

# Written Care Summaries Facilitate Communication Between Families and Providers of ICU Patients: A Pilot Study

**OBJECTIVES:** ICU providers may invite families to participate in daily rounds to inform them of the patient's condition and to support their emotional well-being. Daily written summaries of care may provide complementary benefits.

**DESIGN:** Qualitative interviews with surrogates of ICU patients who received daily written summaries of care.

**SETTING:** Single, urban academic medical center.

**PATIENTS/SUBJECTS:** A convenience sample of 30 surrogates of nondecisional, medical ICU patients.

**INTERVENTIONS:** Daily written summaries detailed each of the patient's main ICU problems, the presumed causes of each of the problems, and the medical team's plan to address each of the problems for each ICU day.

**MEASUREMENTS AND MAIN RESULTS:** There were four ways that written summaries affected the participant's experience: 1) providing clarity to participants regarding the patient's condition, 2) facilitating participant understanding of the patient's clinical course, 3) facilitating communication between participants and medical providers, and 4) facilitating communication between participants and other family members. Overarching themes were that summaries were understandable, had appropriate level of detail, and added value to the ICU experience.

**CONCLUSIONS:** In this pilot study, family members had positive impressions of receiving daily written summaries of care. Further study is needed to determine the extent to which written communication may affect family and patient outcomes.

**KEY WORDS:** communication; family engagement; intensive care unit family experience

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Families of critically ill patients are typically encouraged to play an active role in the patient's care. Families can aid in the patient's medical recovery and reduce the risk of ICU complications such as delirium (1, 2). Family engagement also enables clinicians to support the emotional needs of the family (3). When ICU patients are unable to make decisions for themselves, family engagement is needed to provide surrogates with an understanding of the patient's prognosis so they can fulfill their role as the patient's decision makers (4, 5).

Previous research has suggested that clinicians may improve communication and family engagement by inviting family members to attend daily ICU rounds (6, 7). However, the extent to which this practice improves the comprehension and satisfaction of families is unclear. Families may not benefit from being present during rounds if the information presented is overly complex or if the clinician's communication style is ineffective. Furthermore, family members may be unable to attend rounds due to their work schedule or other commitments.

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DOI: 10.1097/CCE.0000000000000473

We hypothesized that providing families with daily written summaries of care could overcome challenges related to communication between clinicians and families during ICU rounds. In addition, if families were unable to participate in ICU rounds, written summaries may help them feel informed. The purpose of this pilot study was to determine the feasibility and benefits of providing families with daily written updates of an ICU patient's care. We elicited feedback from families of critically ill patients who received written updates and identified themes using qualitative methods. Second, we determined the most common information provided in the daily summaries to develop a template for creating written summaries for future clinical or research purposes.

