Report of the Psychosocial Outcomes Workgroup of the Nursing and Social Sciences Council of the International Society for Heart and Lung Transplantation: Present Status of Research on Psychosocial Outcomes in Cardiothoracic Transplantation: Review and Recommendations for the Field

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Cardiothoracic transplantation's success at prolonging life—and its economic costs—must be considered relative to its psychosocial benefits and costs. Moreover, psychosocial outcomes themselves influence long-term post-transplant morbidity and mortality rates. Although psychosocial outcomes—encompassing patients' physical, psychologic and social functioning, their management of their medical regimen and global quality of life—are the focus of many recent studies, these investigations have yet to yield many evidence-based interventions that are routinely applied to improve patient outcomes. Our goals were to summarize existing work on psychosocial outcomes, delineate areas requiring attention, offer recommendations for steps to advance the field, and thereby provide an impetus for the conduct of clinical trials of interventions to improve these outcomes. We concluded that research must generally shift away from descriptive studies and toward prospective and clinical trial designs to: (a) examine a full range of risk factors and clinical sequelae of patients' psychosocial status; and (b) evaluate the effectiveness of psychosocial interventions. In addition, these issues must be considered across all cardiothoracic recipients, including not only heart recipients but the less-studied populations of lung and heart–lung recipients, and must include longer-term (5+ years) outcomes than is typical in most work. The importance of adequately sized samples to ensure statistical power, and the need to construct study samples representative of the larger cardiothoracic transplant population, cannot be overestimated. Implementing these changes in research design and substantive focus will ensure that psychosocial outcomes research will have maximum impact on transplant recipients' clinical care. J Heart Lung Transplant 2006;25:716–25. Copyright © 2006 by the International Society for Heart and Lung Transplantation.

Although a substantial literature exists regarding clinical outcomes after adult cardiothoracic transplantation (CTTx), there are considerably fewer data on post-transplant psychosocial outcomes. Psychosocial outcomes encompass recipients' physical functional and psychologic status, behavioral management of their medical regimen, social functioning and global perceptions of quality of life (QOL). The success of CTTx at prolonging life demands that these outcomes receive careful attention. This is imperative because the outcomes are themselves critical indicators of the utility of CTTx: both its economic costs and its benefits in prolonging life must ultimately be considered relative to the psychosocial costs and benefits of receiving a new organ.[1,2] In addition, psychosocial outcomes predict morbidity and mortality outcomes post-transplant.[3–5] Thus, transplant programs' ability to maximize patient health and survival may depend in part on their capacity to foster optimal psychosocial outcomes.

Therefore, the Nursing and Social Sciences Council (NSSC) of the International Society for Heart and Lung Transplantation (ISHLT) formed a workgroup to critically evaluate the current state of the science regarding

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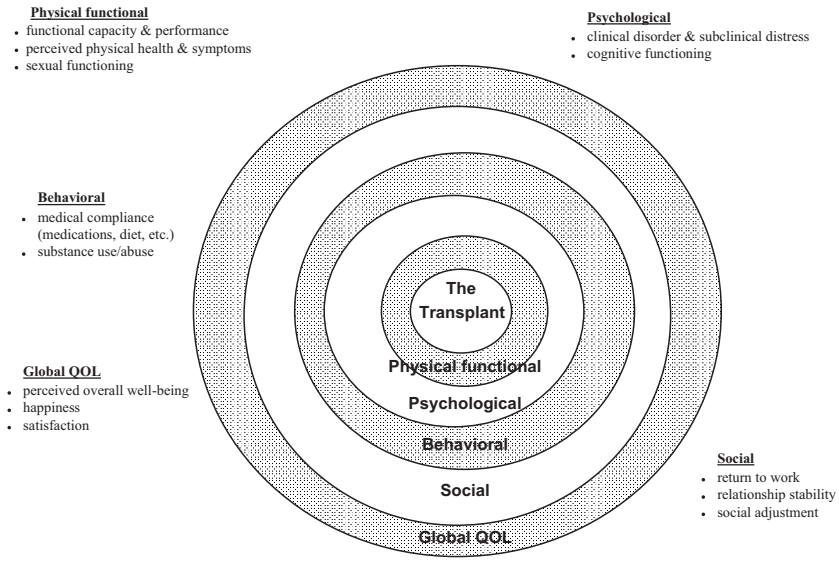

Figure 1. Conceptualization of key post-transplant psychosocial domains and specific outcomes within each. This multidimensional conceptual perspective derives from the larger field of psychosocial and QOL research in the context of chronic illness.[53,98,99] Adapted from Dew MA, Switzer GE, DiMartini AF, et al. Psychosocial assessments and outcomes in organ transplantation. Prog Transplant 2000; 10;239–59. Used with permission.

the nature, predictors and clinical sequelae of psychosocial outcomes in adult CTTx, as well as the status of interventions to improve these outcomes. The international workgroup included members from the fields of nursing, psychology, psychiatry, epidemiology and social work. We were charged with: (1) reviewing the literature on adult CTTx psychosocial outcomes; (2) determining gaps in this literature; and (3) formulating specific recommendations to guide future research to significantly advance the field.

To accomplish these aims, we identified 5 major domains of psychosocial outcomes, as shown in Figure 1. In identifying and defining these domains, we adopted a conceptualization[53] in which the transplant is conceived as generating a series of psychosocial effects that radiate outward through key domains of patients' lives. Physical and psychologic functioning are the most directly and intimately affected, followed by patients' behavior in managing the medical regimen, their social interactions, and ultimately their global QOL perceptions.

