



Clinician-initiated written communication for families of patients at a long-term acute care hospital

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ARTICLE INFO

Keywords:

Long-term acute care hospital
Family engagement
Communication
Rehabilitation

ABSTRACT

Objective: To assess the experience of families and clinicians at a long term acute care hospital (LTACH) after implementing a written communication intervention.

Methods: Written communication templates were developed for six clinical disciplines. LTACH clinicians used templates to describe the condition of 30 mechanically ventilated patients at up to three time points. Completed templates were the basis for written summaries that were sent to families. Impressions of the intervention among families ($n = 21$) and clinicians ($n = 17$) were assessed using a descriptive correlational design. Interviews were analyzed using thematic content analysis.

Results: We identified four themes during interviews with families: Written summaries 1) facilitated communication with LTACH staff, 2) reduced stress related to COVID-19 visitor restrictions, 3) facilitated understanding of the patient condition, prognosis, and goals and 4) facilitated communication among family members. Although clinicians understood why families would appreciate written material, they did not feel that the intervention addressed their main challenge – overly optimistic expectations for patient recovery among families.

Conclusion: Written communication positively affected the experience of families of LTACH patients, but was less useful for clinicians.

Innovation: Use of written patient care updates helps LTACH clinicians initiate communication with families.

1. Introduction

Chronic critical illness (CCI) is a syndrome that develops in some patients who do not fully recover from the acute phase of critical illness; its characteristic features include prolonged mechanical ventilation, neuromuscular weakness, malnutrition, anasarca, skin breakdown, increased susceptibility to infection, and delirium [1,2]. The annual costs of providing care to the estimated 380,000 patients with CCI in the United States exceeds \$25 billion [3]. Patients with CCI experience long-term physical and cognitive impairments, frequent hospital admissions, and are at high risk for death [3,4].

In the United States, patients with CCI are often transferred from intensive care units (ICUs) to long-term acute care hospitals (LTACH). LTACHs are staffed by clinicians who focus on weaning patients from mechanical ventilation and helping them regain functional independence [5-7]. The number of LTACHs in the United States has grown over the last several decades, from under 100 in 1990 to over 400 in 2006 [8]. In 2019, LTACHs accounted for \$3.7 billion of Medicare spending, covering 91,000 admissions [9].

When patients are critically ill, their families typically serve as their surrogate decision makers. Although a focus on family engagement has been described as an attribute of high-performing LTACHs [10], little is known

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about the approaches LTACH clinicians should take to achieve this goal. Previously, we found that providing families of ICU patients with written communication improved their experience [11,12].

In this study, we identified the communication challenges faced by families of patients with CCI and clinicians at an LTACH. We developed and implemented an approach whereby LTACH clinicians could share written summaries of the patient's condition with the patient's family. We determined feasibility and acceptability of this approach among clinicians using validated measures. We used qualitative methods to determine the experience of participating families and clinicians.

2. Methods

2.1. Participants

This study utilized a mixed-methods descriptive correlational design. Participants were families and respective clinicians of patients hospitalized at RML Specialty hospital, a 61-bed LTACH in Chicago, IL, from September 2020 to March 2021. On September 23, 2020, the RML Institutional Review Board waived the need for full IRB review (no reference number) for this study title "Written Care Summaries for Surrogates of Patients at RML Specialty Hospital – A Pilot Study." Procedures were followed in accordance with the ethical standards of the RML IRB and with the Helsinki Declaration of 1975. Participating families and clinicians received an information sheet on the study and provided verbal consent to participate; the need for written consent was waived by the RML IRB.

Adult patients who required mechanical ventilation were screened. Patients were excluded if they had a severe neurocognitive impairment and/or were unable to participate in therapy. For eligible patients, we approached the family member who had been receiving patient updates from RML staff, typically the legally authorized representative. Family members were excluded if they could not read or understand English or could not receive written updates by email. At the time of enrollment, families agreed to receive written updates each week and provide feedback after three weeks or upon patient discharge. For logistical reasons, we attempted to enroll no more than two patients per week. We planned to enroll a convenience sample of 30 patients with one designated family member per patient.

