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Acceptance of Illness Among Patients Pursuing Transplantation or Left Ventricular Assist Device

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Abstract
Acceptance of illness is related to better mental health among patients with chronic illness; however, this construct has not been evaluated as part of routine transplantation evaluations. The purpose of this study was to create a brief measure of acceptance of illness for patients pursuing organ transplantation and examine how acceptance is related to distress. Retrospective medical record reviews were conducted for 290 patients who completed a routine psychosocial evaluation prior to transplant listing which included the Illness Acceptance Scale (IAS). Internal consistency for the IAS was excellent (Cronbach's alpha = .92). Illness acceptance was negatively correlated with depression, anxiety, and catastrophizing and was not related to health literacy or health numeracy. The IAS is a reliable and valid measure for patients who are pursuing thoracic transplant or left ventricular assist device. Clinicians may want to screen transplant candidates for illness acceptance and refer those with lower levels to psychological interventions.

Keywords Transplant · Psychosocial · Acceptance of illness · Depression · Anxiety

Introduction

Due to the complex stressors associated with end-stage organ failure and organ transplantation, many patients experience negative effects on their mental health and quality of life (QoL) (Schulz & Kroencke, 2015). Prevalence of mood and anxiety disorders has been demonstrated in as many as 60% of transplant candidates (Rogal et al., 2013). Depression and anxiety prior to transplant are linked to post-transplant anxiety and depression, as well as lower QoL (Miller et al., 2013; Schulz & Kroencke, 2015). Depression and anxiety are also related to a variety of medical outcomes among patients pursuing transplant including nonadherence, substance use, decreased survival, and all-cause mortality (Corruble et al., 2011; DiMartini et al., 2011; Rogal et al., 2013; Schulz & Kroencke, 2015). When depression is adequately treated, patients tend to have better survival rates post-transplant compared to nontreated or undertreated patients with depression (Rogal et al., 2013). Therefore, it is important for clinicians to understand factors influencing depression and anxiety to optimize outcomes for patients pursuing transplantation.

One factor that may be related to mental health among patients pursuing transplant is acceptance of illness. Two core components of illness acceptance include (1) the resignation of one's continued attempts at changing the negative, stable aspects of their illness and (2) the willingness to experience it without judgment (McCracken, 1998; Viane et al., 2003). The value of illness acceptance was first explored among patients with chronic pain. Those with high levels of pain acceptance had lower levels of depression and anxiety and better QoL (McCracken, 1998; Viane et al., 2003). Consequently, the utility of illness acceptance has been extended to mental health interventions for patients with chronic pain known as Acceptance and Commitment Therapy (ACT). Unlike control-oriented treatments, ACT

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operates on a model of recognition and acceptance of all experiences, regardless of their disposition and without any attempts to alter them (Hayes, Strosahl, & Wilson, 2009; Wetherell et al., 2011). The treatment promotes psychological flexibility and acceptance by helping patients identify their own fundamental values and engage in actions that gratify those values, limiting the effects of uncontrollable experiences and avoidance on their life (Hayes et al., 2009; Wetherell et al., 2011). Patients with chronic pain who engage in ACT experience improvements in emotional (i.e. depression, pain-related anxiety and distress), social (i.e. social activities), and physical functioning (i.e. pain tolerance, disability, daily functioning) (McCracken & Vowles, 2008; McCracken et al., 2005; Vowles & McCracken, 2008; Wetherell et al., 2011).

Given the findings of acceptance of illness among patients with chronic pain conditions, research has been extended to other chronic health conditions. The positive impact of acceptance of illness as it relates to mental health symptoms (i.e. depression and anxiety) and improved QoL (i.e. adaptive coping) has been extended to other chronic diseases, such as heart failure, diabetic neuropathy, and psoriasis (Lewko et al., 2007; Obiegło et al., 2016; Zalewska et al., 2007).

Considering the available literature on the importance of illness acceptance in improving QoL, mental health, and physical health for other patient populations, it is valuable to understand the utility of illness acceptance among transplant candidates. However, the role of illness acceptance on quality of life and mental health among patients pre-and post-transplant procedures has only begun to be explored. The one related study found that among recipients of a kidney transplant or patients on hemodialysis, ACT may improve quality of life (Azari et al., 2020). Further, identifying patients with low acceptance may allow clinicians to refer patients to targeted treatments, such as ACT. Given the research described above among other patient populations, it is hypothesized that higher levels of acceptance of illness will be related to lower levels mental health symptoms among patients pursuing transplantation. Although there are a couple of existing measures to assess acceptance of illness, these are challenging to use in clinical settings. For example, one measure is lengthy (i.e., 33 items) (Beacham et al., 2015), and another measure includes items that assesses personal abilities and reliance on social support (Felton et al., 1984), which inherently change while undergoing the transplant workup and surgical process and may not necessarily reflect acceptance of illness as much as changes due to end stage organ disease. Thus, the purpose of the current study was to (1) develop and validate a brief measure of illness acceptance for patients pursuing left ventricular assist device (LVAD) or thoracic transplant as well as (2) examine the relationship between illness acceptance and depression and anxiety (which are known risk factors for negative health outcomes following transplant) among patients seeking LVAD or thoracic transplant.

