

TITLE: Functional Outcomes, Goals, and Goal Attainment Amongst Chronically Critically Ill Long-Term Acute Care Hospital Patients

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Rationale: Chronically critically ill patients admitted to a long-term acute care hospital (LTACH) setting are a vulnerable population of intensive care unit survivors. Little is known of the goals and functional outcomes achieved by patients after rehabilitation in the LTACH setting.

Objectives: We sought to examine patient goals and functional outcomes, including swallowing function, amongst ICU survivors admitted to an LTACH with a tracheostomy.

Methods: Prospective observational cohort study of chronic critically ill LTACH patients.

Measurements and Main Results: Fifty elderly subjects with a median duration of intubation prior to tracheostomy of 13 days were enrolled. ICU-acquired weakness and cognitive impairment were present in 40 (80%) and 36 (72%) patients, as measured by the Medical Research Council scale and Montreal Cognitive Assessment, respectively. Mental health problems were also common, with 16 (32%) patients experiencing moderate to severe anxiety, 9 (18%) experiencing moderate to severe depression, and 11 (22%) reporting symptoms consistent with PTSD, according to the Hospital Anxiety and Depression Scale and Post-Traumatic Stress Syndrome 10-Questions Inventory, respectively. Pharyngeal dysfunction, as measured by Fiberoptic Endoscopic Evaluation of Swallow exam, was present in 37 (74%) patients. Patient goals, in decreasing order of frequency, included: eating and drinking, speaking, walking, returning home, and toileting. By LTACH discharge, goal attainment was variable, with 97% of those who ranked speaking as important able to speak, 88% able to eat and drink, yet only 21% were walking and 18% were able to self-toilet. Discharge to the home or acute rehabilitation setting, achieved in 52% of the population, was associated with greater

strength, as measured by the total MRC score ($p=0.002$), as well as the EuroQOL domains of mobility ($p=0.008$) and self-care ($p=0.04$).

Conclusions: Goal attainment during this period of recovery was variable. The ability to speak, eat and drink, frequently identified as goals by these patients, were achieved, while functional goals such as walking were rarely achieved. These findings highlight the importance of identifying patient goals and setting realistic expectations informed by functional assessments when rehabilitating this vulnerable patient population in the LTACH and subsequent post-acute care settings.

Introduction

With advances in care, more than 5 million Americans survive an Intensive Care Unit (ICU) admission annually (1). Many ICU survivors develop post-intensive care syndrome (PICS), defined as new or worsening impairment after critical illness in one or more of the following domains: cognition, mental, or physical health (2). Those recovering from chronic critical illness (CCI) are a vulnerable subset of ICU survivors (3-5). The hallmark of CCI is prolonged dependence on mechanical ventilation, defined as the need for mechanical ventilation for ≥ 21 consecutive days or elective placement of a tracheostomy in anticipation of prolonged ventilatory dependence (3, 6).

Many patients recovering from CCI require post-acute care services, with approximately 20% of such patients being discharged to a long-term acute care hospital, or LTACH (7). Patients who develop CCI experience poor health-related quality of life (HRQOL) and a high risk of death in the subsequent year (8-12). However, more recent evidence reveals that prognosis hinges on whether the patient can be liberated from the ventilator (13). For example, compared to 16% of patients who could not be liberated, 67% of patients who could were alive at one year (14). Further, improvements in muscle strength after discharge permitted many to regain functional abilities 6 months later (14).

While functional recovery is known to be important to ICU survivors when describing their goals (15), little is known about the functional status and goals at this stage of recovery, and whether those goals are attained by the time of LTACH discharge. Further, while speech and swallowing dysfunction is common in patients who require prolonged intubation and tracheostomy (16-19), little is known about whether,

and to what degree, these functional abilities are restored by LTACH discharge. To further illuminate the survivors experience, complement recent qualitative studies (12), and to inform realistic goal setting and rehabilitation protocols in the LTACH setting, we conducted an observational cohort study in an LTACH. Herein, we assessed patients for functional impairments, elicited their functional and rehabilitation goals, and ascertained whether patients were able to achieve their stated functional goals by the time of LTACH discharge.

Methods

Setting

We conducted a prospective observational cohort study between February 1, 2016 and October 31, 2017 at the Specialty Hospital at Rittenhouse in Philadelphia, Pennsylvania, a free-standing 36-bed LTACH. The study followed the criteria set forth in the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement (20).