In addition to enrolling clinicians at RML LTACH, we sought feedback on our intervention from eight clinicians with expertise in caring for chronically critically ill patients at Rush University Medical Center, a nearby urban academic medical center in Chicago, IL.

2.2. Development of written summary templates

Prior to participant enrollment, we formed a multidisciplinary group of RML clinicians to create templates that would be the basis for patient

care summaries (Fig. 1A). The group consisted of experts from the following disciplines: respiratory therapy (GP), physical and occupational therapy (LS, CG), speech-language pathology (CB, RR), nutrition (SS), and psychology (GM). The format of templates was based on our previous experience creating written summaries for families of intensive care unit (ICU) patients [11]. Within each discipline, we created a list of the most common problems encountered by LTACH patients. For each problem, we formulated typical management approaches and how patient progress is usually determined. Templates were developed through an iterative process whereby members of the group provided feedback on successive drafts. Prior to implementing the final version of each template, we sought feedback from clinicians who were not involved in the template development process. Final versions of the templates are displayed in Supplemental Fig. 1. Templates were configured as surveys that clinicians could complete online using the application REDcap [13,14].

2.3. Implementation

Upon enrollment, we provided participating families with background on the clinical disciplines that would be included in each week's summary (Supplemental Fig. 2). After being introduced to the project, we asked RML clinicians who had worked with the patient to complete their discipline-specific template on REDcap (Fig. 1B). Subsequent providers who worked with the patient viewed and edited the previous provider's entries. This approach allowed for information to be communicated in a standardized and consistent manner.

We determined that families would receive written summaries on a weekly basis as patients typically were not evaluated by each type of therapist each day. One study investigator (JAG) compiled the completed templates into a narrative summary for each discipline for which the patient was receiving therapy (Fig. 1C). Summaries that did not contain protected health information were securely emailed to families. This process was repeated for two additional weeks. Participants were encouraged to discuss information that they did not understand with the primary team. Participants were encouraged to share summaries with other family members and the patient, if appropriate. An example of a summary provided to a participant is displayed in Supplemental Fig. 3.

2.4. Semi-structured individual interviews

Prior to subject enrollment, we created interview guides for participating RML families and clinicians (Supplemental Figs. 4 and 5). Topics included challenges with communication, impressions of the written summaries, and suggestions for improvement. Families participated in a one-time, semi-structured interview via Zoom after receiving three written summaries or patient discharge (Fig. 1D). Twice during the enrollment period, we also invited participating RML clinicians to participate in

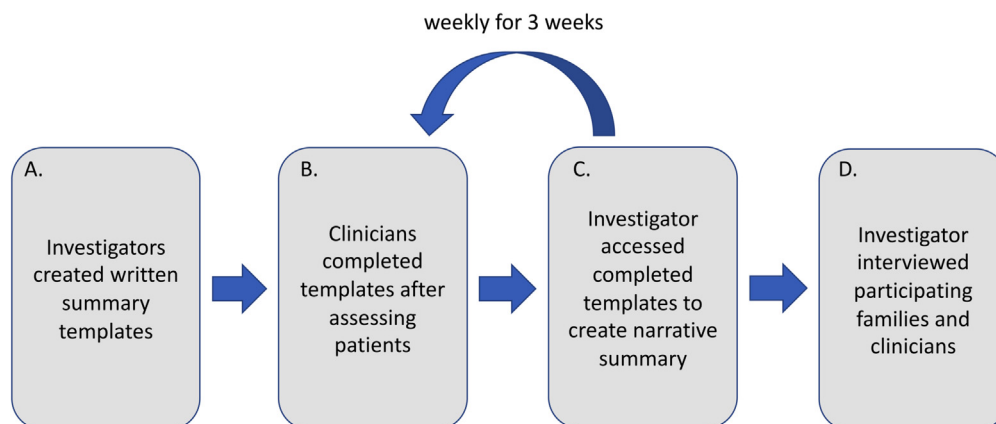


Fig. 1. Process for developing and providing written summaries to families of LTACH patients.

interviews via Zoom. Interviews were conducted by one study investigator (NS). All interviews were recorded and transcribed verbatim and lasted between 15 and 30 min each.

