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Trajectories of self-care agency and associated factors in lung transplant recipients over the first 12 months following transplantation

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Abstract

Self-care agency (SCA), defined as one's ability and willingness to engage in self-care behaviors, can influence actual performance of self-care behaviors in lung transplant recipients (LTRs). Understanding patterns of SCA over time may inform the design of interventions to promote self-care in LTRs. Using group-based trajectory modeling, we sought to identify patterns and correlates of SCA among 94 LTRs over the first 12 months post-transplant. Baseline measures of sociodemographic, clinical, and psychosocial factors, and longitudinally assessed psychological distress were examined for their associations with predicted trajectory group membership. Three distinct stable (ie, zero slope) SCA trajectories were identified as follows: *persistently low*, *persistently moderate*, and *persistently high*. Based on the final multivariate model, requiring a re-intubation after transplant ($P=.043$), discharged to a facility rather than home ($P=.048$), and reporting a higher level of baseline anxiety ($P=.001$) were significantly associated with lower SCA. Linear mixed models revealed that higher levels of anxiety and depression were associated with lower SCA in the *persistently moderate and low SCA* groups over the 12-month time period ($P<.05$). LTRs who require a re-intubation after transplant and are discharged to a facility other than home, and report high psychological distress, may need additional assistance to engage in post-transplant self-care behaviors.

Keywords

group-based trajectory modeling; lung transplant recipients; self-care; self-care agency; self-management

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CONFLICT OF INTEREST

None.

1 | INTRODUCTION

Over the last few decades, lung transplantation has been increasingly performed for individuals with end-stage lung diseases and can lead to markedly improved quality of life.^{1,2} As a medically complex and chronically ill population, lung transplant recipients (LTRs) are prescribed a lifelong medical regimen to follow.³ LTRs are expected to perform a variety of self-care behaviors such as adhering to medication taking, self-monitoring of their lung functions, vital signs and symptoms, and communicating critical changes to their transplant coordinators in a timely manner.^{4,5} Adhering to these activities has been shown to be effective in detecting and preventing early post-transplant complications, improving health outcomes, and reducing health care cost.^{6,7} Despite the widely agreed importance of these self-care behaviors, accumulating evidence shows that actual performance of these behaviors by LTRs is suboptimal and far below the recommended levels.^{4,8,9}

Orem's theory of self-care purports that self-care agency (SCA), defined as one's ability and willingness to engage in self-care behaviors, influences how well an individual performs a wide variety of self-care behaviors across many chronic illness populations.¹⁰ Low level of SCA was associated with low level of engagement in self-care behaviors, poor medication adherence, and suboptimal health outcomes such as poor glycemic control in patients with type 2 diabetes.^{11–14} Furthermore, the theory of self-care posits that SCA is influenced by sociodemographic, clinical, and psychosocial characteristics of an individual.^{10,14}

Although SCA has gained much attention in individuals with chronic conditions such as cystic fibrosis,¹¹ diabetes,¹² chronic obstructive pulmonary diseases,¹⁵ and hypertension,¹⁶ research regarding SCA after lung transplantation is limited. One study has described the levels of SCA and examined its correlates among LTRs prior to discharge from their transplant surgery, and found that LTRs reported higher levels of SCA than patients with other chronic diseases.¹⁷ The authors suggested that, perhaps because SCA was assessed before discharge, LTRs might have been overly confident about their capability to perform self-care behaviors at home.¹⁷ The authors thus called for future work to explore longitudinal patterns of SCA among LTRs.

Given the key role that self-care behaviors play in promoting health outcomes after lung transplantation, it is important to more fully understand the longitudinal patterns and correlates of SCA to guide the development of interventions to promote SCA or prevent a decline in SCA among LTRs. Therefore, the purposes of this study were to (i) identify the distinct patterns of SCA over the first 12 months post-hospital discharge after transplant and (ii) examine correlates of the patterns for SCA among LTRs.

