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Psychosocial factors and quality-of-life after heart transplantation and mechanical circulatory support

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Abstract

Purpose of review—Psychosocial outcomes and quality-of-life (QOL) are important indicators of the success of heart transplantation and mechanical circulatory support (MCS). They warrant further research attention given the increasing frequency of these interventions and the diverse uses of MCS as destination therapy and bridge to transplant.

Recent findings—The literature has continued to identify correlates and predictors of psychosocial outcomes in five domains: physical functioning, psychological, behavioral, social functioning and global QOL. These issues in MCS patients, in particular, are receiving increased attention. Recent work also highlights the potential for psychosocial outcomes to predict transplant-related and MCS-related clinical outcomes, and also emphasizes issues involved in heart transplantation for older adults, heart transplantation for intellectually disabled individuals, and managing end-of-life planning in patients with MCS.

Summary—This field continues to be dominated by descriptive studies. Although recent work has provided a more complete picture of correlates of psychosocial outcomes, there is a need for intervention research to examine strategies to optimize these outcomes in both heart transplant and MCS populations. Clinicians should continue to monitor and address psychosocial issues with their patients in order to achieve posttransplant and postimplantation success that prolongs both quantity and QOL.

Keywords

heart transplantation; mechanical circulatory support; psychosocial outcomes; quality-of-life

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Conflicts of interest

There are no conflicts of interest.

INTRODUCTION

The success of heart transplantation and mechanical circulatory support (MCS) as interventions for end-stage heart failure depends not only on prolonging life but also on optimizing psychosocial outcomes and quality-of-life (QOL). Empirical evidence regarding these outcomes is important to consider for treatment decision-making, patient education and development of targeted interventions. There is also some evidence that these outcomes themselves may predict subsequent morbidity and mortality [1].

In 2006, the Psychosocial Outcomes Workgroup of the Nursing and Social Sciences Council of the International Society for Heart and Lung Transplantation evaluated the literature in this area and identified five major domains of psychosocial outcomes in cardiothoracic transplant patients: physical functional, psychological, behavioral, social and global QOL. Several informative reviews have since been published that update the status of literature in these domains and address psychosocial outcomes in MCS patients [2–4]. However, the major conclusions of the 2006 white paper remain valid in 2012: there is a need for prospective studies to identify predictors of psychosocial and QOL outcomes, and intervention studies that aim to improve these outcomes. This review addresses progress toward achieving these goals in each domain within the past year. In addition, this review considers current findings regarding the impact of psychosocial outcomes on clinical outcomes, which the white paper and other reviews note is an area of needed study. We also discuss several additional timely issues for the heart recipient and MCS populations, including transplantation for older adults and intellectually disabled individuals, and incorporating palliative care into treatment of patients receiving MCS as destination therapy.

PHYSICAL FUNCTIONING DOMAIN

It is well established that physical functioning improves with heart transplantation or MCS. Yet, the literature continues to be dominated by descriptive studies, with few attempts to test interventions to optimize physical functioning outcomes.

Bogaev *et al.* [5] conducted a prospective study that considered a factor relatively neglected among MCS patients to date, namely whether physical functioning gains due to MCS differ by sex. This is an important issue since, prior to continuous flow devices, women's small body surface area made MCS technology less accessible to them. Results showed that, although men walked farther on the 6-min walk test 6 months after receiving MCS, both men's and women's functional status and QOL showed similar levels of pre-to postimplantation improvement. These findings demonstrate that MCS is indeed a suitable prospect for both men and women.

A small ($n = 14$) randomized controlled trial provided promising results regarding the potential of exercise training interventions in MCS populations [6^a]. Hayes *et al.* [6^a] examined physical capacity and QOL in MCS bridge-to-transplant patients who either underwent an 8-week cardiovascular and strengthening exercise training program in conjunction with a home walking program, or completed the walking program only. Both groups experienced significant improvements in exercise capacity and QOL by the end of the study, with the exercise training group showing trends toward relatively greater improvements.