2.5. Outcomes and analysis

For participating families and clinicians, interview transcripts were analyzed using thematic content analysis [15], an established qualitative analytic approach for understanding a person or participant’s lived experience. First, three investigators (NS, DT, JAG) independently coded the first three family interview transcripts and the first three clinician interview transcripts to develop a codebook. Next, two study investigators (subset of the above) coded the remaining interviews. Codes were succinct summary phrases of each interview transcript quote. To ensure intercoder agreement, members of the study team discussed and reached consensus on each code. Codes were grouped into broader themes, they were grouped into broader themes. For example, a participating family member stated.

“Now the summaries, just generally, it’s been something that to me is, is helpful, because you can talk to two or three different people. And you know, it’s half full, half empty, half full, half empty, you know, and you get that kind of, but that is kind of something that I can read, And I can, you know, refer back to when I feel a need to. And it’s, it’s not so much of an opinion of an individual as it is a consensus of the people who are taking care of them.” – Participant #13, Husband

The above statement was coded as “summaries help track patient progress over time” and was grouped into broader the theme “written

summaries helped participants understand patient’s condition, prognosis, and goals.”

After enrollment was complete, participating clinicians at RML and Rush University Medical Center completed the Acceptability of Intervention Measure (AIM), the Intervention Appropriateness Measure (IAM), and the Feasibility of Intervention Measure (FIM). The AIM, IAM, and FIM are validated measures for determining the viability of an intervention [16] (Supplemental Fig. 6). Prior to completing these measures, clinicians were instructed to view their discipline-specific template and an example of how the template was used to create a patient care summary. Responses were measured on a 5-point Likert scale. Average scores greater to or equal to four were judged to signify positive appraisals of the intervention.

3. Results

3.1. Characteristics of participants

From September 2020 to March 2021, we approached a convenience sample of 35 family members of patients at RML Specialty hospital, of whom 30 agreed to participate (Fig. 2). There were 21 participating family members who were interviewed. Most participants who were interviewed identified as female (n = 16, 76%) and as children of the patient (n = 12, 57%), followed by sibling (n = 3, 14%), spouse (n = 3, 14%), parent, grandchild, and niece (n = 1, 5%, respectively). The characteristics of the respective patients are displayed in Table 1.

There were 17 clinicians who provided feedback on the intervention by completing the AIM, IAM and FIM surveys; of the 17 clinicians, there were 9 who were recruited from RML Specialty hospital who had direct