The Specialty Hospital is a joint venture between Good Shepherd Rehabilitation Network and Penn Medicine. Interdisciplinary rounds are held daily, where the patient's medical, respiratory, and rehabilitation care plan is discussed among the care team, which includes an attending Hospitalist, Pulmonary and Critical Care consultant physician, nursing, pharmacy, respiratory therapy, occupational and physical therapy, and speech and language pathology. Psychological consultation is available for patients who exhibit mental health problems such as anxiety, depression, or symptoms of PTSD.

Study Population

Patients admitted to our LTACH were eligible for enrollment if they were 18 years of age or older, had undergone tracheostomy for ventilator dependent respiratory failure, were nil per os (NPO), and were able to tolerate humidified trach collar (HTC) for 4 or more hours per day for 2 or more consecutive days and therefore were eligible for diet advancement considerations. All patients met criteria for or were recovering from chronic critical illness at the time of enrollment (3, 6).

Patients were excluded for the following reasons: mental status that precluded completion of testing, history of dysphagia, structural abnormalities of the larynx/pharynx, oropharyngeal malignancy or radiotherapy to the head or neck, and/or desire to pursue full comfort measures without plans for ventilator weaning. The study was approved by the Institutional Review Board of the University of Pennsylvania (IRB # 823723), and informed consent was obtained from patients.

Health-Related Quality of Life, Functional Outcomes, and Patient Goal Measurements

We assessed HRQOL and functional outcomes using a battery of validated tests. Consent was obtained during the first session by a speech language pathologist as depicted in the study timeline (Figure 1).

HRQOL was assessed using the EuroQol 5D-5L (21) and the Quality of Life Goals Inventory. The EuroQol 5D-5L records a patient's self-rated health on a visual analogue scale and descriptively scores the following five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. We further screened for functional impairments using the Hospital Anxiety and Depression Scale (HADS) (22) and the Post-Traumatic Stress Syndrome 10-Questions Inventory (PTSS-10) (23) for

mental health problems, the Montreal Cognitive Assessment (MoCA) (24-25) for cognitive impairment and the Medical Research Council (MRC) assessment (26-27) for physical impairment. The HADS assesses for the presence of anxiety and depression and provides a numerical subscale score for each. The PTSS-10 examines for symptoms of post-traumatic stress disorder (PTSD). The MoCA, which requires approximately 10-15 minutes to complete, assesses for cognitive impairment in the following domains: (i) visuospatial and executive function, (ii) naming, (iii) attention, (iv) language, (v) abstract reasoning, (vi) delayed recall/memory, and (vii) orientation. The Medical Research Council (MRC) assessment was completed by physical therapists to assess for the presence of ICU-acquired weakness (ICU-AW) (28). Screening instruments were scored according to established criteria (21-28). With the exception of the MRC assessment, which was performed by a physical therapist, testing was performed in-person by one of three trained investigators after consenting study participants (RD, SS, and VF).

Our Quality of Life Goals Inventory, developed and piloted prior to the study at our LTACH (see eSupplement 1), was designed to elicit a patient's functional goals. Designed to align with their rehabilitation in the LTACH, patients were asked to rank-order these goals with respect to their perceived impact on their quality of life. Participants were asked to rank their top five goals from a list of twelve, provided in random order in large print on a note card. Goals included: being less anxious or depressed, being pain free, breathing better (off the ventilator), eating and drinking, grooming, resuming work or leisure activities, returning (to prior residence) home, speaking, thinking clearly, toileting, walking, and "other." As not all goals were ranked,

we created a salience score, wherein the average rank was multiplied by the frequency with which the goal was selected. Upon LTACH discharge, patients were assessed for the attainment of the following goals: speaking, eating and drinking, walking, toileting, grooming, returning to home, and breathing better, as defined as being liberated from the ventilator for ≥ 72 hours.

Swallowing function and pharyngeal muscle strength were assessed using the Clinical Bedside Swallow Evaluation (CBSE) and Fiberoptic Endoscopic Evaluation of Swallow (FEES). CBSEs were conducted by a Speech Language Pathologist (SLP) and included an oral mechanism/cranial nerve examination, determination of Passy Muir Speaking Valve (PMSV) candidacy and swallowing trials (as appropriate). A CBSE takes approximately 20-30 minutes to perform and includes documentation of tracheostomy tube size, tolerance of HTC trials, tolerance of PMSV, current means of nutrition, and recommendations regarding PO and PMSV.