2 | METHODS

2.1 | Study design

This study was a secondary analysis of longitudinal data collected during a randomized controlled trial (R01 NR107011, PI: DeVito Dabbs). The aims of the parent study were to examine the efficacy of Pocket PATH®, a mobile health intervention, compared to usual care for promoting self-care behaviors (primary outcomes), SCA, and transplant-related health

(secondary outcomes) among LTRs over the first 12 months post-hospital discharge after transplant.¹⁸

2.2 | Sample and setting

Eligibility for this study was identical to that of the parent study. Inclusion criteria included LTRs who were (i) >18 years of age; (ii) stable enough to be transferred from the cardiothoracic intensive care unit (ICU) to the acute care unit; and (iii) able to speak and read English. Exclusion criteria were LTRs who (i) had received any prior transplant or (ii) were unable to perform their self-care. All LTRs were recruited from the Cardiothoracic Transplant Program of University of Pittsburgh Medical Center.

The sample for this study was comprised of the 102 LTRs who were randomized to the usual care arm. The rationale to focus only on the usual care group was to avoid the possible intervention effect on SCA. The sample used for this secondary analysis partially overlapped with the sample reported in a prior report,¹⁷ which focused on cross-sectional baseline data (prior to randomization), whereas this investigation included all LTRs randomized to the usual care arm and examined longitudinal patterns of SCA over 12 months.

2.3 | Procedures

IRB approval was obtained for this study. In the usual care arm, LTRs received standard discharge education regarding their self-care requirements during a one-on-one education session with a transplant coordinator who provided written materials and a spirometer for LTRs to monitor lung function at home.¹⁸ LTRs were instructed to self-monitor changes in health parameters such as temperature, spirometry readings, and symptoms for possible complications and to record these data on paper and pencil logs.¹⁸ Prior to hospital discharge, all potential eligible LTRs were approached and asked to sign written informed consent to participate in the parent RCT. Baseline data were collected by trained interviewers after the standard discharge education but prior to discharge and randomization. All participants were re-assessed at 2, 6, and 12 months post-hospital discharge after transplant.

2.4 | Measures

2.4.1 | Dependent variable – Self-care agency (SCA)—We used the 53-item, self-report instrument, perception of self-care agency, to measure SCA.¹⁹ The survey uses a 5-point Likert scale with higher scores indicating higher perceived SCA (possible score range, 53 to 265). A sample item is “*I can choose what is important and least important when taking care of myself*” (1=never like me; 5=always like me). The internal consistency reliability of this scale has been established in prior studies¹⁸ and was 0.94 in this current sample. This scale was completed at baseline (ie, post-transplant but immediately prior to discharge) and at 2, 6, and 12 months post-hospital discharge after transplant.

2.4.2 | Potential correlates of SCA—The following potential correlates were selected to be consistent with the factors outlined by Orem’s self-care theory¹⁰ and prior research in LTRs¹⁷ and other chronic illness populations.^{11,12,14–16}

Sociodemographic correlates: Characteristics such as age, gender, race, marital status, education, and whether respondents felt that their income met their needs were collected at baseline using a sociodemographic profile. Given the small number of nonwhite participants, race was considered descriptively but could not be included in multivariate analyses.

Clinical correlates: Data were abstracted from the medical record for clinical factors including type of lung transplant (single vs double), underlying lung disease (obstructive vs non-obstructive), need for re-intubation (yes vs no), duration of ventilation (<48 hours vs 48 hours), number of days in ICU, number of days with chest drain, length of hospital stay (days), and discharge destination (home vs other facility).

Psychosocial Correlates

Quality of recipient-caregiver relationship: The quality of the relationship between LTRs and their caregivers was assessed at baseline using a 15-item, self-report questionnaire adapted from the Dyadic Adjustment Scale (DAS).²⁰ This adapted scale has been shown valid and reliable in LTRs population in prior reports.^{4,17} Item scores are summed with higher scores indicating higher relationship quality (possible score range: 15–75; Cronbach's alpha = 0.80 in the present sample).

Health locus of control: The Multidimensional Health Locus of Control Scale^{21,22} was used to measure LTRs' beliefs about responsibility for control over their health outcomes at baseline. LTRs rated the extent to which they believed their health outcomes were (i) their own responsibility (Internality subscale), (ii) due to chance (Chance subscale), or (iii) their health care professionals' responsibilities (externality subscale) (Cronbach's alpha in the present sample was 0.78, 0.77, and 0.43, respectively). Each subscale consists of 6 items, with possible score ranging from 6 to 36. Higher subscale scores indicate stronger control beliefs. We omitted externality subscale from analysis because the Cronbach's alpha for this subscale was low (0.43) in our sample.