METHODOLOGY

The empirical literature published between 1980 and 2004 was reviewed via searches of major electronic databases (e.g., MEDLINE, PSYCHINFO, CINAHL). We focused on English-language articles; however, German, French, Dutch and Italian articles were reviewed by workgroup members fluent in those languages.

The next section summarizes the major results of our review, including references to representative publications; individual, exhaustive reviews of each psychosocial domain are available elsewhere.[6–10] The focus and unique contribution of the present review concerns the comprehensive set of conclusions that we generated regarding the methodologic and substantive strengths and limitations of existing literature. These were evaluated by NSSC members at the 2003 and 2004 ISHLT annual meetings, with subsequent revisions. Finally, we present a series of specific recommendations for future research. These recommendations evolved directly from ISHLT annual meeting discussions and were formulated during a series of workgroup meetings.

SUMMARY OF MAJOR FINDINGS FROM PSYCHOSOCIAL OUTCOMES RESEARCH

Physical Functioning

Both objective measures (e.g., exercise capacity) and subjective measures of physical functioning (e.g., perceived functional status) improve with CTTx.[11–17] However, CTTx recipients continue to report significant dysfunction in some areas (e.g., sexual performance).[18–21] They frequently describe new physical symptoms that cause distress post-transplant, arising primarily as immunosuppressant side effects (e.g., altered body appearance).[16,19,22,23] Heart transplant (HTx) recipients' physical functioning remains high for up to 9 years post-transplant[12,24–26] Limited data through the early years after lung transplant (LTx) suggest similarly maintained benefits, whereas heart–lung transplant (HLTx) recipients show renewed impairments over time.[15,27,28] Key predictors/correlates of poorer physical functional outcomes post-transplant are displayed in Table 1. No studies have examined whether physical functional status itself predicts subsequent post-transplant clinical

Table 1. Predictors and Correlates of Poorer Functioning in each Psychosocial Domain (with references to representative studies)

	Psychological functioning		
Physical functioning	Psychiatric disorders/distress	Neurocognitive status	Behavior in managing the medical regimen
Demographic • Older age[26,58] • Female gender[18,19,22] *Clinical* • Higher body mass index, HTx[58,59] • Higher pulmonary vascular resistance, HTx[60,61] • Onset of BOS, LTx[62] • Disease other than CF, LTx[43] • Greater pretransplant psychological distress[63]	*Clinical* • Posttransplant secondary medical complications[18,27] *Psychosocial* • Poor physical functioning at time of CTTx or perioperatively[29,49,63,64] • Pretransplant history of psychiatric disorder[29] • Poorer social supports[29,32,42] • Use of avoidant/passive coping strategies[64–66] • Lower sense of personal control/self-efficacy[64–66] • Lower optimism/hope[67]	*Clinical* • Cumulative cyclosporine dose, HTx[68] • Pretransplant VAD support, HTx[69]	*Demographic* • Younger age[70] *Clinical* • Posttransplant secondary medical complications[36,70] • Disease other than CF, LTx[38] *Psychosocial* • Pretransplant nonadherence[3,40,70] • Physical symptom distress and disability[36,70] • Lower satisfaction with health[36,54] • Pretransplant history of psychiatric disorder or substance abuse[71,72] • Posttransplant psychological distress[35,36] • Poorer social supports[35,36,70] • Use of avoidant/fatalistic coping strategies[35,36] • Low sense of self-efficacy/motivation[3,73] • Negative expectations/beliefs about posttransplant outcomes, need for regimen, or barriers to adherence[36,41,67,74]

BOS, bronchiolitis obliterans syndrome; CF, cystic fibrosis; VAD, ventricular assist device.

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outcomes (Table 2). Four intervention studies that included post-transplant physical functioning outcomes are summarized in Table 3. They provide some evidence of positive effects on exercise capacity but mixed effects for perceived physical functioning.

Psychologic Functioning

Mood and anxiety disorders, as well as sub-clinical psychologic symptoms, are relatively common in the first year after CTTx (and are even more prevalent than before transplant), but abate over the next several years.[29–31] Psychologic distress may increase in the later (5+) years post-transplant.[24,25,32] Neurocognitive status has been examined only in HTx recipients, with inconsistent findings regarding levels and nature of impairment.[33,34] Key predictors/correlates of poorer psychologic functioning post-transplant are displayed in Table 1. Table 2 shows that psychologic disorders and symptomatology themselves predict subsequent clinical outcomes. Of the three intervention studies that considered psychologic outcomes, two noted improvements (Table 3).

Behavior in Managing Post-transplant Medical Regimen

Studies report wide ranges of rates of non-adherence to the CTTx medical regimen, including 0% to 40% for taking medications,[3,35–38] 2% to 27% for keeping clinical appointments,[35–38] 16% to 41% for following prescribed diets,[35–37,39] 13% to 72% for exercising,[35–37,39] 22% to 59% for monitoring vital signs,[35,36] 6% to 35% for cigarette smoking[35,37,40] and 6% to 27% for heavy alcohol use or other substance abuse/dependence.[35,37] Non-adherence in all areas increases with time.[35,36,41] Key predictors/correlates of post-transplant non-adherence are listed in Table 1. Table 2 shows that non-adherence predicts clinical outcomes. The few intervention efforts have obtained mixed effects on adherence (Table 3).