Methods

Participants and Procedure

Participants included in this study were 290 consecutive patients seen for a required, routine psychological evaluation as part of being considered for a lung transplant or a left ventricular assist device placement and/or heart transplant between March 2018 and May 2019. Retrospective medical chart reviews were conducted to extract data from the semi-structured Diagnostic Statistical Manual-V interview, the Illness Acceptance Scale, and assessment measures described below. This study was approved by the health system Institutional Review Board.

Measures

Montreal Cognitive Assessment (MoCA). The MoCA was used as a brief assessment of cognitive functioning and has adequate sensitivity and specificity for detecting cognitive impairment (Nasreddine et al., 2005). The total score ranges from 0 to 30, with a score of 26 or higher interpreted as normal cognitive functioning.

Rapid Estimate of Adult Literacy in Medicine (REALM-SF). The REALM-SF is a validated measure of health literacy and was used to estimate reading level ability (Arozullah et al., 2007). To obtain reading level, patients were instructed to read aloud a list of medical terminology. Patients were considered to have limited health literacy if they had below a 9th grade reading level.

Brief Medical Numbers Test (BMNT). The BMNT measures health-related numerical abilities and was validated among patients pursuing transplant (Dykhuis et al., 2019). Patients who did not score all four mathematical problems correctly were considered to have limited health numeracy.

Hospital Anxiety and Depression Scale (HADS). The HADS is a validated measure with two subscales to assess depression and anxiety symptoms (Zigmond & Snaith, 1983). There are seven items on each subscale and scores on each subscale range from 0 to 21, with higher values indicating greater symptomatology.

Catastrophizing. The Pain Catastrophizing Scale (Sullivan et al., 1995) was adapted into a general illness catastrophizing scale (i.e., pain was replaced with illness). The 13 items were added together to produce a total score. Higher scores indicated higher levels of illness catastrophizing.

Creation of the Illness Acceptance Scale

Items for the IAS were independently generated by two doctoral level clinical psychologists with specific training and experience in acceptance of illness. A total of 40 items were rated by seven additional content experts (i.e., doctoral clinical psychologists who also have specific training and clinical experience in acceptance of illness). Items were rated on a 0–4 scale, from poor to excellent fit to the acceptance of illness construct. Items were retained if the mean score of the raters was average to excellent fit. Items that were deemed repetitive were then identified, and the lower scoring item was deleted. There were 14 items remaining on the final version of the IAS (Table 1). Internal consistency was excellent (Cronbach's alpha = 0.92).

Results

Demographics of candidates are in Table 2. Participants were primarily male and Black/African American, with an average age in the mid-50 s. Participants were fairly equally divided between having end stage heart or lung disease. Half of patients completed the psychological evaluation inpatient and half outpatient.

There were 14 patients (4.8%) who were missing responses on 1 or 2 items on the IAS. In these cases, the missing responses were replaced by calculating an average of the other items on the IAS. Scores on the IAS were not related to age, gender, race, type of end stage organ disease, or illness severity (i.e., outpatient vs. inpatient; Table 2).

Descriptive statistics of all study measures and correlations with IAS scores are reported in Table 3. All scores were normally distributed with the exception of the REALM-SF and Brief Medical Numbers test which were mildly negatively skewed (−2.50 and −1.41, respectively) because a higher proportion of patients reached the maximum score on these measures. Scores on the IAS were negatively correlated with scores on the depression, anxiety, and catastrophizing measures (Table 3). Although scores for cognitive functioning were positively correlated with IAS scores (Table 3), scores on the IAS were not significantly related to whether a patient scored in the normal range for cognitive functioning ($t = -1.80$, $p = .07$), health literacy ($t = -0.95$, $p = .35$), or health numeracy ($t = -1.28$, $p = 0.20$), and were not correlated with scores on the health literacy and health numeracy measures (Table 3).

