantation and/or MCS. The evaluator must therefore have competence—by virtue of qualifications, knowledge, and experience—to sensitively and accurately assess and report on the multiple domains encompassed by the evaluation. There is no one discipline or training path that is necessarily best for the individual serving in this role. The evaluator should have training in a health-care discipline directly relevant to the evaluation's content. The evaluator should be registered or licensed as required by local regulations, and receive an orientation to the evaluator becoming responsible for conducting role before evaluations. 260–262 Ongoing educational opportunities should be encouraged so that the evaluator can continue to build skills and meet professional and local credentialing requirements.<sup>260-264</sup>

#### 2. Performance of the psychosocial evaluation

Expert reviews and commentaries support a set of central tenets for the process of performing the evaluation. 7.9–11,17,19–22,24–26,265 The evaluator must inform patients about the evaluation's purpose and that it is only one component of the assessment for cardiothoracic and/or MCS candidacy. Patients must be given the opportunity to participate fully, without language barriers. The psychosocial evaluation should encompass multiple meetings if patients' medical status precludes its completion in a single interview and/or because additional questioning or testing is necessary. Consistent with general ISHLT guidelines and consensus statements for candidate selection, 1,2 patients should be re-evaluated at regular intervals while awaiting transplantation/implantation in order to update psychosocial information.

Direct patient interview is the centerpiece of the psychosocial evaluation. However, the evaluator should also consider collecting collateral information from medical records, health-care providers, family members, and other sources, to corroborate or supplement patient reports. Although in most situations collateral information is highly desirable, the evaluator should weigh the potential reliability and utility of such information before seeking it. For example, some patients, particularly if socioeconomically disadvantaged, may have had few health-care contacts and no long-standing relationships with health-care providers. Thus, intensive attempts to obtain records may provide little yield.

When the psychosocial evaluation can be only partially completed through patient interview (due, e.g., to patients' medical status), priority areas for assessment are those most

**Table 4** Consensus Recommendations on Processes and Procedures Related to Psychosocial Evaluation of Adult Cardiothoracic Transplant Candidates and Long-term MCS Candidates

#### Process factor

#### Specific recommendations

- 1. Qualifications and experience of the evaluator
- The evaluator should have training in a health-care discipline relevant to the content of the psychosocial evaluation.
- The evaluator should be registered or licensed in their discipline, according to local regulations; additional specialized credentialing is encouraged when available.
- For individuals new to the evaluator role, orientation to the transplant and/or MCS program, including familiarization with local policies and procedures and ISHLT guidelines, should occur before evaluations are conducted independently.
- Ongoing evaluator education and training should be encouraged by the transplant or MCS program and should be in accordance with any local credentialing requirements.
- 2. Performance of the psychosocial evaluation
- The patient should be informed about the evaluation's purpose and goals
  and that its results will be considered in the context of other information
  collected by the transplant or MCS team.
- The evaluation interview should be conducted in a language in which the
  patient can engage in interactive conversation. Interpreter services (via a
  source with no personal connection to the patient) should be utilized for
  patients with language comprehension barriers.
- The evaluation interview should be expanded beyond a one-time meeting with the patient if complex issues are uncovered that require additional questioning or assessments by other specialists.
- After the initial evaluation, patients who are waitlisted for transplantation or do not immediately undergo MCS implantation should be re-evaluated at regular intervals to update their psychosocial status.
- The patient should be directly interviewed when possible in order to complete the psychosocial evaluation. In these circumstances, the evaluator should also consider whether collateral information is needed from medical records, other care providers, family members, or other parties.
- When the patient can be directly interviewed but it is unlikely that a full
  psychosocial interview can be completed (e.g., due to the patient's medical
  status), priority should be given to key elements, including treatment
  adherence, mental health status, current substance use/abuse, cognitive
  status, social support, and (for MCS) capacity to manage the device.
- When the patient cannot complete the full interview or is unable to be interviewed, the evaluator should collect collateral information to address as many elements of the psychosocial evaluation as possible.
- Given that transplant and MCS teams commonly require that the patient
  have a primary support person (i.e., an individual available to provide
  ongoing assistance and support to the patient after hospital discharge), this
  individual should be interviewed to determine his/her understanding of the
  patient's needs and his/her willingness and ability to provide assistance.
- 3. Use of templates or checklists as adjuncts for completing the psychosocial evaluation
- The evaluator should consider routinely using a standard template or checklist that includes each element of the psychosocial evaluation, in order to systematically address, record notes, and prepare a summary of all components of the evaluation.
- 4. Screening for capacity to give informed consent
- If, based on the evaluation or patient history, cognitive impairment is suspected, use of a standardized, validated screening tool should be considered in order to aid in assessing cognitive status and in decisions about whether to refer the patient for more extensive evaluation.
- Because language, health literacy and medical conditions may complicate
  assessment of cognitive status and the capacity to give informed consent,
  the evaluator should consider whether additional steps (use of interpreter,
  additional education at literacy level of patient, treatment for medical