Social Functioning

The majority of CTTx recipients report positive perceptions of interpersonal relationships, social role participation and leisure activities.[14,24,27,42–46] Social functioning improves over pre-transplant levels, and continues to improve with time, especially for HTx recipients.[15,24,27,43,46–48] Employment rates post-transplant are variable across studies, ranging from 12% to 74%,[26,42,49–52] due in part to varying definitions of employment. Employment rates appear to increase over time post-transplant. Table 1 displays key predictors/correlates of poorer social functioning, although no study has examined whether social functioning affects clinical outcomes. A single intervention study found some positive effects on social functioning (Table 3).

Global QOL. We considered perceived global QOL as a separate outcome because transplant recipients' global perceptions are often only modestly related to functioning in other specific psychosocial domains.[53] CTTx recipients report high global QOL.[11,15,18,19,27,45,54,55]

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Social functioning		
General social functioning	Employment	Global QOL
Clinical • Greater pretransplant illness severity[49] • Poorer perioperative medical status[75] • Long-term corticosteroid use[76] *Psychosocial* • Poorer general health perceptions[42] • Posttransplant psychological distress[32,42]	*Demographic* • Older age[51,52] • Less education[52,77] *Psychosocial* • Feel physically unable to work[52,77] • Unstable employment history pretransplant and/or longer period of pretransplant disability[51,52,77] • Poorer perceived physical and emotional functioning pretransplant[78] • Likely to lose health insurance or disability income[52,79]	*Demographic* • Younger age[54,80] • More education[46] • Unmarried[54] *Clinical* • Posttransplant secondary medical complications[27,54] • Onset of BOS, LTx[18,62] *Psychosocial* • Poorer perceived physical functioning and symptom distress[11,19,45,80] • Posttransplant psychological distress[11] • Personality disorder[81] • Lower sense of personal control/self-efficacy[46,82] • Unemployed and/or less job satisfaction[83]

These perceptions improve over pre-transplant levels,[11,27,56] and they remain stable or further improve with time post-transplant.[56] Key predictors/correlates of global QOL post-transplant are displayed in Table 1; this outcome has not been considered as a predictor of clinical outcomes. A single intervention trial found no impact on global QOL (Table 3).

CONCLUSIONS

Substantive Findings and Areas of Omission in Present Research

Table 4 summarizes the distribution of published data in each psychosocial domain. Although there have been many descriptive studies in most areas of research, there are considerably fewer data on predictors and correlates of CTTx recipients' psychosocial status. These limited data constitute an important impediment to progress: optimal patient management to maximize psychosocial outcomes is feasible only when we can clearly identify who is at risk for sub-optimal outcomes, and under what circumstances this risk is increased. Finally, little information is available on the impact of most psychosocial domains on post-transplant clinical outcomes, and little progress has been made in evaluating potentially useful interventions. Given even the small amount of literature showing that psychosocial outcomes themselves predict clinical morbidity and mortality, it is imperative to identify intervention strategies to improve post-transplant psychosocial functioning.

Table 4 also highlights differences in the current knowledge base *across* the 5 psychosocial domains. For example, among descriptive studies, there is a notable lack of work on neurocognitive functioning. Among studies of predictors/correlates of psychosocial outcomes, there are fewer data for neurocognitive and social role functioning than for other outcomes. Finally, Table 4 shows that HTx recipients have been studied much more extensively than other CTTx populations.

It is noteworthy that the 5 psychosocial domains themselves encompass many specific outcomes.

Table 2. Post-transplant Psychosocial Variables Found to Predict Subsequent Clinical Outcomes in CTTx Recipients

Predictors from post-transplant psychosocial domains	Subsequent post-transplant clinical outcomes
Physical functional status	—[a]
Psychologic functioning	
Greater depressive and anger symptoms	Increased risk of onset of chronic graft rejection, HTx[4]
Posttraumatic stress disorder related to the transplant	Increased risk of mortality, HTx[4]
Behavior in managing the medical regimen	
Medication non-adherence	Increased risk of acute and chronic rejection and graft loss, HTx[3,4,37,84–86]
Poorer dietary and exercise adherence	Increased risk for morbidity and mortality, HTx[4,87]
Smoking	Increased risk of lung cancer, HTx, LTx[40,88–91]
Social functioning	—[a]
Global QOL	—[a]

[a]No studies have examined psychosocial variables from the domain as predictors of subsequent clinical outcomes in CTTx recipients.

Table 3. Empirical Evaluations of Interventions Designed to Improve Psychosocial Outcomes in CTTx Recipients

Intervention	Type of CTTx recipient	Psychosocial outcome domain	
		Physical functioning	Psychologic functioning
Randomized, controlled trial of structured exercise training[92]	HTx	Improved exercise capacity	—[a]
Uncontrolled trial of structured exercise training[93]	LTx	Improved exercise capacity	—[a]
Controlled trial of multicomponent psychosocial intervention to improve knowledge, coping and well-being[94]	HTx	No improvements in perceived physical functioning	Improved psychologic symptom levels
Uncontrolled trial of a meditation-based stress reduction program[95]	LTx and non-CTTx organ recipients	—[a]	Improved psychologic symptom levels
Uncontrolled trial of multicomponent home spirometry education intervention[96]	LTx	—[a]	—[a]
Controlled trial comparing usual vs enhanced education about home spirometry[97]	LTx, HLTx	—[a]	—[a]

[a]Outcome domain not considered in the clinical trial.

