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Evaluation of a hand-held, computer-based intervention to promote early self-care behaviors after lung transplant

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Abstract: Background: Lung transplant recipients are expected to perform self-care behaviors to maximize transplant-related health outcomes. Despite high non-adherence rates in performing these self-care behaviors, and the dire clinical consequences of such non-adherence, interventions are lacking. Pocket Personal Assistant for Tracking Health (Pocket PATH) is a hand-held device developed for patients to record health data, review data trends, and report condition changes to the transplant team.
Methods: A pilot trial was conducted to compare self-care agency, self-care behaviors, and health-related quality of life (HRQOL) between recipients randomized to use Pocket PATH (n = 15) vs. standard care (n = 15) for the first two months following hospital discharge after lung transplantation.
Results: Baseline characteristics were equivalent across groups. Patients in the Pocket PATH group showed significantly higher ratings of self-care agency, performed self-care behaviors at significantly higher rates, and reported significantly better HRQOL than standard care controls.
Conclusion: Pocket PATH is more efficacious than standard care in promoting early self-care agency, self-care behaviors, and HRQOL in lung recipients. A large-scale randomized controlled trial is needed to test the impact of Pocket PATH on long-term self-care behaviors.

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Key words: adherence – hand-held computer device – health informatics – lung transplant – mobile computing – patient-centered technology – personal digital assistant – self-care

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Lung transplantation is one of the few treatments shown to improve health-related quality of life (HRQOL) and survival for persons with end-stage lung disease (1, 2). To date, over 20 000 persons have undergone lung transplantation worldwide (2). Although great strides have been made, survival rates decline more precipitously after the first year than in other solid organ transplant recipients; only 62% are alive at three yr after transplant (2, 3). In comparison, three-yr survival rates are 91% for kidney, 80% for heart, and 79% for liver transplant recipients (4). Most lung transplant recipients (LTR) experience an early dramatic improvement in their underlying conditions, but they are at great risk for developing transplant-related complications such as allograft rejection and recurrent infection that interfere with the long-term success of transplant (5). Complications are more likely to be effectively reduced if therapies are employed promptly, highlighting the importance of exploring strategies to promote self-care behaviors that enhance prevention and early detection of complications (6). Thus, LTR are prescribed a complex medical regimen that includes self-monitoring (e.g., home-based spirometry, symptoms, vital signs), adhering to life-long medications and other post-transplant requirements (e.g., diet and exercise), and communicating changes to the transplant team in a timely manner (7, 8).

Although performing these behaviors is known to prevent or detect early declines that can signal the onset of complications (7–11), many LTR find it difficult to perform self-monitoring, identify worrisome trends, and decide what values to report to the transplant coordinator (12). Furthermore, a recent prospective evaluation of adherence to the medical regimen during the first two yr after lung transplant (13) found the following cumulative incidence rates of persistent non-adherence for monitoring blood pressure (70%), measuring spirometry (62%), following dietary instructions (34%), completing blood work (28%) and taking immunosuppressants (13%). Despite such high non-adherence and its dire clinical consequences such as rejection and infection, graft loss, and death (14–21), interventions to promote the performance of these behaviors after lung transplant are lacking.

Several studies support the direct relationship between self-care agency (i.e., an individual's ability to meet one's self-care needs), the performance of self-care behaviors, and ultimately health outcomes (22–30). Additionally, computerized interventions have been shown to help patients with a variety of chronic illnesses to perform self-care behaviors and be more actively involved in managing their illnesses (31–40). Thus, we designed Pocket Personal Assistant for Tracking Health (Pocket PATH University of Pittsburgh, Pittsburgh, PA, USA), personal assistant for tracking health, a hand-held device with customized data recording, trending and decision-support programs to promote self-care behaviors after lung transplant. These self-care behaviors include performing self-monitoring, adhering to the medical regimen and health habits, and communicating changes to the transplant team (Table 1). The process of involving LTR in the design and testing of the Pocket PATH prototype was described previously (41). The purpose of this current study was to evaluate the efficacy of Pocket PATH for promoting self-care agency, self-care behaviors, and HRQOL in the early months after lung transplantation.