Psychological distress: The anxiety and depression subscales of the Symptom Checklist 90-Revised (SCL-90-R)²³ was used to measure self-reported psychological distress at all four time points, baseline, 2, 6, 12 months post-hospital discharge after transplant. The subscales focus on the past 2 weeks and use a 5-point rating scale (0=not at all to 4=extremely distressed). Higher scores indicate higher levels of distress. The subscale scores were calculated by averaging item scores (possible score range: 0–4). Cronbach's alpha in the current sample for baseline scores was 0.86 for the anxiety subscale and 0.82 for depression subscale.

2.5 | Statistical analysis

Descriptive analyses were performed using IBM® SPSS® Statistics for Windows (version 23, IBM, Corp., Armonk, NY, USA). The significance level was set to .05 for two-tailed hypothesis testing. For continuous variables without outliers, we reported means and standard deviations. For continuous variables with outliers, we reported medians and interquartile ranges. Categorical variables were summarized using frequency counts and percentages. Outliers for each variable were examined and replaced with the next highest/

lowest values that are not outliers.²⁴ We did not impute any missing data given evidence that the missing data points appeared likely to be missing completely at random (MCAR) (Little's MCAR test $P=.53$); ignorable missingness can be handled directly by the trajectory modeling.²⁵

The TRAJ procedure (PROC TRAJ) in SAS (version 9.4, SAS Institute, Cary, NC, USA) was used to perform group-based trajectory modeling^{25,26} to identify distinct trajectories of SCA over the first 12 months after discharge after transplant. Censored normal modeling was chosen because the dependent variable, SCA, is a continuous variable. We determined the appropriate number of groups and the shapes of trajectories by comparing Bayesian information criteria (BIC) and Bayes factor for competing models.^{25,26}

We applied ordinal logistic regression assuming proportional odds to examine the baseline correlates of predicted membership by the trajectory modeling. In order to maximize the ratio of sample size to number of variables, we first performed univariate ordinal logistic regression considering each baseline correlate singly to screen for candidate variables for the multivariate modeling. Given the relatively small sample size for this investigation, we used a liberal 0.30 P -value cutoff for univariate screening to retain likely important candidate variables in the final model.²⁷ Using a backward elimination approach, a final parsimonious multivariate model was determined where all retained variables were statistically significant ($P<.05$). The proportional odds assumption was met for all ordinal logistic regression models. For the longitudinally measured psychosocial correlates of anxiety and depression, we applied linear mixed modeling to examine the associations between these time-dependent covariates and the predicted group membership for SCA over the first 12 months after discharge after transplant.

3 | RESULTS

3.1 | Sample characteristics

We excluded eight participants who died during the study, leading to a final sample for analysis of 94 LTRs. There was no difference between these eight participants and the rest of the sample, except that those eight LTRs were more likely to be discharged to facilities other than home. Table 1 summarizes the sociodemographic, clinical, and psychosocial characteristics of the 94 LTRs. Our samples were mostly White (88.3%), currently married (71.3%) and had above high school education (67.0%), and male (59.6%) with a mean age of 57.2 ± 13.6 years. Majority of them had bilateral lung transplantation (83.0%), and 42.6% had the pre-transplant diagnosis of obstructive disease. These characteristics were representative of the lung transplant population in the United States.²⁸

3.2 | Trajectories of Self-care Agency

Based on the group-based trajectory modeling, a model with three distinct stable (ie, zero slope) trajectory groups provided best fit to the data ($BIC=-1573.58$). As shown in Figure 1, group 1 (*persistently low SCA*) consisting of 20.2% of the sample ($n=19$) was characterized by a flat trajectory (zero slope) with an intercept of 199.65 ($P<.001$). This group had a relatively low SCA (199.65 of 265) at baseline that persisted throughout the 12 months of

follow-up. Group 2 (*persistently moderate SCA*, $n=47$, 50.0%) also had a flat trajectory (zero slope) but with a relatively higher intercept (intercept, $b_0=223.32$, $P<.001$). This trajectory was characterized by a moderate level of SCA (223.32 out of 265) at baseline that persisted at this level over 12 months of follow-up. Group 3 (*persistently high SCA*, $n=28$, 29.8%) had a flat zero-slope trajectory ($b_0=247.26$, $P<.001$). These participants started at a relatively high level of SCA (247.26 of 265) compared to the other two groups and stayed at this level over 12 months of follow-up.