Discussion

Findings from this study demonstrated the IAS is a reliable and valid tool for the evaluation of the degree of acceptance of illness among individuals seeking LVAD/heart transplantation or lung transplantation. First, the high level of internal consistency suggests that this measure is reliable. Second, there was evidence of convergent validity as the IAS was inversely associated with measures of depression, anxiety, and catastrophizing. Finally, divergent

Table 1 Illness Acceptance Scale (IAS)

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
We are interested in the ways that your illness may affect you. Using the scale below, please indicate how much you agree or disagree with the following statements					
When answering, please respond about your diagnosis of: _____					
1. I can still live my life despite my illness	0	1	2	3	4
2. I am able to think about things other than my illness	0	1	2	3	4
3. It is okay for me to experience symptoms of my illness	0	1	2	3	4
4. Although things may have changed because of my illness, I am still able to enjoy life	0	1	2	3	4
5. I am social despite my illness	0	1	2	3	4
6. I feel as if all I can think about is my illness	4	3	2	1	0
7. It is okay if I do not feel my best every day	0	1	2	3	4
8. Even though I have an illness, I am able to find meaning in my life	0	1	2	3	4
9. I feel confident in my ability to manage my illness	0	1	2	3	4
10. I need to control my illness before I can do other things in my life	4	3	2	1	0
11. I can still do enjoyable activities even though I have an illness	0	1	2	3	4
12. It is difficult to find value in my life because of my illness	4	3	2	1	0
13. I can still pursue my goals with my illness	0	1	2	3	4
14. I avoid thinking about my illness	4	3	2	1	0

Table 2 Demographics and relation to Illness Acceptance Scale (IAS) scores

Age, years			IAS scores			
	M	*SD*			*r*	*p*
	56.6	11.3			.07	.67
	%	*n*	*M*	*SD*	*t*	*p*
Gender						
Male	66.6	193	39.23	8.36	.30	.76
Female	33.4	97	39.56	8.10		
Race/Ethnicity						
Black/African American	65.9	191	37.84	8.80	− 1.44[a]	.15
White/Caucasian	27.6	80	39.59	8.09		
Other/multiracial	6.5	19				
Type of organ failure						
Heart	53.1	154	40.24	7.97	1.83[b]	.07
Lung	46.6	135	38.36	8.51		
Both	0.3	1				
Setting of psychological evaluation						
Inpatient	50.0	145	39.63	8.10	.54	.59
Outpatient	50.0	145	39.01	8.42		

[a]Analysis only included Black/African American vs. White/Caucasian

[b]Analysis only included heart vs. lung

Table 3 Descriptives of study measures and relationship to the Illness Acceptance Scale (IAS)

Measure	Range	*M*	*SD*	IAS score	
				r	*P*
Illness acceptance scale	17–56	39.33	8.26	–	–
Montreal cognitive assessment	10–30	22.62	3.68	.15	.01
REALM-SF	0–8	6.35	1.33	.11	.07
Brief medical numbers test	0–4	3.47	.82	.08	.22
HADS-anxiety	0–16	5.30	3.61	− .47	< .001
HADS-depression	0–15	5.10	3.42	− .65	< .001
Catastrophizing	0–50	15.33	10.65	− .52	< .001

REALM-SF Rapid Estimate of Adult Learning in Medicine—Short Form

HADS Hospital Anxiety and Depression Scale

validity was present as scores on the IAS were not associated with demographics (i.e., age, gender, race), type of end stage organ disease (heart vs. lung), illness severity, health literacy, or health numeracy. This was important to evaluate to ensure that acceptance of illness extends beyond just understanding the illness and that it was independent of severity of the illness. Further, we had a demographically diverse patient sample that is representative of patients seeking LVAD and/or thoracic transplantation at our institution. Though this may not be representative of the demographics of patients pursuing transplant across the United States, the variability of the sample suggests that the IAS is valid among diverse patients.

The degree to which individuals pursuing thoracic transplant or LVAD accept their illness appears to be associated with lower levels of current psychiatric symptoms. Chiefly, those who exhibited higher levels of acceptance of their illness had lower levels of depression, anxiety, and catastrophizing. This aligns with past research that showed lower acceptance of chronic illness has been associated with poorer levels of psychological and physical functioning (McCracken, 1998; Oris et al., 2018; Viane et al., 2003), and extends the state of the literature by showing similar associations among thoracic transplantation or LVAD candidates. As mentioned, this may be especially important for patients pursuing thoracic transplant or LVAD since mental health prior to transplant is related to post-transplant mental health and physical functioning outcomes (Corruble et al., 2011; DiMartini et al., 2011; Miller et al., 2013; Rogal et al., 2013; Schulz & Kroencke, 2015).