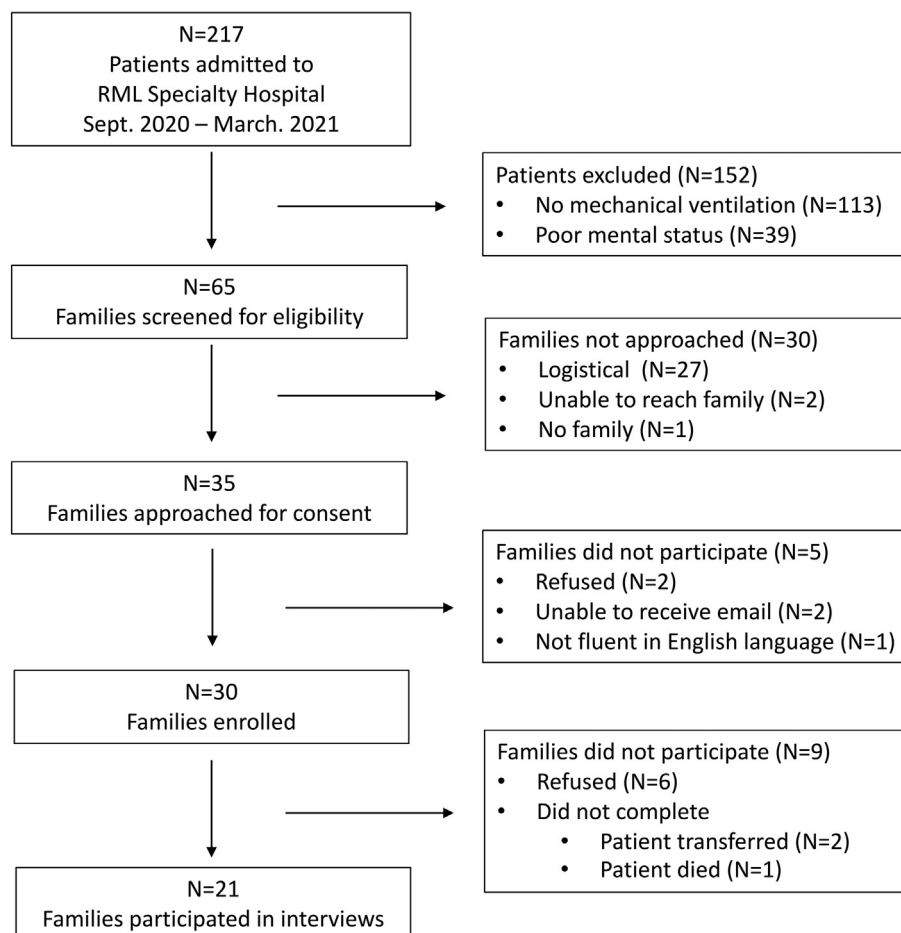


Fig. 2. Enrollment.

Table 1
Patient characteristics.

Patient characteristic	N = 30
Age, mean years (SD)	65 (11)
Gender, n (%)	
Male	16 (53)
Female	14 (47)
Race/ethnicity, n(%)	
Hispanic	13 (43)
Black, not-Hispanic	11 (37)
White, not-Hispanic	5 (17)
Other	1 (3)
Respiratory failure etiology, n(%)	
COVID-19 pneumonia	10 (33)
Bacterial pneumonia	6 (20)
Abdominal sepsis	4 (13)
Cardiac	4 (13)
Neurological*	5 (17)
Trauma	1 (3)
Length of stay at LTACH (days), median [IQR]	50 [29–72]
Liberated from mechanical ventilation at LTACH, n (%)	20 (67)
LTACH days on ventilator [†] , median [IQR]	8 [6–31]
LTACH disposition, n (%)	
Skilled nursing facility	10 (33)
Acute care hospital	9 (30)
Acute rehabilitation hospital	5 (17)
Home	3 (10)
Died/hospice	3 (10)

* drug overdose, stroke, guillan-barre syndrome.

[†] subset of 20 patients liberated from ventilator.

experience with the intervention and 8 clinician experts who were recruited from Rush University Medical Center. A total of 6 RML clinicians participated in interviews (two were interviewed twice).

Table 2
Communication challenges among participants. Subject numbers and relationship/role are in parentheses.

Challenge	Family member quote	Clinician quote
Timing and frequency of communication between clinicians and families was not consistent	In the beginning, they [clinicians] were giving, almost like daily briefings, but that kind of slowed down. (23, Son)	We don't like call every single family member or every single patient's family in order to give an update, it's more of just like a requested basis (01, Physical Therapist)
Visitor restrictions made communication between clinicians and families more difficult	Because if there were a visit, I would be there. I will be, you know, crossing personnel there, or something while they were there... now, it is difficult. (16, Sister)	Well, COVID, obviously was the biggest logistic barrier because visits to common means of communication with a patient was patient's family was a phone call. (03, Speech-Language Pathologist)
Families lack understanding of patient's condition, prognosis, and goals	I want to know more about like his condition what's the next step for him (the patient), you know, more information on about him. (21, Daughter)	So we have to correct a lot of those misconceptions because they're in their [family's] head, Oh, my, my dad should be getting up and moving and all the meanwhile the patient's unresponsive. (01, Physical Therapist)
	And that was it. Up to now I have been requested through the care coordinator to talk to the doctor to find out medically what is going on with my mom. And I have not heard from him after this moment. (15, Daughter)	But I do know, of many, many examples where, where families are not that well informed, really. (05, Psychologist)

3.2. Qualitative findings from interviews with families and clinicians

3.2.1. The family perspective

3.2.1.1. Communication challenges. Participating families identified three types of communication challenges (Table 2). First, family members noted inconsistent communication from clinicians. Families typically spoke to LTACH clinicians less frequently than they did with ICU clinicians, leading to some dissatisfaction with communication at the LTACH. Families also noted stress when trying to initiate communication with LTACH providers. Second, visitor restrictions related to the COVID-19 pandemic negatively impacted communication. Families wished they could be present to communicate directly with LTACH providers and to support and advocate for their loved ones. Third, families felt that they did not receive enough information from LTACH clinicians to understand the issues facing their loved ones.