3.3 | Baseline correlates of self-care agency

Based on the univariate analyses, seven candidate correlates met the threshold of $P<.30$ and were included in the full multivariate model: age, need for re-intubation, discharge destination, length of stay, pre-discharge anxiety, pre-discharge depression, and quality of recipient-caregiver relationship. Using a backward elimination approach, we obtained the most parsimonious multivariate model with only three correlates retained, including need for re-intubation during hospital stay (OR=2.61, 95% CI: 1.03–6.55, $P=.043$), discharged to a facility other than home (OR=3.53, 95% CI: 1.01–12.30, $P=.048$), and reporting a higher level of pre-discharge anxiety (OR=4.06, 95% CI: 1.79–9.21, $P=.001$) (see Table 2). In other words, requiring a re-intubation, discharged to a facility other than home, and reporting a higher anxiety level were associated with relatively low level of SCA.

3.4 | Longitudinal correlates of self-care agency

Figures 2 and 3 show the linear mixed modeling results for longitudinal correlates of SCA. There was a significant group effect ($P=.002$) for anxiety, suggesting that the changes in anxiety scores over the 12 months were distinctly different among the three SCA groups such that the *persistently high SCA* group had significantly lower anxiety levels than both the *persistently low SCA* group ($P=.03$) and the *persistently moderate SCA* group ($P=.049$) (Figure 2). There was a significant group effect ($P<.001$) and group-by-time interaction effect ($P=.01$) for depression, suggesting that the changes in depression among the three SCA groups differed over time (Figure 3). Specifically, significantly lower levels of depression were observed in the *persistently high SCA* group relative to those observed in both the *persistently low SCA* group ($P=.002$) and the *persistently moderate SCA* group ($P<.001$). This suggests that higher depression levels were associated with relatively lower SCA levels in *persistently moderate and low SCA* groups.

4 | DISCUSSION

This study examined patterns of SCA over the first 12-months post-hospital discharge after transplant. Three patterns of SCA were identified as follows: a *persistently low SCA group*, a *persistently moderate SCA group*, and a *persistently high SCA group*. This suggests that, under usual care condition, SCA levels remained relatively stable within each group over time. Of particular note, there were approximately 20-point differences in SCA levels among the three trajectory groups. Although higher scores indicate higher perceived SCA, it is unclear whether these 20 points reflect clinically meaningful differences. While we found that under a usual care condition SCA levels were stable in each group, others have demonstrated that SCA is responsive to interventions and can improve over time.^{5,29} Taken

together, these suggest the importance of assessing LTRs' SCA prior to discharge and intervening early to reinforce and/ or strengthen LTRs' SCA,³⁰ and ultimately to promote better health outcomes over time.

This study also examined correlates associated with patterns of SCA. We found that LTRs who required re-intubation during the transplant hospitalization or were discharged to care facilities other than home were more likely to be in the lower SCA groups. Requiring a re-intubation or discharged to care facilities may indicate the poor physical health status of LTRs. The relationship between poorer physical health and lower SCA has been reported in other chronic diseases population.³¹ It is possible that poor physical health status diminishes one's confidence in ability to perform self-care behaviors.³² In cases where SCA is likely to be significantly compromised by poor health over time, it may be important to engage family caregivers as co-managers of the LTRs' health after transplant.³³ Given that factors such as discharged to facilities other than homes and requiring a re-intubation were associated with relatively low SCA levels, it may be valuable to include a measure of frailty in future studies.

The current study revealed a significant negative correlation between psychological distress and SCA level with higher levels of baseline anxiety associated with lower SCA. This finding is consistent with the earlier report,¹⁷ which found that LTRs with higher levels of psychological distress prior to discharge were more likely to report lower SCA. This negative relationship has also been reported in other populations, such as patients with chronic obstructive pulmonary diseases.¹⁵ This significant baseline association suggests that it may be important for future studies to assess LTRs' psychological distress levels before transplant, which may provide further explanation for the high levels of anxiety at baseline in the persistently low SCA group. The current study not only confirms that baseline anxiety level is inversely related to baseline SCA levels, but also adds to our understanding that this negative association persists over time. Interestingly, we observed anxiety level in the persistently low SCA group was trending down toward that in the moderate SCA group over time, yet the SCA level did not change for the low SCA group. The lack of improvement in SCA for the low SCA group may be due to the fact that this group remained at significantly higher levels of depression than the moderate group at 2 and 6 months post-discharge, which may adversely affect their confidence of self-care and potentially explain the low SCA. Psychological distress includes symptoms of anxiety and depression and has been shown to negatively influence a person's motivation, self-concept, and ability to problem solve and cope.³⁴ This may explain why LTRs with higher distress report lower SCA, highlighting the importance of screening and monitoring psychological distress over time and intervening to reduce the distress among LTRs following transplantation when needed.