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These outcomes differ dramatically in their coverage in the literature. For example, in the physical functioning domain, there are considerably more data about exercise capacity and perceived physical functioning than about sexual functioning. In the literature on behavior in managing the medical regimen, medication adherence has received the greatest attention. Furthermore, outcomes in all psychosocial domains have been examined primarily in the early, rather than later, post-transplant years.

Methodologic Strengths and Limitations in Present Research

Several encouraging trends are apparent. Increasing numbers of studies in all psychosocial domains provide more complete sample descriptions (e.g., sampling frame, rates of refusal, attrition). There has also been a movement toward larger sample sizes, especially in studies of HTx recipients. Increased sample sizes enable more precise estimates of rates of specific psychosocial outcomes and their associations with other variables. Finally, a growing number of reports utilize standardized assessment instruments with known psychometric properties. This increase in assessment rigor has led to greater understanding of the nature of post-transplant psychosocial outcomes.

A variety of limitations remain, however. Despite increased sample sizes, many studies remain statistically underpowered. When studies report null findings due to lack of power to detect effects (Type II error), potentially important relationships of psychosocial variables with other patient or clinical characteristics are likely to be discounted and not pursued further.

An additional limitation is reliance on samples that are not representative of the patient population under study, or do not include important sub-groups in sufficient numbers to examine them separately. For example, failure to include both genders in studies designed to be generalized to all HTx or LTx recipients, or failure to include representative proportions of ethnic sub-groups, relative to their sizes in the larger patient population at a given center or in a given country, can reduce generalizability.

Although assessment methodologies have improved, continuing conceptual ambiguities exist in defining distinct elements of psychosocial outcomes. The problem is not necessarily the fact that differing definitions of variables are used across studies so much as it is that CTTx researchers do not consistently state how or why they chose to measure some facets of the psychosocial domains and not others. The need for conceptual and measurement clarity in examining these domains is not unique to transplantation; it is an issue for all areas of psychosocial assessment, and it is currently undergoing extensive study within the United States National Institutes of Health roadmap of strategic activities, under the Patient-Reported Outcomes Measurement Information System (PROMIS) initiative.[57] In the meantime, conceptual and measurement rigor—that is, careful definition of domains to be assessed, and care in instrument selection and administration—requires continued attention in CTTx research to maximize understanding and generalizability of study findings.

With respect to study design, the literature on CTTx psychosocial outcomes continues to rely heavily on cross-sectional strategies, rather than longitudinal or prospective designs that allow for clearer conclusions regarding which variables are predictors or risk factors vs those that are outcomes. This weakness has limited the conclusions that can be drawn about: (a) which patients are truly at risk for poorer psychosocial outcomes; (b) whether these outcomes themselves predict clinical outcomes; and (c) what variables should be targeted for interven-

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Behavior in managing the medical regimen	Social functioning	Global QOL perception
—[a]	—[a]	—[a]
—[a]	—[a]	—[a]
No improvements in overall adherence, but improved adherence in patients using the intervention more frequently	Improved social functioning; no change in specific aspects of role functioning	—[a]
—[a]	—[a]	No improvement in perceived global QOL
Improved adherence to home spirometry	—[a]	—[a]
No reliable differences in intervention groups	—[a]	—[a]

tion. Concerning the few interventions conducted to date, important study design limitations include the lack of control groups in many of the studies, and (among those with controls) failure to use randomized designs. Both factors reduce the strength of any conclusions that can be drawn.

RECOMMENDATIONS FOR FUTURE PSYCHOSOCIAL RESEARCH

Substantive Issues

1. CTTx psychosocial outcomes research should, with few exceptions (e.g., neurocognitive functioning), shift away from purely descriptive studies and toward longitudinal and prospective studies that examine risk factors and outcomes of CTTx recipients' psychosocial functioning.
2. Studies that examine risk factors for psychosocial outcomes should place greater emphasis on including a full range of factors believed to be important. This would enable stronger conclusions regarding: (a) the unique impact of particular risk factors relative to others; and (b) whether the combined effects of series of risk factors are additive or synergistic.
3. Greater attention is needed in evaluating the impact of CTTx recipients' psychosocial functioning on clinical outcomes. A more complete understanding of effects on morbidity and mortality has critical implications for clinical management and intervention to improve clinical outcomes.
4. Trials of promising interventions to maximize psychosocial outcomes must be conducted. Numerous psychologic, behavioral and rehabilitation interventions evaluated in other chronic disease fields are potentially relevant. Some may be easily adapted and tailored to the unique medical and psychosocial concerns in CTTx recipients. Alternatively, novel interventions could be designed based directly on the existing psychosocial outcomes literature in CTTx recipients.
5. Given the generally greater number of studies on HTx recipients, greater focus is needed on psychosocial outcomes for LTx recipients, especially given their improved survival rates.
6. Greater consideration is needed of long-term (5+ years post-transplant) psychosocial outcomes and their determinants for all types of CTTx recipients.