Table 1. Features of Pocket PATH intervention to support self-care behaviors

Self-monitoring	Adhering	Communicating with team
Direct entry of data (vitals, symptoms, labs)	Calendar functions	Prompts to report critical values
Log and graphical displays	Reminder systems	Log for tracking feedback
Critical thresholds marked	Note-keeping feature	Log for tracking contacts
Automatic trending over time		Automatic data upload

Pocket PATH, Pocket Personal Assistant for Tracking Health.

Patients and methods

Design

A randomized, controlled pilot trial was conducted to determine the effects of Pocket PATH compared to standard care during the first two months following hospital discharge after lung transplantation. This early study interval was selected because studies have shown that patients' orientation toward sharing responsibility with their health care providers is malleable, with intervention effects seen as early as eight wk (24).

Study participants

All adults (aged 18 +) who received lung transplants at the University of Pittsburgh Medical Center and survived the Intensive Care Unit recovery period were candidates for inclusion in the study. They were not eligible if any of the following criteria were met: (i) recipient of any prior transplant (to avoid history and experiential effects); (ii) existence of a condition that precluded discharge from the hospital; (iii) failure to spend at least seven consecutive days at home during the two-month study period; and (iv) inability to fully participate in care or provide informed consent.

Procedures

The protocol had Institutional Review Board approval. All LTR received standard care to prepare for discharge that consisted of a one-on-one, educational session delivered by the transplant coordinator, plus a spirometer and written instructional materials including paper logs for recording daily health parameters (e.g., pulse, BP, temperature, spirometry, and symptoms). All LTR were given identical instructions for the types and levels of changes in these readings that should prompt them to contact the transplant coordinator. Per transplant protocol, all patients were scheduled to return to the transplant center for routine follow-up evaluations, typically within the first week, then monthly for the first few months, and more frequently as needed.

Once written consent was obtained, pre-randomization, baseline data were collected by trained interviewers. When hospital discharge seemed likely, all LTR participated in the standard

discharge preparation followed by randomization to either the Pocket PATH or standard care control group using a pre-trial permuted block randomization schedule.

In addition to standard care, patients assigned to the intervention group were given the Pocket PATH device and a user manual, and they were trained to use the device according to a scripted protocol. LTR were requested to enter data using the device instead of recording data on the paper logs, review data trends by using the screens and graphs, and follow feedback instructions regarding reporting changes to their transplant coordinator. An alternate training session of comparable duration was delivered to patients in the standard care group. The control patients were tutored in the use of the standard paper/pencil logs to record data. Patients in both groups were instructed to contact their transplant coordinator for any clinical questions or issues. Follow-up was identical for both groups at two months post-discharge.

Intervention evaluation measures

Self-care agency. The perception of self-care agency (PSCA) scale is a 53 item, Likert-type, self-report instrument with established psychometric properties (42). Items are scored as (1 = never like me, to 5 = always like me) and summed, yielding a score ranging from 53 (low perceived self-care agency) to 265 (high perceived self-care agency). The PSCA was administered at baseline and two months. Cronbach's alpha, a measure of internal consistency (how well the items of the scale are intercorrelated and hence provide consistent measurement) for the PSCA in the present study was 0.94, well above the acceptable level for reliability (0.70) (43).

Self-care behaviors. These measures were administered during or at the end of the follow-up period (but were not assessed at baseline because patients had not yet been required to engage in any outpatient self-care). We relied on a combination of self-report plus other methods to measure the performance of the three self-care behaviors of interest. Our rationale for this strategy derived from the results of several meta-analyses which have shown that self-report, either alone, or in combination with other strategies such as collateral reports or historical chart reviews, is more likely to yield evidence of non-adherence to a variety of aspects of the medical regimen than any other methodology (44–46).