Several limitations in this study must be recognized. The sample was recruited from a single transplant program, which may limit our findings' generalizability, although the sample was representative of LTRs population in the United States.²⁸ Our sample included only the participants of the parent study who were randomized to the usual care group, which limited our sample size. However, we employed several strategies in the analyses (ie, univariate screening and backward elimination) to ensure that the respondent-to-variable ratio met the suggested target of 10:1.³⁵ Lastly, some of the correlates, such as the quality of recipient-

caregiver relationship, were only measured at baseline, limiting our ability to explore how these correlates may be associated with SCA over time.

5 | CONCLUSIONS

In conclusion, this is the first study to examine longitudinal patterns and correlates of SCA in LTRs over the first 12 months after discharge from transplant hospitalization. Three stable patterns of SCA were identified, indicating that under usual care conditions, over the first 12 months after discharge, SCA is a relatively stable phenomenon. Health care providers may use the risk information such as requiring a re-intubation after transplant and being discharged to a facility other than home to identify and target high-risk population for low SCA. The negative association between psychological distress and SCA points to potential important targets for strengthening SCA, promoting self-care, and ultimately optimizing health outcomes after lung transplantation.

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FIGURE 1.

Trajectory groups for self-care agency (SCA) over the first 12 mo after discharge from lung transplant. Solid lines are based on actual SCA scores, and dashed lines are based on predicted values from group-based trajectory modeling

FIGURE 2.
Levels of anxiety over 12 mo by self-care agency (SCA) groups

FIGURE 3.
Levels of depression over 12 mo by self-care agency (SCA) groups

TABLE 1

Sample characteristics at baseline (N=94)

	Baseline characteristics	Mean±SD or n(%)
Sociodemographics	Age (y)	57.20 (13.58)
	Male	56 (59.6%)
	White	83 (88.3%)
	>High school	63 (67.0%)
	Income met needs	75 (79.6%)
	Currently married	67 (71.3%)
Clinical correlates	Obstructive lung disease	40 (42.6%)
	Re-intubated post-transplant (No)	67 (71.3%)
	Bilateral lung transplant	78 (83.0%)
	<2 d on ventilator	59 (62.8%)
	Discharge to home	81 (86.2%)
	Length of ICU stay (d) ^a	6.50 (3.00–13.00)
	Chest drain (d) ^a	12.00 (10.00–19.00)
Psychosocial correlates	Length of hospital stay (d) ^a	32.00 (20.75–47.50)
	DAS quality of recipient-caregiver relationship ^a (possible score range: 0–75)	67.00 (63.25–70.75)
	MHLC-internal subscale (possible score range: 6–36)	23.71 (6.59)
	MHLC-chance subscale (possible score range: 6–36)	18.26 (7.10)
	SCL-90 anxiety ^a (possible score range: 0–4)	0.40 (0.10–0.80)
	SCL-90 depression ^a (possible score range: 0–4)	0.46 (0.31–0.82)

SD, standard deviation; ICU, intensive care unit; DAS, dyadic adjustment scale; MHLC, multidimensional health locus of control; SCL, symptom checklist.

^aMedian and interquartile range was used to describe those variables given there are outliers for those variables.

TABLE 2

Adjusted odds ratios for membership in the persistently low self-care agency (SCA) group

Baseline correlates	Adjusted OR	95% CI	P value
Discharged to a facility (vs home)	3.53	1.01, 12.30	.048
Required a re-intubation during hospital stay (vs no re-intubation)	2.61	1.03, 6.55	.043
SCL-90 anxiety	4.06	1.79, 9.21	.001

OR, odds ratio; CI, confidence interval; SCL, symptom checklist.