Table 4. Extent of Empirical Evidence on Nature, Predictors, Clinical Outcomes and Relevant Interventions for 5 Psychosocial Domains in CTTx Recipients

	Descriptive information			Predictors/correlates			Predictors of clinical outcomes			Interventions		
Psychosocial domain	HTx	LTx	HLTx	HTx	LTx	HLTx	HTx	LTx	HLTx	HTx	LTx	HLTx
Physical functioning	+++	++	+	++	+	+	0	0	0	+	+	0
Psychologic functioning												
Psychiatric disorders/distress	+++	+	+	++	+	+	+	+	0	+	+	0
Neurocognitive functioning	+	0	0	+	0	0	0	0	0	0	0	0
Behavior in managing the post-transplant regimen	+++	+	0	++	+	0	+	+	0	+	+	+
Social functioning												
Roles and relationships	+++	++	+	+	+	0	0	0	0	+	0	0
Employment	+++	++	+	++	++	0	0	0	0	0	0	0
Global QOL	+++	++	+	++	+	0	0	0	0	0	+	0

Key: +++, extensive amount of data available; ++, moderate amount of data available; +, little data available; 0, no data found.

7. Studies must include adequate representation of important patient sub-groups whose outcomes may differ from the majority of CTTx recipients. This would include, for example, adequate representation of women in HTx samples, and adequate representation of ethnic minorities in CTTx samples.

Methodologic Issues

1. Sample composition and sub-group inclusion are also methodologically important. For findings to be generalizable, studies of psychosocial outcomes must enroll subjects from a known sampling frame to ensure representativeness to the larger patient population.
2. Greater attention is needed to evaluating and ensuring that sample sizes are large enough to provide adequate statistical power to address study questions.
3. Increased use of multicenter designs would strengthen the potential for large, representative samples and increase the likelihood that critical sub-group analyses could be performed with adequate statistical power.
4. Studies must adopt state-of-the-art strategies to minimize refusal and attrition rates. These strategies, such as repeat mailings for mailed surveys and interviewer training to develop rapport with subjects, are not uniformly employed in this area of study.
5. Assessment strategies must become even more highly standardized and must derive from clear, explicit definitions of the domains to be measured. A multi-method approach will often be optimal. For example, adherence to the medical regimen is likely to be best assessed through a combination of self-report, informant report and indirect measures (e.g., electronic medication monitoring). Use of novel assessment strategies (e.g., internet-based data collection) may facilitate recruitment, retention and repeated evaluation of subjects.
6. Study designs appropriate for drawing inferences regarding risk factors or causal relationships must be employed. These would include longitudinal, prospective and experimental designs and would largely exclude cross-sectional studies, for which the direction of effects is usually indeterminate.
7. Greater use must be made of analytic strategies that are flexible with regard to missing datapoints, once the nature of the missing data (ignorable vs non-ignorable) has been examined. Such strategies would include not only survival analysis but mixed effects models for repeated-measures data.
8. Effect size information must be routinely reported. These data are critical for the appropriate cumulation of studies' findings (i.e., meta-analysis) and for evaluation of clinical significance.
9. Intervention studies of strategies to improve CTTx psychosocial outcomes must consist of controlled, randomized trials, with routine blinding of assessors collecting outcome data.

REFERENCES

1. Dew MA, Switzer GE, DiMartini AF, et al. Psychosocial assessments and outcomes in organ transplantation. Prog Transplant 2000;10:239–61.
2. Krakauer H, Beiley RC, Lin MJ. Beyond survival: the burden of disease in decision making in organ transplantation. Am J Transplant 2004;4:1555–61.
3. De Geest S, Abraham I, Moons P, et al. Late acute rejection and subclinical noncompliance with cyclosporine therapy in heart transplant recipients. J Heart Lung Transplant 1998;17:854–63.
4. Dew MA, Kormos RL, Roth LH, et al. Early posttransplant medical compliance and mental health predict physical morbidity and mortality 1 to 3 years after heart transplantation. J Heart Lung Transplant 1999;18:549–62.
5. Dobbels F, De Geest S, Van Cleemput J, Droogne W, Vanhaecke J. Effect of late medication noncompliance on subsequent outcome after heart transplantation: a 5-year follow-up study. J Heart Lung Transplant 2004; 23:1245–51.
6. Cupples SA, Stilley C. Cognitive function in adult cardiothoracic candidates and recipients. J Cardiovasc Nurs 2005; 20(suppl):S74–87.
7. Dew MA, DiMartini AF. Psychological disorders and distress after adult cardiothoracic transplantation. J Cardiovasc Nurs 2005;20(suppl):S51–66.
8. De Geest S, Dobbels F, Fluri C, Paris W, Troosters T. Adherence with the therapeutic regimen in heart, lung, and heart–lung transplant recipients. J Cardiovasc Nurs 2005;20(suppl):S88–98.
9. Grady KL, Lanuza DM. Physical functional outcomes after cardiothoracic transplantation. J Cardiovasc Nurs 2005; 20(suppl):S43–50.
10. Paris W, White-Williams C. Social adaptation after cardiothoracic transplantation: a review of the literature. J Cardiovasc Nurs 2005;20(suppl):S67–73.
11. Lanuza DM, Lefaiver C, McCabe M, Farcas GA, Garrity E Jr. Prospective study of functional status and quality of life before and after lung transplantation. Chest 2000; 18:115–22.
12. Givertz MM, Hartley LH, Colucci WS. Long-term sequential changes in exercise capacity and chronotropic responsiveness after cardiac transplantation. Circulation 1997;96:232–7.
13. Lands LC, Smountas AA, Mesiano G, et al. Maximal exercise capacity and peripheral skeletal muscle function