Adhering to elements of the medical regimen. The Health Habits Assessment, a self-report measure, uses an ordinal response format to determine post-transplant adherence in 10 areas: (i) taking medications in general; (ii) taking the primary immunosuppressant (cyclosporine or tacrolimus); (iii) attending clinic appointments; (iv) completing blood work; (v) monitoring home blood pressure, (vi) following a prescribed diet; (vii) following a prescribed exercise plan; (vii) abstaining from tobacco use; (ix) limiting alcohol consumption; and (x) performing home spirometry. An identical version of the Health Habits Assessment was administered to each patient's primary family caregiver (e.g., the spouse, a parent, or sibling) as a collateral report. The instrument was originally developed to assess performance of health behaviors by kidney transplant recipients (47), but has since been revised and utilized with heart and lung recipients and their family caregivers (17, 45, 48). Responses for each element were then dichotomized to indicate whether LTR adhered to the minimum level acceptable by the Cardio-Thoracic Transplant Program (i.e., missing immunosuppressant medications less than once per month, or exercising at least several times per week, etc). To arrive at a single measure for adherence to each element, we judged that respondents were more likely to underreport non-adherence than to state that a LTR was not adhering to an element when he/she was in fact adhering. Thus, we took any report of non-adherence to each element, whether from recipient or caregiver, as evidence of non-adherence to that element. To estimate overall adherence, we summed the number of elements (out of the maximum of 10) for which LTR met criteria for acceptable levels of adherence. Because the distribution of this variable was skewed, it was dichotomized (using the sample median) to reflect high adherence to the regimen (adherent to 9+ areas) vs. lower adherence.

Performing self-monitoring. We also directly measured daily monitoring by calculating the ratio of the number of days that patients actually recorded values for symptoms, temperature, or blood pressure to the number of days at home. For LTR in the Pocket PATH group, the device electronically recorded the date that patients entered self-monitoring data. Subjects in the standard control group recorded the date that they entered self-monitoring data on paper logs. The devices and paper logs were reviewed to determine the percentage of days that they performed monitoring. Because the distribution of this variable was skewed, it was dichotomized (using the sample median) such that individuals who recorded monitoring at least 80% of days were considered to have performed acceptable levels of self-monitoring.

LTR are also expected to monitor home spirometry at least three times per week. We reviewed the Pocket PATH and paper log entries to determine how often patients measured spirometry. Responses were then dichotomized to indicate the percentage of LTR who performed home spirometry at least three times per week, the minimum level acceptable by the computed tomography Program.

Communicating with transplant coordinator. Transplant coordinators, who were blinded to recipients' group assignment, routinely maintain an electronic record of all interactions with lung transplant recipients. These records were retrospectively reviewed to determine the number of patient-initiated contacts to coordinators during the first two months after discharge. Data for this variable were normally distributed.

Health-related quality of life. These measures were assessed at baseline and at the two-month follow-up. The Short-Form Health Survey (SF-36), a 36-item self-report measure, was used to assess global HRQOL (49–51). Physical and mental component scales were calculated as specified by Ware et al. (50) such that resulting values were *T*-scores normed against a mean of 50 and a standard deviation of 10 (higher scores being more positive with less limitation). In this study, internal consistency alphas for the physical and mental components were 0.83 and 0.83, respectively.

In addition to global measures, domain-specific measures of emotional and physical health status were assessed. Psychological distress was measured using the anxiety and depression subscales of the Symptom Checklist 90-Revised (SCL-90-R) (52). These subscales measure the severity of anxiety and depression symptoms during the prior two wk. Items are rated on a five-point scale (0 = not at all, to 4 = extremely distressed). Subscale scores were computed by averaging items. Higher scores reflect higher levels of distress. Internal consistency alphas in this study were 0.88 and 0.80 for the anxiety and depression subscales, respectively. Because the distributions of these scores were skewed, data were logarithmically transformed prior to analysis.