3.2.1.2. Impressions of written communication. In general, participating families appreciated that written summaries were a dependable form of communication and often looked forward to receiving a weekly written update. The written summaries were understandable and included the appropriate amount of detail.

Families reported that written communication helped address some of the challenges they faced (Table 3). First, written communication helped participants communicate with LTACH staff. Summaries helped participants understand information provided by clinicians and ask informed questions. Some participants felt that the written summaries decreased their need to speak with LTACH staff for updates. Second, written

Table 3
Impact of Written Summaries on the Family Experience. Subject numbers and relationship/role are in parentheses.

Benefit of Written Summary	Family member quote
Helped participants communicate with staff	And once I found out [from the summary], then I call back and ask [the staff] more questions like, okay, I didn't know that he was getting visiting a psychologist. (19, Mother) ...we now are able to clearly see what's going on and kind of have an idea of what's going on, we were able to catch up with what the nurses or the doctors are telling us. So it's [the summary has] been very helpful, just because like I said, it is kind of hard to get a nurse or a doctor on the phone with us, just because I completely understand RML is probably pretty busy. (29, Daughter)
Help with stress of not being able to visit	It's comforting in a way because at least you receiving [sic] communication because now with COVID, there's ... restriction on visiting." (23, Son) [The summaries have] been very helpful, just because ... it is kind of hard to get a nurse or a doctor on the phone with us (29, Daughter)
Helped understand patient's condition, prognosis, and goals	[The summary] went more into detail about things, you know, because on the phone with the phone call, everything wasn't discussed. I was just getting like different pieces of information. But in the emails that I felt relieved with the emails because I got more information from the email. (08, Daughter) Because I can go back and you know, look like last week, okay. You know, this is what happened, and then go to the, the, the week that I'm in and be like, okay, it is getting better, you know, things like that. (07, Sister)
Facilitated communication between participants and other family members	It was nice to be able to give them [family] something to read instead of trying to explain it all. (17, Wife) For some family members who maybe like... is there any proof that he's [the patient is] actually improving? And you can show him the text (23, Son)

communication alleviated some of the stress related to not being able to visit the hospital. Third, written summaries helped participants understand patient's condition, prognosis, and goals. Finally, written summaries facilitated communication between participants and other family members. Some participants felt that written communication made it easier to provide patient updates to multiple other family members.

In regards to suggestions for improvements to the intervention, some families believed that additional disciplines should be included such as wound care. Others suggested additional features for the summaries such as embedded weblinks for additional information and an online portal that allowed direct communication with clinicians.

3.2.2. The clinician perspective

3.2.2.1. Communication challenges. LTACH clinicians identified three communication-related challenges. Similar to families, clinicians noted inconsistent communication as a challenge. Due to time constraints, they typically would reach out to family members only by request. Clinicians also found that visitor restrictions imposed during the COVID-19 pandemic negatively impacted communication with families. They believed that prior to the pandemic, communication was more frequent and less burdensome because family members could be present at the patient's bedside. Finally, clinicians believed that many family members had unrealistic expectations for patient recovery that would persist regardless of the quality or frequency of communication with clinicians.

3.2.2.2. Impressions of written communication. Average scores on the AIM, IAM, and FIM questionnaires were 4.2 (SD 0.7), 4.0 (SD 0.6) and 3.9 (SD 0.6), respectively, indicating positive appraisals of the intervention. Qualitatively,

clinicians agreed that written communication could alleviate some of the challenges experienced by both families and clinicians. Clinicians understood why families would find written communication useful. They believed that families members would likely feel less anxious about the LTACH hospitalization if they were able to read about all the services being provided to the patient and share the document with other family members.