As part of a rehabilitation pathway for the CCI patient that includes daily physical and occupational therapy, standard practice at our LTACH is to develop a treatment plan during the first CBSE and perform a FEES most often during the third session, given our experience that patients with or recovering from chronic critical illness have a high incidence of silent aspiration. FEES examination takes approximately 5 minutes to complete and is conducted by a SLP and Pulmonologist at our LTACH in accordance with internal established protocols utilizing a 3.3-mm diameter distal chip flexible rhinolaryngoscope (model VNL-1070STK, Pentax, Montvale, NJ), light source (KayPentax, model EPK-1000), and a digital swallow workstation (KayPentax, model 7200).

Data Collection

We abstracted the following clinical information from the electronic health record: age, gender, race/ethnicity, LTACH length of stay, recommended diet level, tracheostomy status, the total number of speech/swallow therapy sessions, and patient disposition.

Data collected from the FEES included: total number of hours tolerating HTC, trach tube size, trach tube occlusion status, laryngeal anatomy description, secretions level (Marianjoy 5-Point Secretion Scale) (29), pharyngeal residue (The Yale Pharyngeal Residue Severity Rating Scale) (30), penetration/aspiration (PAS-5 for FEES) (31) and diet recommendations. Subsequent CBSE and FEES were performed at the discretion of the treating SLP.

Statistical Analysis

We present categorical data as counts and percentages, and continuous variables as means and standard deviation or median and interquartile range (IQR), as appropriate. We tested for associations between ICU-AW and the following predictors of aspiration: 1.) poor management of secretions (secretion level > 2); 2.) pharyngeal weakness (Yale > 2); 3.) pharyngeal dysfunction (Yale > 2 in valleculae and/or pyriform sinuses or PAS > 1); 4.) aspiration risk (PAS > 1). Two-sided Fisher's exact test was used to examine for an association between these dichotomous variables. We tested for associations between ICU-AW and discharge disposition as well as secretion level during FEES with aspiration risk (PAS > 1) and aspiration (PAS ≥ 4) using the Wilcoxon rank-sum test to examine the association between non-normally distributed continuous

variables and dichotomous variables. Statistical analyses were performed using Stata 14 (StataCorp, College Station, Texas); significance was defined as an alpha less than 0.05.

Results

Patient characteristics

Of the 165 patients admitted to our LTACH between February 1, 2016 and October 31, 2017 who had undergone tracheostomy, 56 were eligible to participate, 52 consented, and 50 completed HRQOL and functional outcomes testing, including FEES. As detailed in Figure 2, the most common reasons for exclusion were mental status that precluded completion of testing, failure to meet HTC requirement prior to transfer to an acute care hospital or skilled nursing facility, and patient preference for comfort care without plans for ventilator weaning.

On average, testing was completed in 45 minutes, with an additional 5 minutes required to complete the MRC. The 50 patients who completed testing had a median age of 65 years (interquartile range [IQR] 58-72), 24 (48%) were men, 34 (68%) were white, had a median hospital length of stay of 36 days (IQR 28-47) and the median time to evaluation after LTACH admission was 4 days (IQR 1-13). Duration of intubation prior to tracheostomy was a median of 13 days (IQR 9-18), with 19 (38%) patients requiring multiple intubations. The median time to evaluation after tracheostomy was 22 days (IQR 14-42). The most common discharge disposition was to acute inpatient rehabilitation (Table 1).

Health-Related Quality of Life, Functional Outcomes, and Patient Goals

HRQOL, as measured by the EuroQol visual analogue scale, was low (32), with a median of 50 (IQR 30-60). Problems in one or more domains of PICS was identified in 48 (96%) of patients; physical impairment was the most common functional impairment. Specifically, ICU-AW, as determined by the MRC score, was present in 40 (80%) patients. Cognitive impairment was present in 36 (72%) patients, with mild, moderate, and severe impairment being present in 25 (50%) patients, 9 (18%), and 2 (4%) patients, respectively. Mental health problems were also common, with 16 (32%) survivors experiencing moderate to severe anxiety and 9 (18%) experiencing moderate to severe depression. Additionally, 11 (22%) reported symptoms consistent with PTSD and 44 (88%) patients reported pain/discomfort (Table 2).