The physical dimension of the Sickness Impact Profile (SIP) was used to measure the effect of illness on physical activities related to carrying on one's life (53). Statements are aggregated into 12 categories of activities, three of which (ambulation, body care and movement and mobility) comprise the physical dimension. Respondents select items that they are unable to perform for health reasons. Higher scores indicate higher levels of impairment. Internal consistency for the SIP physical dimension subscale in this study was 0.86. Data were logarithmically transformed to reduce skewness.

Analysis. To determine whether subjects in the Pocket PATH and standard-care control groups were equivalent with regard to variables measured at baseline, between group differences were evaluated using chi-square statistics of proportions for categorical variables and *t*-tests for continuous variables. To determine the effect of the intervention on the self-care behaviors during the follow-up period, between-group differences were evaluated using chi-square for dichotomous variables (daily monitoring, spirometry and adhering to elements of the medical regimen) and univariate analysis of variance (ANOVA) for continuous variables (self-care agency and communicating with the coordinator). For the subset of these outcomes that had been evaluated at baseline as well as during follow-up (self-care agency, HRQOL), baseline values were included as covariates in the ANOVAs (i.e., we tested between-group differences adjusted for baseline levels. In order to limit type I error, since we had multiple outcome variables, we adjusted our p levels within each group of outcome variables (i.e., the four variables reflecting self-care behaviors and the five variables reflecting HRQOL) using Holm's modification of the Bonferroni procedure (54). Data transformations were employed as needed to correct for skewed distributions. Effect sizes, expressed as Pearson's *r*, were calculated; since *r* values can be computed for both continuous and dichotomous variables, it facilitates direct comparisons of effect sizes across all outcomes.

Results

Over a six-month period, all 42 LTR who survived the intensive care unit recovery period were considered for participation in the study. Fig. 1 depicts the flow of participants through each stage of the trial including the numbers of participants randomly assigned, receiving intended treatment, completing the study protocol, and analyzed for the primary outcomes. Of the 39 recipients who agreed to consider participation, three were deemed ineligible (one did not speak English, one was legally blind, and one depended on others for all care). Prior to randomization, two withdrew from the study; one was unwilling to accept either randomization allocation, the other recipient reported feeling too anxious to participate in any studies. Of the 34 who were randomized, four individuals did not meet our minimum criterion for