Clinicians agreed that in some circumstances, providing written summaries might reduce the time generally spent communicating with families through other means. However, most clinicians felt that completing written templates on all LTACH patients would be too time consuming with their current workflow and not equally beneficial for all families and patients. Importantly, clinicians did not feel that the intervention addressed one of their main communication challenges – overly optimistic expectations for patient recovery among families.

Clinicians suggested providing summaries to select LTACH patients or to use only in certain situations (i.e. to signify that important patient milestones had been met). Clinicians understood the purpose of the templates was to standardize information being presented. However, some clinicians felt that the templates were too restrictive and did not adequately allow clinicians to communicate nuances associated with patient conditions.

4. Discussion and conclusion

4.1. Discussion

In this study, we found that written communication addressed some of the challenges faced by families and clinicians at an LTACH. Clinicians reported that they typically communicated with family members who were in the patient's room at the time of therapy or if an update was requested by family. According to both clinicians and families, this standard communication approach was made more difficult when visitation was restricted due to the COVID-19 pandemic. With written material, LTACH clinicians were able to proactively initiate communication with families. This intervention had definite benefits. Family members reported that written communication increased awareness of the types of therapy patients were

receiving and whether progress was being made. It also provided families with a dependable update without the stress of having to initiate contact with clinicians. Both families and clinicians agreed that this type of communication was particularly beneficial during times that families could not be present at the patient's bedside.

Ensuring high quality communication with patients and families is an important aspect of caring for patients with chronic critical illness (CCI) [10,17,18]. Despite these recommendations, previous research has found that patients with CCI and their families often do not receive the types of prognostic information needed to make informed decisions, which may contribute to overly optimistic expectations for recovery [19,20]. These studies are typically set in ICUs; less is known about communication challenges at LTACHs, the institutions where many patients with CCI receive care. In one previous study, Lamas et al. demonstrated the feasibility of implementing goals of care discussions at an LTACH [21].

Our study demonstrates that a communication approach that was initially conceived to be used in the ICU can be adapted to be used in the LTACH setting. In our previous ICU study, families were enrolled during the early phase of the patient's critical illness. Summaries were organized by the types of organ failure that were the source of the patient's critical illness and were updated daily [12]. In contrast, in this study, LTACH clinicians first completed specialty-specific templates. To ensure consistent communication after the first summary, clinicians edited the previously completed templates. Finally, the process was overseen by a study investigator, who used the clinician assessments as a basis for a narrative summary. Both families and clinicians approved of this communication approach and believed that the process allowed for accurate communication of the patient's condition and progress towards rehabilitation goals.

Although families and clinicians reported some similar challenges with communication at an LTACH, there were some notable differences. That is, families believed that poor communication quality prevented them from understanding the patients' condition, whereas clinicians believed that family members' unrealistic expectations for patient recovery was what interfered with their ability to understand and process information. This observation aligns with studies of health-related expectations among CCI patients, families, and clinicians at long-term care facilities in Canada [22] and United States [23]. The fact that families and clinicians had different opinions on the adequacy of the existing communication method in conveying information to families may explain why they had different opinions on the added value of the written communication approach. Further refinement of the written communication approach in ways that help reinforce realistic expectations for patient recovery may make its use more appealing to clinicians.

A strength of our study is that we made efforts to adhere to guidelines of high-quality qualitative research [24]. To enhance the study's credibility, we conducted data collection at RML LTACH over a six month period and involved clinical experts at multiple points in the study. To establish dependability, we provided a detailed methodological description of the protocol and ensured intercoder reliability when analyzing interview transcripts. Finally, confirmability was enhanced through the use of interview scripts and review of data by multiple study investigators.

This study has several limitations. First, its transferability was limited by the inclusion of only family members who spoke English at a single LTACH in an urban area. In addition, this study occurred during the COVID-19 pandemic, and the communication challenges described by families and clinicians may have been heightened by visitor restrictions. Second, family members were not involved in development of the templates. However, one of the objectives of this study was to gather family impressions to refine the approach. In this study, we did not formally assess whether the summaries affected family members' understanding of patient prognosis, satisfaction with care, emotional distress. Finally, our approach to creating written communication relied on a study investigator for compiling and summarizing information for families. Future research may incorporate an implementation science approach to evaluate methods of integrating the written summaries into clinician workflows in ways that are self-sustaining.