PSYCHOLOGICAL DOMAIN

Heart recipients and MCS patients continue to experience relatively high levels of psychological distress even after recovery from their respective surgical procedures. We recently reported that major depression was the most prevalent mood or anxiety disorder

developing in heart recipients prospectively followed during the first 2 years after transplantation, with prevalence of 26% [7[■]]. Although a pretransplant history of disorder increased depression risk, nearly 20% of those with major depression had their first lifetime episode posttransplant. Risk was further increased by poor family caregiver support and coping strategies focused on support seeking and expressing emotions. Posttraumatic stress disorder related to the transplant, although less common, was observed in nearly 15% of the sample. Despite the prevalence of these disorders, less than 45% of those affected sought care. Given these findings, early screening and intervention may be important for reducing the burden of mental illness in this population.

A systematic review of MCS literature found that, although patients experience improvements in anxiety and depression following MCS implantation, they continue to experience higher levels of distress in these domains than do heart recipients [3]. Prospective studies have reported that preexisting fatigue, anxiety, depression and sleep disturbances may not dissipate after MCS implantation [8,9]. Patients receiving transplants after being bridged with MCS required more psychotherapeutic intervention for their continued psychological distress than those who received heart transplants without prior MCS, those who received MCS as destination therapy and those who received MCS but were still waiting for transplant [10].

Cognitive impairment is particularly important to monitor, as advanced heart failure can affect brain function through cerebral hypoperfusion and sympathetic nervous system elevation. Gaviria *et al.* [11] suggest incorporating the Montreal Cognitive Assessment into the clinical assessment of heart failure patients, as cognitive impairment could result in deficits in memory, attention, psychomotor abilities and executive function, possibly compromising patients' self-care and medical decision-making abilities. A review by Vitale *et al.* [12] suggests that cognitive impairment, in particular, delirium, persists in up to one-third of heart failure patients even after they receive MCS.

BEHAVIORAL DOMAIN

Although nonadherence has received little consideration in MCS patients, a large literature has examined reported rates of nonadherence to the many behaviors that comprise the posttransplant medical regimen. Our meta-analysis found that these rates are highly variable, due in part to the method of assessing nonadherence [13]. We therefore recommended using multimodal strategies of nonadherence assessment. De Bleser *et al.* [14[■]] corroborate this recommendation by suggesting the use of a composite of self-report data, clinician assessment and blood assays. In their longitudinal study of heart recipients, they utilized these methods as well as electronic monitoring of pill taking, and observed that not only was there variability based on method of assessment but also across specific parameters of medication-taking. For example, self-reported nonadherence to taking immunosuppressants (i.e., missing a dose in the last 4 weeks) was only 5% at the final assessment, whereas self-reported nonadherence to timing of medication taking (i.e., taking it late or early) was 18%. In addition, nonadherence to taking and timing requirements was considerably higher for nonimmunosuppressants than immunosuppressants. These rates remained stable over a 3-month period. Overall, these findings suggest that clinicians must ask their patients about multiple parameters of medication taking and timing, as well as variability across types of prescribed medications, in order to fully understand the difficulties that patients may have with their medication regimen.

SOCIAL DOMAIN

Patients' social functioning has been shown to improve as heart transplantation or MCS reduces the physical limitations associated with heart failure. The ability to return to work

has long been considered a marker of success after transplant, although it has less frequently been tracked through the extended years of posttransplant survival. White-Williams *et al.* examined correlates and predictors of return to work at 5 and 10 years posttransplant [15]. At both time points, recipients who were working were more likely than nonworking recipients to be younger and to report less depression and less disability in overall functioning. Whereas physical functioning and number of coexisting illnesses were associated with working at 5 years posttransplant, they were not linked to working status at 10 years posttransplant.