As detailed in Table 3, the most salient goal was eating and drinking, with a score of 100 given an average rank of 2.5 and having been ranked in the top 5 goals by 40 (80%) of subjects. The next highest scoring goal was toileting, followed by walking, returning home, breathing comfortably, speaking, feeling less anxious/depressed, grooming, being pain free, thinking clearly, and resuming work or leisure activities.

At the time of the initial FEES exam, 31 (62%) of the patients had pharyngeal weakness, 37 (74%) had pharyngeal dysfunction (Yale > 2 or PAS-5 > 1), and 36 (72%) were identified as an aspiration risk. Based on the results from the FEES exam, 14 (28%) were cleared for a regular or chopped diet, 29 (58%) for a modified food/liquid diet and 7 (14%) remained NPO. By LTACH discharge, a median of 14 speech/swallow treatment sessions (IQR 10-18) were performed per patient and 27 (54%) patients were tolerating a regular or chopped diet, 17 (34%) a modified food/liquid diet and 6 (12%) remained NPO (Table 4). Patients were able to initiate a PO diet (regular or modified

PO diet) at a median of 51 days (IQR 29) from time of intubation and median of 13 days (IQR 16) from date of LTACH admission. ICU-AW was not associated with poor management of secretions (secretion level >2 , $p=0.62$), pharyngeal weakness or dysfunction ($p=1.0$), or aspiration risk ($PAS>1$, $p=0.70$); however, secretion level during FEES was associated with both aspiration risk ($PAS>1$, $p=0.01$) and aspiration ($PAS\geq 4$, $p=0.00$)

Of the goals ascertained at the time of LTACH discharge, patients obtained their goals at the following frequencies, in descending order: breathing better (off ventilator, defined as being liberated from the ventilator for 72 hours) 100% (23/23); speaking 97% (32/33); eating and drinking 88% (35/40); grooming 36% (5/14); walking 21% (6/29); toileting 18% (4/22), and returning home 13% (3/24).

At the time of LTACH discharge, after a median LTACH length of stay of 41.5 days (IQR: 23-65), 47 (94%) patients were liberated from mechanical ventilation and 28 (56%) patients were decannulated. The most common discharge destination was acute rehabilitation (40%), followed by skilled care facility placement (30%) and only 7 (14%) of the study population was discharged home (Table 1). Discharge to the home or acute rehabilitation setting was associated with greater strength, as measured by the total MRC score ($p=0.002$), as well as the EuroQOL domains of mobility ($p=0.008$), self-care ($p=0.04$), and pain and discomfort ($p=0.02$).

Discussion

In our prospective cohort study of LTACH patients, we found that nearly all patients experience some form of functional impairment, many experience swallowing

dysfunction, and health-related quality of life was low in the midst of their LTACH stay. However, by the time of LTACH discharge, most of the patients studied were liberated and able to speak, eat, and drink. While only 13% returned directly home, an additional 40% were able to continue their recovery at acute rehabilitation. Related, physical function in the LTACH predicted those who were able to be discharged directly home or to acute rehabilitation.

Prior research efforts have focused on the experience, expectations and goals of CCI patients and their surrogates, finding poor patient-reported quality of life as well as overly optimistic recovery expectations and poor planning for medical setbacks (12). While transitions of care are common for this patient population, many will die in the year that follows, and few return home with no functional limitations in the long-term (13-14, 33), more recent data (14) reveals a more nuanced story exists.

Looking back 6 months after an LTACH stay, 34% and 39% of survivors recalled shortness of breath and difficulties communicating, respectively, and 85% were willing to receive mechanical ventilation again, if needed (14). These data support the notion that the “experiencing” self is distinct from the “remembering” self (14). Our study provides further contextual information to understand the LTACH patient experience. Specifically, in our study, after 6 weeks of rehabilitation at the LTACH, we found that patients liberated from mechanical ventilation were able to meet their goals to be able to breathe better, and most of the cohort was able to speak, eat and drink. In contrast, goals focused on activities of daily living, such as grooming, walking, and toileting, were largely unmet, requiring discharge to a skilled care facility setting or acute rehabilitation.