4.2. Innovation

Although previous investigators have described the issue of inadequate consistency and quality of communication between clinicians and families of patients with CCI, there are no standardized approaches to address these shortcomings. Our study adds to growing evidence that written communication can be used to supplement traditional verbal communication [25,26]. In this study, we describe a novel approach, using clinician-initiated written summaries of care to augment standard communication with family members of patients with CCI at an LTACH.

4.3. Conclusion

Families of LTACH patients experience communication challenges with clinicians, which negatively affects their experience and contributes to them feeling uninformed. Written communication has the potential to improve the family experience by facilitating the initiation and consistency of communication from clinicians and by helping families understand the patient condition. For a written communication approach to be readily adopted by clinicians, it must address the belief held by clinicians that many families have unrealistic expectations for patient recovery. In addition, increased automation of the process for creating written communication would ease the burden on clinicians, thereby helping to overcome the primary barrier for implementation. In the context of research that shows that high levels of family engagement are hallmarks of high-performing LTACHs, this study suggests that providing personalized summaries of care to patients and their family could be one way for LTACHs to add to the value of the care they provide.

Funding

None.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

CRediT authorship contribution statement

Nathaniel H. Schwartz: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Don N. Teed:** Formal analysis, Writing – review & editing. **Crystal M. Glover:** Formal analysis, Methodology, Writing – original draft, Writing – review & editing. **Santosh Basapur:** Conceptualization, Methodology, Writing – review & editing. **Carly Blodgett:** Conceptualization, Methodology, Writing – review & editing. **Connor Giesing:** Conceptualization, Methodology, Writing – review & editing. **Gerald Lawm:** Methodology, Writing – review & editing. **Glenn Podzimek:** Conceptualization, Methodology, Writing – review & editing. **Roger Reeter:** Conceptualization, Methodology, Writing – review & editing. **Laura Schorfheide:** Conceptualization, Methodology, Writing – review & editing. **Sara Swiderski:** Conceptualization, Methodology, Writing – review & editing. **Jared A. Greenberg:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

No author has a relevant competing interest that might lead to bias.

Acknowledgements

The authors wish to thank the patients and their families, the clinicians at RML Specialty Hospital and Rush University Medical Center who participated, and RML Specialty Hospital for hosting it.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2023.100179>.