following lung transplantation. J Heart Lung Transplant 1999;18:113–20.
14. Grady KL, Jalowiec A, White-Williams C. Improvement in quality of life in patients with heart failure who undergo transplantation. J Heart Lung Transplant 1996; 15:749–57.
15. Gross CR, Savik K, Bolman RM III, Hertz MI. Long-term health status and quality of life outcomes of lung transplant recipients. Chest 1995;108:1587–93.
16. MacNaughton KL, Rodrigue JR, Cicale M, Staples EM. Health-related quality of life and symptom frequency before and after lung transplantation. Clin Transplant 1998;12:320–3.
17. TenVergert EM, Essink-Bot ML, Geertsma A, et al. The effect of lung transplantation on health-related quality of life: a longitudinal study. Chest 1998;113:358–64.
18. Limbos MM, Joyce DP, Chan CKN, Kesten S. Psychological functioning and quality of life in lung transplant candidates and recipients. Chest 2000;118:408–16.
19. Lough ME, Lindsey AM, Shinn JA, Stotts NA. Impact of symptom frequency and symptom distress on self-reported quality of life in heart transplant recipients. Heart Lung 1987;16:193–200.
20. Dumas DH, Cassidy C, Randrup E. Sexual function in men following cardiac transplantation. J Transplant Coord 1994; 4:115–8.
21. Limbos MM, Chan CK, Kesten S. Quality of life in female lung transplant candidates and recipients. Chest 1997; 112:1165–74.
22. Lanuza DM, McCabe M, Norton-Rosko M, Corliss JW, Garrity E. Symptom experiences of lung transplant recipients: comparisons across gender, pretransplantation diagnosis, and type of transplantation. Heart Lung 1999;28: 429–37.
23. Reyes CJ, Evangelista LS, Doering L, et al. Physical and psychological attributes of fatigue in female heart transplant recipients. J Heart Lung Transplant 2004;23:614–9.
24. Bunzel B, Laederach-Hofmann K. Long-term effects of heart transplantation: the gap between physical performance and emotional well-being. Scand J Rehabil Med 1999;31:214–22.
25. Bunzel B, Laederach-Hofmann K, Grimm M. Survival, clinical data, and quality of life 10 years after heart transplantation: a prospective study. Zeitschrift Kardiol 2002;91:319–27.
26. DeCampli WM, Luikart H, Hunt S, Stinson EB. Characteristics of patients surviving more than ten years after cardiac transplantation. J Thorac Cardiovasc Surg 1995; 109:1103–15.
27. Vermeulen KM, Ouwens JP, van der Bij W, de Boer WJ, Koeter GH, TenVergert EM. Long-term quality of life in patients surviving at least 55 months after lung transplantation. Gen Hosp Psychiatry 2003;25:95–102.
28. Hummel M, Michauk I, Hetzer R, Furhmann B. Quality of life after heart and heart–lung transplantation. Transplant Proc 2001;33:3546–8.
29. Dew MA, Kormos RL, DiMartini AF, et al. Prevalence and risk of depression and anxiety-related disorders during the first three years after heart transplantation. Psychosomatics 2001;42:300–13.
30. Grandi S, Fabbri S, Tossani E, et al. Psychological evaluation after cardiac transplantation: the integration of different criteria. Psychother Psychosom 2001;70:176–83.
31. Shapiro PA, Kornfeld DS. Psychiatric outcome of heart transplantation. Gen Hosp Psychiatry 1989;11:352–7.
32. Dobbels F, De Geest S, Martin S, et al. Prevalence and correlates of depression symptoms at 10 years after heart transplantation: continuous attention required. Transplant Int 2004;17:424–31.
33. Bornstein RA, Starling RC, Myerowitz PD, Haas GJ. Neuropsychological function in patients with end-stage heart failure before and after cardiac transplantation. Acta Neurol Scand 1995;91:260–5.
34. Riether AM, Smith SL, Lewison BJ, Cotsonis GA, Epstein CM. Quality of life changes and psychiatric and neurocognitive outcome after heart and liver transplantation. Transplantation 1992;54:444–50.
35. Dew MA, Roth LH, Thompson ME, Kormos RL, Griffith BP. Medical compliance and its predictors in the first year after heart transplantation. J Heart Lung Transplant 1996; 15:631–45.
36. Grady KL, Jalowiec A, White-Williams C. Patient compliance at one year and two years after heart transplantation. J Heart Lung Transplant 1998;17:383–94.
37. Paris W, Muchmore J, Pribil A, Zuhdi N, Cooper DKC. Study of relative incidences of psychosocial factors before and after heart transplantation and the influence of posttransplantation psychosocial factors on heart transplantation outcome. J Heart Lung Transplant 1994;13: 424–32.
38. Teichman BJ, Burker EJ, Weiner M, Egan TM. Factors associated with adherence to treatment regimens after lung transplantation. Prog Transplant 2000;10:113–21.
39. Balestroni G, Bosimini E, Centofanti P, et al. Life style and adherence to the recommended treatments after cardiac transplantation. Ital Heart J 2002;3(suppl):652–8.
40. Nagele H, Kalmar P, Rodiger W, Stubbe HM. Smoking after heart transplantation: an underestimated hazard? Eur J Cardiothorac Surg 1997;12:70–4.
41. Cherubini P, Rumiati R, Bigoni M, Tursi V, Livi U. Long-term decrease in subjective perceived efficacy of immunosuppressive treatment after heart transplantation. J Heart Lung Transplant 2003;22:1376–80.
42. Littlefield C, Abbey S, Fiducia D, et al. Quality of life following transplantation of the heart, liver, and lungs. Gen Hosp Psychiatry 1996;18(suppl):36S–47S.
43. Vermeulen KM, van der Bij W, Erasmus ME, et al. Improved quality of life after lung transplantation in individuals with cystic fibrosis. Pediatr Pulmonol 2004; 37:419–26.
44. Bunzel B, Laederach-Hofmann K, Schubert MT. Patients benefit—partners suffer? The impact of heart transplantation on the partner relationship. Transplant Int 1999; 12:33–41.
45. Forsberg A, Lorenson U, Nilsson F, Backmana L. Pain and health related quality of life after heart, kidney and liver transplantation. Clin Transplant 1999;13:453–60.
46. Salyer J, Flattery MP, Joyner PL, Elswick RK. Lifestyle and quality of life in long-term cardiac transplant recipients. J Heart Lung Transplant 2003;22:309–21.