Among MCS recipients, a small qualitative study found that, in contrast to the findings among heart recipients noted above, those who were quickest to return to work following MCS implantation were older. Their ability to do so appeared to be linked to having a secure job before receiving MCS [16].

Another important concern within the domain of social functioning pertains to the impact of treatment for advanced heart failure on intimacy in both physical and social relationships. A qualitative study reported that patients who had lived with MCS for at least 3 months experienced improvements in sexual functioning in tandem with improvements in overall perceived health [17[■]]. This situation led to increased physical and emotional intimacy with their partners, both of which the authors suggest are critical to optimizing QOL and reestablishing normalcy in social relationships.

GLOBAL QUALITY-OF-LIFE DOMAIN

Although both heart transplantation and MCS typically bring about global QOL improvements, the strategy adopted to assess QOL may affect the findings. Using quantitative self-report data, Abbey *et al.* [18] detected poor QOL in only 22% of heart recipients. However, using qualitative interviews, they noted pervasive distress in 52% and significant transient distress in 88% of the same individuals. These findings suggest that studies using quantitative assessments alone may overestimate QOL and that clinicians, who do not question patients extensively enough to reveal their areas of difficulties may miss opportunities to intervene.

Patients eligible for MCS may experience a drastic reduction in QOL during the preimplantation phase as they decide whether to opt for symptom control or MCS implantation as destination therapy [4]. Typically, MCS recipients experience improvement in QOL by 3 months postimplantation and sustain that improvement through 2 years postimplantation [4,19,20]. Although type of device utilized for MCS does not appear to influence QOL [19], data are mixed about whether patients receiving MCS as destination therapy or as a bridge to transplant experience larger QOL improvements [2,4].

Impact of psychosocial factors on clinical outcomes

A growing literature has begun to document the role of psychosocial factors in affecting risk for poor clinical outcomes in both transplant recipient and MCS populations. Recently, Grandi *et al.* [21] suggested that demoralization, that is, the feeling that one is unable to cope with a stressful situation, in combination with depression may have particularly deleterious effects. In their sample of heart recipients, those who were both depressed and demoralized had more acute rejection episodes by 6 years posttransplant than those who were either depressed or demoralized. Similarly, our recent review found that certain symptoms of depression in heart recipients, such as irritability and sense of worthlessness, increased posttransplant mortality risk over two-fold [22].

Among patients receiving MCS as destination therapy, a recent review concludes that correlates of poor clinical outcomes span multiple psychosocial domains: psychological (history of psychiatric diagnosis), behavioral (poor adherence to the medical regimen, substance abuse), social (lack of caregiver support, low literacy, financial problems, lack of electrical support in home, uncooperative behavior toward hospital staff) [4]. Future work is needed to determine whether these correlates are also predictors of clinical outcomes.

EMERGING ISSUES

Three areas of growing interest deserve attention given their potential impact on psychosocial outcomes and clinical care.

Transplantation and mechanical circulatory support in older adults

Medical and technological advances have allowed older adults to be considered more frequently as candidates for heart transplantation and MCS. Because older individuals are more vulnerable to morbidity and mortality, they are typically viewed as higher risk candidates. However, at least among long-term heart transplant survivors (who may reflect a select and 'hardy' group), psychosocial outcomes appear to be at least as good if not better than in younger patients. Shamaskin *et al.* [23[■]] reported that heart recipients aged 65+, who were at least 5 years posttransplant, experienced higher satisfaction with overall QOL, health functioning and social support; had less difficulty adhering to posttransplant self-care regimens; felt less negative affect, depression and transplant-related stress; and used fewer negative coping strategies than younger recipients.

Vitale *et al.* [12] discussed the specific challenges of MCS implantation as destination therapy in patients aged 70+, which included complex medical management of perioperative and long-term issues, as well as a high postimplantation prevalence of adjustment disorder and major depression. Despite these challenges, older patients who received MCS reported improved heart failure-related QOL outcomes.