References

- [1] Nelson JE, Cox CE, Hope AA, Carson SS. Chronic critical illness. *Am J Respir Crit Care Med.* 2010;182(4):446–54.
- [2] Carson SS. Definitions and epidemiology of the chronically critically ill. *Respir Care.* 2012;57(6):848–56. (discussion 856–8).
- [3] Kahn JM, Le T, Angus DC, Cox CE, Hough CL, White DB, et al. The epidemiology of chronic critical illness in the United States*. *Crit Care Med.* 2015;43(2):282–7.
- [4] Unroe M, Kahn JM, Carson SS, Govert JA, Martinu T, Sathy SJ, et al. One-year trajectories of care and resource utilization for recipients of prolonged mechanical ventilation: a cohort study. *Ann Intern Med.* 2010;153(3):167–75.
- [5] Kahn JM, Werner NM, Appleby D, Carson SS, Iwashyna TJ. Long-term acute care hospitalization in elderly patients with chronic critical illness. *Med Care.* 2013;51(1):4–10.
- [6] Miller T, Canfield C, Buckingham T, Johnston G, Hammerman S, Skinner G, et al. Long-term acute care: where does it fit in the health care continuum? *Am J Crit Care.* 2016;25(4):364–7.
- [7] Seneff MG, Wagner D, Thompson D, Honeycutt C, Silver MR. The impact of long-term acute-care facilities on the outcome and cost of care for patients undergoing prolonged mechanical ventilation. *Crit Care Med.* 2000;28(2):342–50.
- [8] Kahn JM, Benson NM, Appleby D, Carson SS, Iwashyna TJ. Long-term acute care hospital utilization after critical illness. *JAMA.* 2010;303(22):2253–9.
- [9] Medicare Payment Advisory Commission. https://www.medpac.gov/wp-content/uploads/import_data/scrape_files/docs/default-source/reports/mar21_medpac_report_to_the_congress_sec.pdf; 2021.
- [10] Rak KJ, Ashcraft LE, Kuza CC, Fleck JC, DePaoli LC, Angus DC, et al. Effective care practices in patients receiving prolonged mechanical ventilation. An ethnographic study. *Am J Respir Crit Care Med.* 2020;201(7):823–31.
- [11] Bulger JL, Quinn TV, Glover CM, Basapur S, Shah RC, Greenberg JA. Written care summaries facilitate communication between families and providers of ICU patients: a pilot study. *Crit Care Explor.* 2021;3(7):e0473.
- [12] Greenberg JA, Basapur S, Quinn T.V., Bulger J.L., Schwartz N.H., Oh S.K., et al. Daily written care summaries for families of critically ill patients: a randomized controlled trial. *Crit Care Med* 2022. Sep 1;50(9):1296-1305.
- [13] Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, et al. The REDCap consortium: building an international community of software platform partners. *J Biomed Inform.* 2019;95:103208.
- [14] Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform.* 2009;42(2):377–81.
- [15] Creswell JW, Creswell Báez J. 30 essential skills for the qualitative researcher. 2nd ed. Thousand Oaks, California: SAGE Publications, Inc; 2021.
- [16] Weiner BJ, Lewis CC, Stanick C, Powell BJ, Dorsey CN, Clary AS, et al. Psychometric assessment of three newly developed implementation outcome measures. *Implement Sci.* 2017;12(1):108.
- [17] Nelson JE, Kinjo K, Meier DE, Ahmad K, Morrison RS. When critical illness becomes chronic: informational needs of patients and families. *J Crit Care.* 2005;20(1):79–89.
- [18] Rose L, Istanbulian L, Allum L, Burry L, Dale C, Hart N, et al. Patient and family centered actionable processes of care and performance measures for persistent and chronic critical illness: a systematic review. *Crit Care Explor.* 2019;1(4):e0005.
- [19] Cox CE, Martinu T, Sathy SJ, Clay AS, Chia J, Gray AL, et al. Expectations and outcomes of prolonged mechanical ventilation. *Crit Care Med.* 2009;37(11) (2888–94; quiz 2904).
- [20] Nelson JE, Mercado AF, Camhi SL, Tandon N, Wallenstein S, August GI, et al. Communication about chronic critical illness. *Arch Intern Med.* 2007;167(22):2509–15.
- [21] Lamas DJ, Owens RL, Nace RN, Massaro AF, Pertsch NJ, Moore ST, et al. Conversations about goals and values are feasible and acceptable in long-term acute care hospitals: a pilot study. *J Palliat Med.* 2017;20(7):710–5.
- [22] Howard AF, Crowe S, Choroszewski L, Kovatch J, Haynes AJ, Ford J, et al. Health-related expectations of the chronically critically ill: a multi-perspective qualitative study. *BMC Palliat Care.* 2021;20(1):3.
- [23] Lamas DJ, Owens RL, Nace RN, Massaro AF, Pertsch NJ, Gass J, et al. Opening the door: the experience of chronic critical illness in a long-term acute care hospital. *Crit Care Med.* 2017;45(4):e357–62.
- [24] Forero R, Nahidi S, De Costa J, Mohsin M, Fitzgerald G, Gibson N, et al. Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. *BMC Health Serv Res.* 2018;18(1):120.
- [25] Federman A, Sarzynski E, Brach C, Francaviglia P, Jacques J, Jandorf L, et al. Challenges optimizing the after visit summary. *Int J Med Inform.* 2018;120:14–9.
- [26] Pathak S, Summerville G, Kaplan CP, Nouri SS, Karliner LS. Patient-reported use of the after visit summary in a primary care internal medicine practice. *J Patient Exp.* 2020;7(5):703–7.