47. Hetzer R, Albert W, Hummel M, et al. Status of patients presently living 9 to 13 years after orthotopic heart transplantation. Ann Thorac Surg 1997;64:1661–8.
48. Karam VH, Gasquet I, Delvart V, et al. Quality of life in adult survivors beyond 10 years after liver, kidney and heart transplantation. Transplantation 2003;76:1699–704.
49. Grady KL, Jalowiec A, White-Williams C. Quality of life 6 months after heart transplantation compared with indicators of illness severity before transplantation. Am J Crit Care 1998;7:106–16.
50. Brann WM, Bennett LE, Keck BM, Hosenpud JD. Morbidity, functional status, and immunosuppressive therapy after heart transplantation: an analysis of the Joint International Society for Heart and Lung Transplantation/United Network for Organ Sharing Thoracic Registry. J Heart Lung Transplant 1998;17:374–82.
51. Kavanagh T, Yacoub MH, Kennedy J, Austin PC. Return to work after transplantation: 12-year follow-up. J Heart Lung Transplant 1999;18:846–51.
52. Paris W, Diercks M, Bright J, et al. Returning to work after heart transplantation: a replication. Res Soc Work Pract 1997;7:370–7.
53. Dew MA, Switzer GE, Goycoolea JM, et al. Does transplantation produce quality of life benefits? A quantitative analysis of the literature. Transplantation 1997; 64:1261–73.
54. Barr ML, Schenkel FA, Van Kirk A, et al. Determinants of quality of life changes among long-term cardiac transplant survivors: results from longitudinal data. J Heart Lung Transplant 2003;22:1157–67.
55. Grady KL, Jalowiec A, White-Williams C. Preoperative psychosocial predictors of hospital length of stay after heart transplantation. J Cardiovas Nurs 1999;14:12–26.
56. Molzahn AE, Burton JR, McCormick P, et al. Quality of life of candidates for and recipients of heart transplants. Can J Cardiol 1997;13:141–6.
57. Patient-reported Outcomes Measurement Information System of the National Institutes of Health. http://www.nihpromis.org. Accessed November 30, 2005.
58. Mulligan T, Sheehan H, Hanrahan J. Sexual function after heart transplantation. J Heart Lung Transplant 1991;10: 125–8.
59. Leung TC, Ballman KV, Allison TG, et al. Clinical predictors of exercise capacity 1 year after cardiac transplantation. J Heart Lung Transplant 2003;22:16–27.
60. Andreassen AK, Kvernebo K, Jorgensen B, et al. Exercise capacity in heart transplant recipients: relation to impaired endothelium-dependent vasodilation of the peripheral microcirculation. Am Heart J 1998;136:320–8.
61. Al-Rawas OA, Carter R, Stevenson RD, Naik SK, Wheatley DJ. Exercise intolerance following heart transplantation. Chest 2000;118:1661–70.
62. Vermeulen KM, Groen H, van der Bij W, et al. The effect of bronchiolitis obliterans syndrome on health related quality of life. Clin Transplant 2004;18:377–83.
63. Cohen L, Littlefield C, Kelly P, Maurer J, Abbey S. Predictors of quality of life and adjustment after lung transplantation. Chest 1998;113:633–44.
64. Stilley CS, Dew MA, Stukas AA, et al. Psychological symptom levels and their correlates in lung and heart–lung transplant recipients. Psychosomatics 1999;40: 503–9.
65. Dew MA, Simmons RG, Roth LH, et al. Psychosocial predictors of vulnerability to distress in the year following heart transplantation. Psychol Med 1994;24:929–45.
66. Evangelista LS, Doering L, Dracup K, Vassilakis ME, Kobashigawa JA. Hope, mood states, and quality of life in female heart transplant recipients. J Heart Lung Transplant 2003; 22:681–6.
67. Leedham B, Meyerowitz BE, Muirhead J, Frist WH. Positive expectations predict health after heart transplantation. Health Psychol 1995;14:74–9.
68. Grimm M, Yeganehfar W, Laufer G, et al. Cyclosporine may affect improvement of cognitive brain function after successful transplantation. Circulation 1996;94:1339–45.
69. Dew MA, Kormos RL, Winowich S, et al. Quality of life outcomes after heart transplantation in individuals bridged to transplant with ventricular assist devices. J Heart Lung Transplant 2001;20:1199–212.
70. De Geest S, Dobbels F, Martin S, Willems K, Vanhaecke J. Clinical risk associated with appointment noncompliance in heart transplant recipients. Prog Transplant 2000;10: 162–8.
71. Shapiro PA, Williams D, Foray AT, et al. Psychosocial evaluation and prediction of compliance problems and morbidity after heart transplantation. Transplantation 1995; 60:1462–6.
72. Harper RG, Chacko RC, Kotik-Harper D, Young J, Gotto J. Self-reported evaluation of health behavior, stress vulnerability, and medical outcome of heart transplant recipients. Psychosom Med 1998;60:563–9.
73. Meyendorf R, Dassing M, Scherer J, et al. Predictive and rehabilitative perspectives in heart transplantation. Herz 1989;14:308–21.
74. Sabati N, Snyder M, Edin-Stibbe C, Lindgren B, Finkelstein S. Facilitators and barriers to adherence with home monitoring using electronic spirometry. AACN Clin Issues 2001;12:178–85.
75. Strauss B, Thormann T, Strenge H, et al. Psychological, neuropsychological and neurological status in a sample of heart transplant recipients. Qual Life Res 1992;1:119–28.
76. Salyer J, Sneed G, Corley MC. Lifestyle and health status in long-term cardiac transplant recipients. Heart Lung 2001; 30:445–57.
77. Cicutto L, Braidy C, Moloney S, et al. Factors affecting attainment of paid employment after lung transplantation. J Heart Lung Transplant 2004;23:481–6.
78. Caine N, Sharples LD, English TA, Wallwork J. Prospective study comparing quality of life before and after heart transplantation. Transplant Proc 1990;22:1437–9.
79. Paris W, Woodbury A, Thompson S, et al. Returning to work after heart transplantation. J Heart Lung Transplant 1993;12:46–53.
80. Grady KL, Jalowiec A, White-Williams C. Predictors of quality of life in patients at one year after heart transplantation. J Heart Lung Transplant 1999;18:202–10.
81. Brennan AF, Davis MH, Buchholz DJ, Kuhn WF, Gray LA Jr. Predictors of quality of life following cardiac transplantation. Psychosomatics 1987;28:566–71.