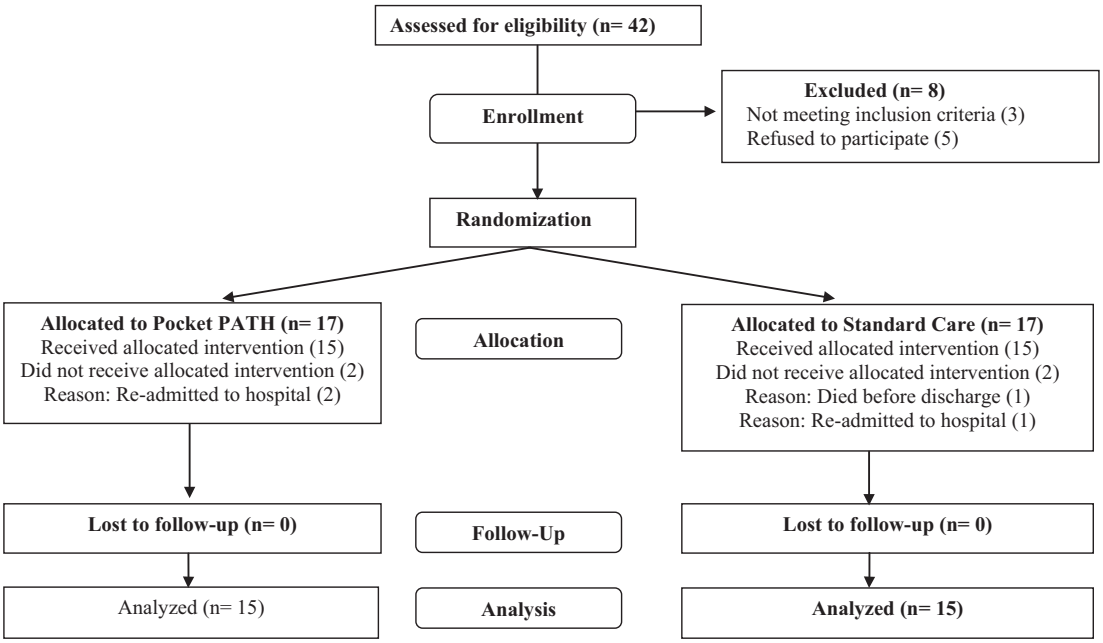

Fig. 1. Flow diagram (56).

data collection on self-care behaviors (one LTR expired prior to discharge and three others were re-hospitalized without spending one full wk at home during the study period). Otherwise, these four LTR did not differ with regard to any demographic or transplant-related characteristics from the final sample of 30 who provided study data.

Baseline characteristics for the sample are shown in Table 2. There was no statistically significant difference between groups on any sociodemographic or clinical characteristics at baseline. There were also no statistically significant differences between groups for any of the outcome variables that were assessed at baseline (self-care agency and HRQOL).

By the end of follow-up, LTR in the Pocket PATH group reported significantly higher levels of perceived self-care agency (M = 250.14, SE = 4.4) than standard care controls (M = 228.8, SE = 4.4; $F_{1,\ 27} = 10.95$; p = 0.003; $r = 0.54$). Fig. 2 displays the results for the self-care behavior outcomes assessed during the first two months following hospital discharge. The figure shows that LTR in the Pocket PATH group performed daily monitoring and spirometry at significantly higher rates than standard care controls during the follow-up period. They also were more likely to show high adherence to the medical regimen, and a higher average number of patient-initiated contacts with the transplant coordinator. Effect sizes (r) for these outcomes ranged between 0.45 and 0.57.

Fig. 3 shows the results for the HRQOL outcomes; the values displayed are mean levels at the two-month follow-up adjusted for subjects' baseline HRQOL scores. After adjustment of p levels to control for type I error, LTR in the Pocket PATH group showed significantly lower anxiety and depression symptom levels and significantly higher scores on the physical functioning component of the SF-36 than standard care controls. Effect sizes (r) for these three outcomes ranged between 0.41 and 0.46. LTR in the Pocket PATH group reported better functioning in the SF-36 mental health domain and SIP scores of physical dysfunction than standard care controls, but the differences in these outcomes did not reach statistical significance.

Discussion

LTR are on the "front line" for detecting complications and following a complex medical regimen from home, yet strategies to maximize their performance of self-care behaviors have received little attention. To our knowledge, this is the first computerized intervention designed to assist LTR to perform self-care behaviors and thus be actively involved in preventing and detecting complications with the aim of improving transplant-related health outcomes. Features that set the Pocket PATH intervention apart from paper and pencil logs and home monitoring alone is the computerization that supports the tasks of self-monitoring,