Models of adjustment to chronic disease suggest that acceptance impacts how the individual copes with and adapts to the disease (Walker et al., 2004). Knowing that acceptance is related to mental health prior to undergoing thoracic transplant or LVAD, it may be beneficial for patients with low levels of acceptance to engage in ACT. Although acceptance and psychiatric symptoms were highly correlated, the average depression and anxiety scores did not reach clinical significance, yet many patients may still struggle with acceptance. Thus, the IAS may capture patients who

score within the normal range on a measure of depression or anxiety, but could still benefit from ACT to assist with acceptance and adjustment. Indeed, there is limited evidence that ACT may be useful for improving quality of life among patients who received a kidney transplant or were on hemodialysis (Azari et al., 2020). We also hypothesize that ACT treatment would reduce symptoms of depression and anxiety among thoracic transplant or LVAD candidates, since it has improved psychiatric symptoms among patients with other chronic illnesses (Graham et al., 2016). Psychiatric symptoms have been associated with adherence post-transplant, and nonadherence is related to poorer transplantation outcomes (Burra et al., 2011). As such, improving acceptance through ACT could improve mental health, ultimately leading to better post-transplant outcomes. Further, benefits of ACT have been observed among cancer survivors (Mathew, Doorenbos, Jang, & Hershberger, 2020), whose fears of cancer recurrence may be similar to fears of organ rejection among transplant candidates (Forsberg et al., 2018, 2020). Thus, ACT may be particularly useful for patients who struggle with the uncertainty inherent to their medical condition. ACT holds promise toward impacting mental health and medical outcomes for patients pursuing transplantation, which would be a valuable area for future study.

Although the findings of this study are promising regarding the association between acceptance of illness and symptoms of anxiety and depression, this must be interpreted with caution as the findings are correlational. Another limitation worthy of noting is that participants in this study completed the IAS as part of their pre-surgical psychological evaluation for LVAD and/or thoracic transplantation and therefore may be inclined to present favorably in order to obtain psychological clearance. Future research in this area could consider administering a measure of social desirability, such as the Marlowe-Crown Social Desirability Scale or Personality Assessment Inventory Positive Impression Management, which have been used in pre-surgical bariatric evaluations (Ambwani et al., 2013; Butt et al., 2020). Additionally, we did not measure test–retest reliability or predictive validity of the IAS, or examine the IAS with an existing measure of illness acceptance; these could be addressed in future studies. Our catastrophizing measure was designed for pain catastrophizing and the adapted version we used in this study has not been validated. Finally, although we used the setting of the evaluation as a proxy for illness severity, we did not have other information regarding severity or duration of illness.

Individuals pursuing LVAD and/or thoracic transplantation who are able to acknowledge their illness while continuing to find meaning in their lives may experience lower levels of depression, anxiety, and catastrophizing. Healthcare providers evaluating individuals for transplant could consider adding the IAS to their assessment battery. If the IAS suggests an individual has low levels of acceptance of illness, providers may also want to consider utilizing acceptance-based strategies or referring for ACT treatment. Providers may also want to consider assessing acceptance of illness post-LVAD or post-thoracic transplant, as many patients may continue to adjust. Future research would benefit from evaluating whether acceptance is similar for other types of transplant candidates (i.e., abdominal, bone marrow), if acceptance varies based on type of treatment offered (i.e., LVAD, transplant, or palliative care), and whether improving acceptance among patients pursuing organ transplant yields better mental health outcomes prior to transplant as well as mental health and medical outcomes after transplantation.

Authors' Contributions Lisa R. Miller-Matero—Concept/design, data analysis and interpretation, drafting of the article, approval of article; Leah M. Hecht—Data interpretation, drafting of the article, approval of article; Farah Elsiss—Data interpretation, drafting of the article, approval of article; Mary Kate Miller—Concept/design, data acquisition and interpretation, critical revision of article, approval of article; John Son—Data acquisition and interpretation, critical revision of article, approval of article; Shu Ling—Data acquisition and interpretation, critical revision of article, approval of article; Antú Segal—Concept/design, data interpretation, critical revision of article, approval of article; Kelly Bryce—Concept/design, data interpretation, critical revision of article, approval of article.

Availability of data and material Data will be made available to those interested with reasonable requests.

Compliance with Ethical Standards

Conflict of interest Lisa R. Miller-Matero, Leah M. Hecht, Farah Elsiss, Mary Kate Mille, John Son, Shu Ling, Antú Segal, and Kelly Bryce declare that they have no conflict of interest.

Ethical Approval Approval was obtained from the IRB at Henry Ford Health System. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Informed Consent Informed consent was waived to do the retrospective nature of the study.

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