82. Bohachick P, Taylor MV, Sereika S, Reeder S, Anton BB. Social support, personal control, and psychosocial recovery following heart transplantation. Clin Nurs Res 2002; 11:34–51.
83. Duitsman DM, Cychosz C. Psychosocial similarities and differences among employed and unemployed heart transplant recipients. J Heart Lung Transplant 1994;13: 108–15.
84. Ortalli G. Suicide by interruption of immunosuppressive therapy. J Cardiothorac Vasc Anesthesiol 1992;6:644.
85. Ruygrok PN, Agnew TM, Coverdale HA, Whitfield C, Lambie NK. Survival after heart transplantation without regular immunosuppression. J Heart Lung Transplant 1994;13:208–11.
86. Schweizer RT, Rovelli M, Palmeri D, et al. Noncompliance in organ transplant recipients. Transplantation 1990;49: 374–7.
87. Rickenbacher PR, Kemna MS, Pinto FJ, et al. Coronary artery intimal thickening in the transplanted heart: an in vivo intracoronary ultrasound study of immunologic and metabolic risk factors. Transplantation 1996;61:46–53.
88. Arcasoy SM, Hersh C, Christie JD, et al. Bronchogenic carcinoma complicating lung transplantation. J Heart Lung Transplant 2001;10:1044–53.
89. Choi YH, Leung AN, Miro S, et al. Primary bronchogenic carcinoma after heart or lung transplantation: radiologic and clinical findings. J Thorac Imaging 2000;15:36–40.
90. Curtil A, Robin J, Tronc F, et al. Malignant neoplasms following cardiac tranplantation. Eur J Cardiothorac Surg 1997;12:101–6.
91. Goldstein DJ, Williams DL, Oz MC, et al. De novo solid malignancies after cardiac transplantation. Ann Thorac Surg 1995;60:1783–9.
92. Kobashigawa JA, Leaf DA, Lee N, et al. A controlled trial of exercise rehabilitation after heart transplantation. N Engl J Med 1999;340:272–7.
93. Stiebellehner L, Quittan M, End A, et al. Aerobic endurance training program improves exercise performance in lung transplant recipients. Chest 1998;113:906–12.
94. Dew MA, Goycoolea JM, Harris RC, et al. An internet-based intervention to improve psychosocial outcomes in heart transplant recipients and family caregivers: development and evaluation. J Heart Lung Transplant 2004;23: 745–58.
95. Gross CR, Kreitzer MJ, Russas V, et al. Mindfulness meditation to reduce symptoms after organ transplant: a pilot study. Adv Mind-Body Med 2004;20:20–9.
96. Chlan L, Snyder M, Finkelstein S, et al. Promoting adherence to an electronic home spirometry research program after lung transplantation. Appl Nurs Res 1998; 11:36–40.
97. Goldstein NL, Snyder M, Edin C, Lindgren B, Finkelstein SM. Comparison of two teaching strategies: adherence to a home monitoring program. Clin Nurs Res 1996;5: 150–66.
98. Testa MA, Simonson DC. Assessment of quality-of-life outcomes. N Engl J Med 1996;334:835–40.
99. Ware JE. Conceptualization and measurement of health-related quality of life: comments on an evolving field. Arch Phys Med and Rehabil 2003;84(suppl 2):S43–S51.