Table 2. Characteristics of the study sample at baseline

Characteristics	Total sample (n = 30)	Pocket PATH group (n = 15)	Standard care group (n = 15)	Test statistic[a]
Sociodemographics				
Age, M (SE)	56 (11.0)	55 (12.7)	57 (11.0)	0.53
Gender, n (%) female	12 (40)	6 (40)	6 (40)	0.00
Marital status, n (%) married	21 (70)	11 (73)	10 (66)	0.16
Race, n (%) white	23 (77)	10 (66)	13 (87)	1.67
Income, n (%) ≥$50,000[b]	16 (55)	7 (44)	9 (56)	0.91
Education, n (%) ≥ high school	22 (73)	12 (80)	10 (66)	0.68
Employed, n (%) yes	5 (16)	2 (13)	3 (20)	0.24[d]
Family caregiver, n (%) spouse[c]	20 (66)	11 (73)	9 (60)	0.60[d]
Computer experience, n (%) yes	23 (77)	13 (86)	10 (66)	1.67
Clinical characteristics				
Lung disease, n (%) obstructive	13 (43)	8 (53)	7 (46)	1.22
Initial hospital stay, days M (SE)	31 (15)	29.7 (11.6)	32.6 (17.7)	0.53
Days spent in ICU, M (SE)	10 (8)	8.8 (5.4)	10.9 (10.6)	0.80
Self-care agency and HRQOL				
Perceived self-care agency, M (SE)	222 (26)	230.7 (20.3)	213.7 (28.2)	1.89
SF-36 physical component, M (SE)	29.9 (1.2)	30.4 (8.2)	29.5 (4.8)	0.33
SF-36 mental component, M (SE)	48.3 (2.3)	52.5 (11)	44.1 (13)	1.89
SCL-90 anxiety, M (SE)	0.89 (0.7)	0.73 (0.73)	1.04 (.60)	1.30
SCL-90 depression, M (SE)	0.90 (0.5)	0.76 (0.52)	1.04 (.55)	1.44
SIP physical, M (SE)	73.69 (7.3)	44.94 (26.7)	62.46 (50)	1.40

SF-36, Short-Form-36 Health Survey; SCL-90, Symptom Checklist 90; SIP, Sickness Impact Profile; HRQOL, health-related quality of life.
[a]Between group comparisons based on *t*-tests for continuous variables and x^2 for categorical variables; no statistically significant differences were found for any baseline characteristics ($p < 0.05$).
[b]One subject refused to provide data for income, analysis based on 29 subjects.
[c]One subject had no primary family caregiver, analysis based on 29 subjects.
[d]Fisher's exact test was computed due to small sample sizes in some cells.
Data for SIP and SCL scores were log transformed to reduce skewness; group means and standard errors are reported using the original scaling to facilitate interpretation of results.

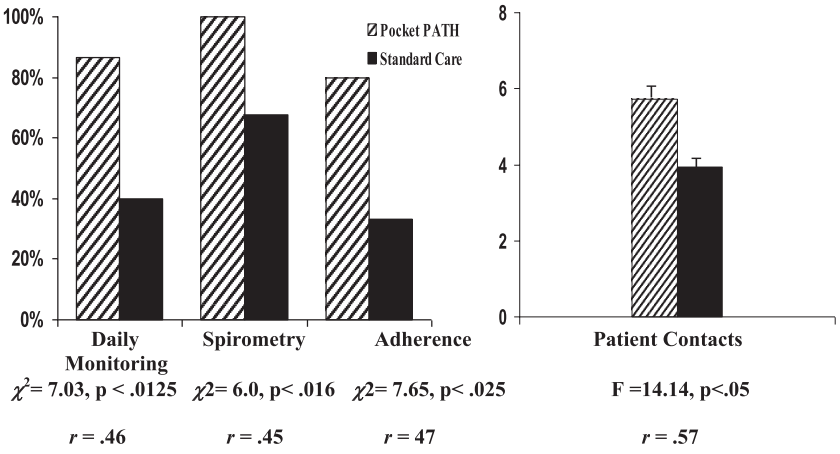

Fig. 2. Comparison of self-care behaviors between groups. Daily monitoring > 80% of days (%); Spirometry > three per wk (%); High overall adherence to the medical regimen (%); Patient initiated contacts to coordinator (M, SE); Value of *F* has 1,27 df; Reported p values are after adjustment for multiple comparisons. p values < threshold are considered to be statistically significant; p values above threshold are not considered statistically significant.