Transplantation in intellectually disabled populations

In noncardiac areas of transplantation, there is no clear evidence that outcomes for intellectually disabled patients are poorer than outcomes for other patients [24–26]. A single case series examined five heart recipients spanning a range of intellectual disabilities and found positive outcomes in four of the five cases, with survival averaging 12 years [27]. Although concerns about the ability of intellectually disabled individuals to function independently have generally been considered the main prohibitive factor for transplanting these individuals, only one case involved problems with independent functioning. All patients had a secure caregiver at the time of transplantation, and the one case in which nonadherence led to adverse outcomes was due to functional decline in the recipient's caregiver. The authors suggest that intellectual disability should not be considered an absolute contraindication but must be regarded in the context of the patient's other medical and psychosocial characteristics. Although these issues have not been considered in depth in MCS populations, the evidence to date suggests that these recommendations should hold for MCS candidates as well.

Palliative care for mechanical circulatory support recipients

There is growing recognition that end-of-life planning is essential to address throughout the MCS implantation process given that, by definition, MCS is life sustaining or prolonging but not curative [4,12,28]. Vitale *et al.* stress the need for preemptive involvement of the palliative care team for monitoring and managing symptoms; this would allow individuals to prepare for MCS deactivation and subsequent natural death when their heart failure has

progressed so far that MCS cannot sustain an acceptable QOL or functional status [12]. Issues that arise specifically during the final MCS-specific end-of-life phase involve planning for extracorporeal membrane oxygenation, do not resuscitate and do not intubate orders; removing life support; comfort care; and MCS deactivation processes and preferences. One review noted evidence indicating that less than half of MCS patients have advance directives, most of which do not address plans for MCS deactivation [4]. This represents a gap in clinical care for these patients because their end-of-life circumstances require careful advance planning of both technical and comfort-related issues.

CONCLUSION

Recent work has added incrementally to our understanding of psychosocial outcomes in heart recipients, although we continue to lack high-quality studies examining the full range of risk factors for these outcomes. The literature is smaller for MCS recipients, but descriptive studies have begun to carefully characterize psychosocial outcomes and their correlates in multiple domains. Because there are few prospective studies of MCS patients, work is needed to identify true risk factors for (as opposed to correlates of) psychosocial difficulties. For both heart recipient and MCS populations, some evidence suggests that psychosocial outcomes themselves can increase risk for poor clinical outcomes, but relatively few studies have considered these effects. Additionally, there is a critical need for intervention studies that aim to optimize psychosocial outcomes for heart recipients and MCS patients in all five domains we considered. Given observations from correlational studies, important goals for intervention include improving physical functioning, early identification and reduction of psychological symptoms, and enhancing adherence. Moreover, existing evidence suggests that carefully selected older adults and intellectually disabled patients can have positive outcomes after heart transplantation or MCS implantation. However, more research is needed in order to understand the full range of outcomes and their risk factors in these specific populations.

Collectively, this research underscores the need for clinicians to be attuned to psychosocial factors throughout their patients' posttransplant or post-MCS implantation course. Palliative care warrants inclusion in standard care for both of these populations but especially for those receiving MCS as destination therapy. By addressing both medical and psychosocial issues, clinicians can optimize quality and perhaps also quantity-of-life in these medically ill patients.

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Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 577–579).

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KEY POINTS

- Improvements in physical and social functioning are common after heart transplantation and mechanical circulatory support (MCS) implantation; intervention studies are needed to further optimize these outcomes.
- Heart recipients and patients with MCS are at risk for high levels of psychological distress and cognitive impairment, and adherence to the medical regimen is an important issue for both groups as well.
- Growing evidence indicates that psychosocial factors are correlated with and may predict clinical outcomes in heart and MCS recipients.
- Carefully selected older adults and patients with intellectual disabilities have favorable outcomes following heart transplantation and appear likely to benefit from MCS as well.
- Palliative care warrants inclusion in standard care for MCS recipients in order to plan for technical and comfort-related end-of-life issues.