Continued on page 815

Process factor	Specific recommendations
	<ul> <li>conditions) are needed before capacity can be determined.</li> <li>Formal evaluation of the patient's capacity to make medical decisions may be pursued, according to the local standard of practice, if deemed necessary by the evaluator.</li> </ul>
5. Communication with the transplantation or MCS team about psychosocial evaluation findings	<ul> <li>A written evaluation report should be placed within the patient's medical record.</li> <li>The report should contain a concise summary of findings and recommendations for additional testing and/or interventions, with a more detailed narrative appended as needed.</li> <li>The report should be prepared with specific reference to the type of procedure for which the patient is being considered (transplantation or long-term MCS).</li> <li>When psychosocial risk factors are identified, the report should state whether the risk factors can be ameliorated and, if so:  — Make recommendations for treatment or intervention (both of which could include referrals for specific services), and</li> <li>— Make recommendations regarding the timing of such treatments or interventions (i.e., whether they should occur before transplant or MCS, or whether it is acceptable for them to be carried out after transplant or MCS if the patient's medical status is precarious).</li> <li>Recommendations stated in the report regarding treatments or interventions should be based on best available evidence and should take into account what is feasible.</li> <li>The report should be an integral part of multidisciplinary meetings when transplant listing decisions or MCS decisions are discussed. The evaluato or his/her delegate should be present at these meetings in order to communicate evaluation results and recommendations.</li> </ul>
6. Coordination of recommended psychosocial treatments or interventions, and assessment of progress	<ul> <li>The evaluator should coordinate all intervention activities, or designate another team member to coordinate recommended interventions.</li> <li>The evaluator should identify who will monitor intervention progress and who (if not the evaluator) will communicate progress to the team.</li> <li>The evaluator should specify before an intervention is initiated how progress/success will be defined; standardized measures that specify progress/success criteria may be considered when available.</li> <li>The evaluator should provide specific criteria (e.g., a time line or clinical benchmarks) indicating when any psychosocial re-evaluation should be performed to determine whether interventions have been effective.</li> </ul>

pertinent to candidate selection based on ISHLT guidelines and consensus statements<sup>1–3</sup> (e.g., adherence history, mental health, and substance use/abuse). Collateral information should be obtained when patients cannot be interviewed fully. In medically urgent circumstances when no patient interview is possible, the evaluator should rigorously search for collateral information on as many content domains of the psychosocial evaluation as possible.

MCS, mechanical circulatory support.

Given ISHLT guidelines and consensus statements, <sup>1-3</sup> transplantation and MCS teams commonly require patients to have a designated primary support person (i.e., a family member or friend taking on "caregiver" responsibilities). This individual should be interviewed to determine understanding, willingness, and ability to assist with the patient's care needs and medical regimen before and after transplantation/implantation.

## 3. Use of templates or checklists as adjuncts for completing the psychosocial evaluation

Tools such as standard templates or checklists can be useful for guiding the evaluation and summarizing results. 9,12,17,19,21,22,28 These tools are not completed by patients; they are instruments that evaluators should consider for their own use to ensure that all evaluation content domains are assessed and accurately summarized.

The evaluator may create a template or checklist, or may use or adapt one of the published tools for transplant candidates<sup>29,31,32</sup> or MCS candidates.<sup>30</sup> There is insufficient evidence for the superiority of any given tool over the others.<sup>11,12,28</sup> Furthermore, the Writing Committee does not endorse the use of any of these tools to generate a numerical "score" or "rating" of a patient's psychosocial suitability for

transplantation/implantation, given very limited information on such metrics' validity. However, they can be useful when used as heuristic tools to aid in evaluation completion and reporting. 9,11,12,17,19,22,28

#### 4. Screening for capacity to give informed consent

Because informed decision-making and consent are vital for cardiothoracic transplantation and MCS, <sup>1–3</sup> consideration of patients' capacity to give consent is relevant for not only the content but the process of the psychosocial evaluation. <sup>21,22,250,251</sup> Although the evaluation need not include a full neurocognitive assessment, the evaluator should consider augmenting his/her questioning on patients' history or perceptions of cognitive limitations by administering a valid, reliable screening tool. <sup>17,21,131,251</sup> Among valid tools, selection may be guided by evaluator training and experience.