graphing trends overtime and prompting recipients to act on the findings. The results of this randomized controlled trial provide encouraging evidence that Pocket PATH, a hand-held, patient-centered health technology, is acceptable to LTR and superior to the more commonly used paper–pencil methods for tracking and interpreting health information. This mobile application is particularly promising since its benefits lie in promoting adherence, vigilance and communication between LTR and transplant providers during the intervals between routinely scheduled return visits to the transplant center. Moderate to large intervention effects were found for improvements in self-care agency, self-care behaviors, global physical health and levels of anxiety and depression symptoms for LTR in the Pocket PATH group. Group differences in physical dysfunction were not detected, perhaps because the SIP (lower scores mean less impairment) assesses severe impairments such as

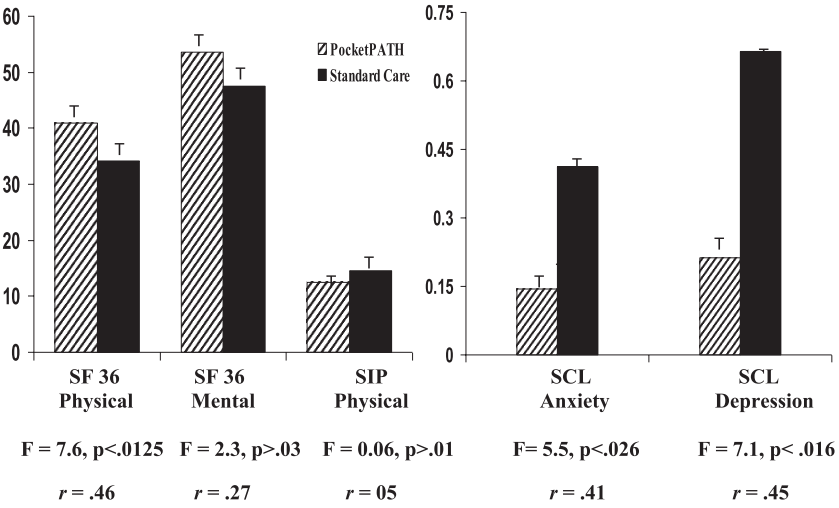

Fig. 3. Comparison of HRQOL outcomes between groups, means at follow-up. Adjusted for baseline levels. HRQOL, health related quality of life; SF-36, Short-Form-36 Health Survey; SCL-90, Symptom Checklist 90; SIP, Sickness Impact Profile. Data for SIP and SCL scores were log transformed to reduce skewness; group means and standard errors are reported using the original scaling to facilitate interpretation of results. Values of F have 1,27 df. Reported p values are after adjustment for multiple comparisons. p values $<$ threshold are considered to be statistically significant; p values above threshold are not considered statistically significant.

inability to get out of bed, walk without assistance, or use stairs, which are unlikely to be experienced by ambulatory patients such as LTR at two months post-transplantation.

Several limitations must be considered when drawing conclusions about our findings. The sample size was small and this limited our power to detect effects that were less than moderately large, according to conventional criteria (55). However, smaller effects may not be of clinical importance; in contrast, the effects that we detected, all of which were fairly large, would be of clinical importance. Also, although we found no statistically significant differences in any baseline characteristics between the groups, some characteristics, such as race (fewer minorities) tended to favor the standard care group, while computer experience tended to favor the Pocket PATH group. Furthermore, our two-month follow-up period was relatively brief. However, the aim of this trial was to estimate the effects of the Pocket PATH compared to standard care during the early post-transplant period. Based on our promising results, a full-scale randomized controlled trial is now in progress to rigorously test the efficacy of Pocket PATH in promoting self-care agency, self-care behaviors, HRQOL and transplant-related health outcomes for the first year after lung transplant and to explore the influence of sociodemographic characteristics on the utilization of Pocket PATH.

In conclusion, the Pocket PATH intervention addresses a critical clinical problem: the need for interventions that assist LTR to perform self-care and thus be actively involved in the prevention and detection of complications that interfere with the long-term success of lung transplantation. We see this approach as augmenting routine clinical care in a manner that strengthens the individual recipient's contribution to reducing morbidity, mortality and promoting better HRQOL after lung transplantation.

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