Coupled with the recent study by Jubran and colleagues, who found that most patients required full assistance for activities of daily living at LTACH discharge, yet improved to partial assistance or independence after 6 months (14), our findings support the notion that rehabilitation goals and expectations for CCI patients should evolve over time. In the LTACH setting, a multidisciplinary program focused on liberating the patient from mechanical ventilation can facilitate realistic goal attainment in the domains of pulmonary function, speech, and swallowing. While physical and occupational therapy are critical across the continuum of care, beginning in the ICU and continuing to and through the LTACH (34), patients and family should be educated that recovery in terms of strength and functional status takes months, and that functional status improvement after LTACH discharge is realistic (14).

With respect to the frequent and highly ranked goal of eating and drinking, our LTACH uses FEES to inform the advancement of CCI LTACH patient diets. We found that three-quarters of patients were silently aspirating thin liquids at the time of the initial FEES evaluation, indicating no sensory response to the aspiration. The high rate of observed silent aspiration and dysphagia are most likely the combined effects of sarcopenia (35) and presbyphagia amongst these elderly patients along with the further rapid oropharyngeal muscle atrophy, altered sensorium, reduced oropharyngeal and laryngeal sensation during critical illness, and prolonged ventilator dependency (16, 36-37).

While pharyngeal dysfunction and aspiration were common in CCI LTACH patients, swallowing function improved, as only 6 (12%) patients remained NPO at the time of LTACH discharge. As such, recovery of swallowing function appears to be a

feasible short-term goal as most patients initiated a PO diet within 2 weeks of LTACH admission and a median of 51 days from time of intubation.

In addition to being used to guide dysphagia management, the FEES was also utilized to guide tracheostomy tube management during the LTACH stay. Many patients (63%) had laryngeal abnormalities, including supra- and/or sub-glottic edema identified during the FEES, that impacted swallow function and informed tracheostomy tube management by delaying tracheostomy downsizing and/or decannulation. Unlike previously reported studies, we did not find ICU-AW to be correlated with pharyngeal dysfunction or aspiration risk (17). Alternatively, we found secretion level during FEES to be associated with aspiration risk. For institutions evaluating swallow function exclusively by CBSE without the ability to conduct FEES, secretion level would not be identified, and aspiration risk may be misjudged.

Distinct from swallowing, speech is critical to overall patient recovery and to reducing anxiety. To that end, 92% of patients obtained verbal communication prior to hospital discharge as more than half (56%) of patients were decannulated, and one third (36%) were either tolerating trach capping or speaking valve. The remaining 8% were limited to non-verbal communication secondary to continued ventilator dependence and/or supraglottic edema and/or tracheal stenosis.

We acknowledge several limitations. First, our study was limited to patients with the mental status to complete testing. As a result, our findings likely overestimate the proportion of patients who were liberated from mechanical ventilation and may underestimate the burden of cognitive impairment among mechanically ventilated patients cared for in LTACHs. Additionally, the functional assessment battery was

performed at a single point in the LTACH stay, not allowing for assessment of temporal trends in these patient-centered outcomes. While we varied the order of goals, we acknowledge that the timing of testing (i.e., linked to speech and swallowing assessment) may have biased the results; as such, confirmatory studies are warranted. Furthermore, PICS presence was ascertained with the MoCA, HADS, PTSS-10, and the MRC documenting impairment at the time of assessment. However, we were unable to confirm if some of these impairments predated a patient's hospitalization. While reliable and valid, some of our screening tools deviate from recent recommendations to assess for long-term functional impairments in ICU survivors (38-39). As our study excluded patients with a history of dysphagia, the rates of dysphagia amongst all CCI LTACH patients is likely higher. Lastly, while our Quality of Life Goals Inventory has face validity, it requires further validation, and the study only included patients with or recovering from CCI at one LTACH, limiting the generalizability of the findings to the broader ICU survivor population.

Conclusions

HRQOL is low and functional impairment is common in LTACH patients recovering from CCI. However, certain patient-centered functional goals, such as those focused on breathing, speech, and swallowing, were attained while in the LTACH, while physical goals required further rehabilitation post-discharge. Our results can be used to inform post-ICU rehabilitation programs and to more effectively align CCI patient's goals with expectations in the LTACH and afterwards.

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