Factors such as language barriers, low health literacy and the patient's medical condition may hinder determinations of capacity to give consent. 7,11,19,21,126,255,265 The evaluator should consider modifications to the psychosocial evaluation process to remove or limit these factors' impact. 131 For example, the evaluator may require that patients receive decision aids (which typically address literacy and health literacy barriers 173,177–179) and/or other educational strategies before the psychosocial evaluation is conducted. Beyond requiring education or cognitive testing, the evaluator should have the option to refer patients for formal evaluation of capacity if there are any doubts about patients' ability to understand their health situation, engage in informed decision-making, and provide voluntary, informed consent. 131

## 5. Communication with transplant or MCS team about psychosocial evaluation findings

The written report summarizing evaluation findings, as entered into the patient's medical record, provides the starting point for effective communication regarding findings. 9,20,264 It is important that the evaluator or his/her delegate attend candidate selection meetings in order to discuss report conclusions.

The report provides a key opportunity to recommend treatments and interventions to ameliorate any identified psychosocial contraindications to transplantation and/or MCS. For example, many evidence-based interventions are available for mental health and substance use/abuse problems: pharmacologic and psychotherapeutic strategies can be used safely and effectively to treat mental health issues before and after transplantation and during MCS. 4,6,10–12,15,27,34,60,256,266,267 Addiction treatment plans can lower substance use relapse risk before and after transplantation, 4,11,12,21,22 and help patients to achieve programs' abstinence requirements. Although not yet tested in transplantation or MCS candidates, behavioral interventions can improve medical adherence in cardiothoracic 268,269 and other organ transplant recipients. 270,271 If

patients' medical status precludes immediate intervention participation, treatment recommendations should note whether it is acceptable to begin treatment after transplantation/implantation.

# 6. Coordination of recommended psychosocial treatments or interventions, and assessment of progress

Implementation, progress, and outcomes of recommended treatments or interventions should be monitored to allow timely updates to the transplantation or MCS team. 12,21,265 This is particularly important for treatments implemented to ameliorate psychosocial contraindications to transplantation/implantation. Whether the psychosocial evaluator or another transplant/MCS team member will monitor treatment progress and completion, and who will communicate this information to the team, should be delineated at the time of referral. Taking these steps will help to avoid problems related to diffusion of responsibility and will foster identification of the most appropriate team member to monitor progress. Regardless of who monitors treatment progress, the psychosocial evaluator, by virtue of his/her expertise and judgment that a referral was needed, should specify what constitutes treatment success, and whether those criteria were met. For example, success may be defined by remission of psychiatric disorder, or by months of abstinence from substance use. Criteria for success may need to consider the patient's medical urgency, 10,15,21 with deferral of treatment completion requirements until after transplantation/implantation. Re-evaluation of the patient's psychosocial status may be required after treatments are initiated; the evaluator should indicate what factors will determine when re-evaluation is warranted.

#### **Conclusions**

This document provides the first set of consensus-based recommendations on the content and process of the psychosocial evaluation of candidates for heart transplantation, lung transplantation, and long-term MCS implantation. The recommendations dovetail with ISHLT guidelines and consensus statements for candidate selection. The recommendations are intended to promote consistency across programs in conducting the psychosocial evaluation. Because the recommendations are for international use, they must be considered in the context of local requirements, and transplantation and MCS programs may require additional elements of content and process as part of standard operating procedures. The recommendations delineated herein form a core set of elements that should be employed but can be expanded as necessary to meet programs' needs and goals.

#### Disclosure statement

Thomas Schlöglhofer is a consultant for Medtronic/HeartWare, Inc., and Abbott, Inc. Jeffrey J. Teuteberg is on the advisory boards and has been a speaker for Medtronic/HeartWare, CareDx, and

Abiomed. He is on the HeartMate 3 Clinical Events Committee for Abbott/Thoratec. Roger D. Yusen is a consultant for Janssen Pharmaceuticals, Inc., Portola Pharmaceuticals Inc., and Spiration/Olympus. He is a legal consultant for Ortho Pharmaceuticals, Inc., Organon, Inc., and Merck. The remaining authors have no financial interests or potential con icts of interest to disclose.

#### **Appendix**

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