## MATERIALS AND METHODS

### Participants

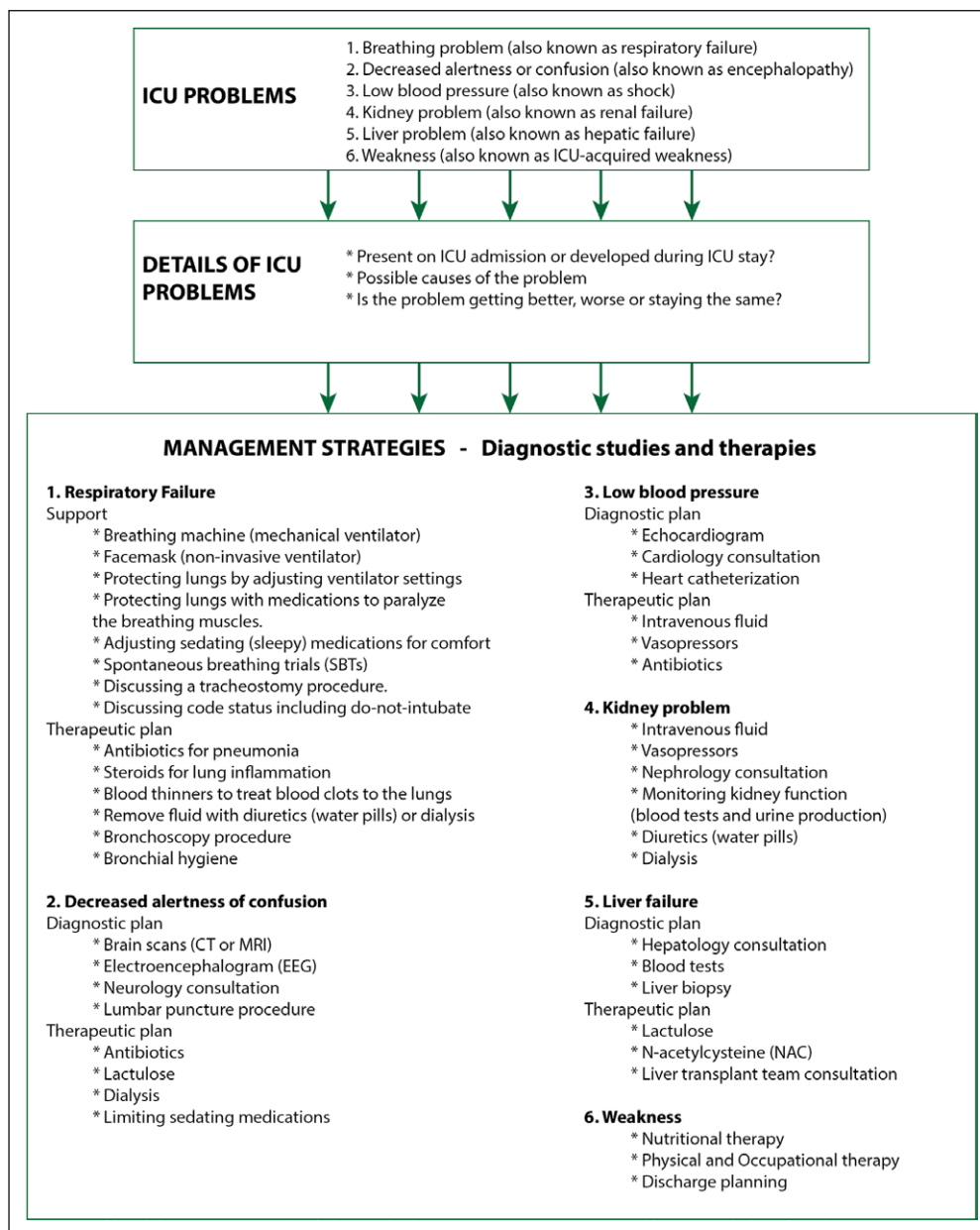
This study was conducted in the 28-bed medical ICU at the Rush University Medical Center, an academic, tertiary-care medical center in Chicago, IL. From August 2, 2018, to April 12, 2019, we screened incapacitated patients who were expected to require invasive mechanical ventilation for at least 96 hours and/or who were predicted to have at least a 40% risk of hospital mortality according to the patient's physician. During the enrollment period, family presence was encouraged in the ICU; it was standard practice to invite families to participate in morning rounds with the ICU team. We enrolled a convenience sample of surrogate decision makers who spoke English, self-identified as participating directly in healthcare decision-making for the patient under Illinois law, agreed to receive daily written communication in addition to standard family engagement practices, and agreed to provide feedback on their experience. This study was undertaken with approval of the Rush University Medical Center Institutional Review Board (18062607-IRB01). Participants provided informed consent. If patients regained decision-making capacity, they provided consent to allow their surrogate to continue participating in the study. Written summaries were offered to patients who regained decision-making capacity. No patients withdrew from the study. We planned to enroll 30 surrogates in this pilot study.

### Materials

**Written Summaries.** The intended goal of the daily summary was to supplement the experience of a family's participation in rounds with the ICU team. Thus, the format of the written summary was modeled on a patient presentation during morning rounds. Summaries were organized by ICU problem. The summary addressed the following: the suspected etiology of the problem, whether was present on or developed during the ICU admission, and what was being done to address the problem including diagnostic testing and therapies. The template used to create daily summaries was refined using an iterative approach. The most commonly listed ICU problems were: 1) respiratory failure, 2) encephalopathy, 3) shock/hypotension, 4) renal failure, 5) liver failure, and 6) ICU-acquired weakness. The template described management approaches that were common for medical ICU patients with these problems (**Fig. 1**). An example of a written summary that was provided to a study participant is displayed in **Supplemental Figure 1** (<http://links.lww.com/CCX/A697>).

To standardize the information provided to participants, the summaries were created or updated by one study investigator (J.A.G.) each day, not a member of the clinical team. Summaries were typically written each afternoon after the study investigator reviewed the patient chart and/or discussed the patient directly with the clinical team. Changes from day to day were noted by bolding or underlining text in subsequent summaries. The initial summary for each patient typically took about 30 minutes to complete with subsequent summaries taking about 15 minutes. Based on participant preference, summaries were printed or securely emailed, devoid of protected health information. Surrogates were encouraged to share written summaries with other engaged family members and friends.

**Semistructured Individual Interviews.** Prior to enrolling subjects, we created an interview guide to determine participant perceptions of the summary (i.e., understandability and level of detail) and how the participant used the summary (**Fig. 2**) (8). Surrogates participated in a one-time, semistructured individual interview via telephone once they had received at least five summaries or the patient was transferred from the ICU (9). Prior to completing the phone interview, subjects were given the opportunity to discuss any topic



**Figure 1.** Template for creating daily written summaries. First, ICU problems were identified using lay and medical terminology. Second, details of each problem were provided. Finally, ICU problem-specific management approaches were listed.

they believed was relevant to the written summaries or their ICU experience. Interviews lasted approximately 15 minutes. We aimed to audio-record all interviews; however, due to scheduling and other study logistics, we were unable to audio-record nine interviews, with a total of 16 interviews that were audio-recorded.

## Analysis

**Individual Interviews.** We analyzed transcripts of audio-recorded interviews to understand surrogate

perspectives on the feasibility and utility of written daily summaries. Transcripts formed the basis of analyses for the qualitative individual interviews with surrogates. Two investigators (J.L.B., T.V.Q.) analyzed data using a thematic content analysis, thus illuminating themes across the data (10). First, analysts identified codes across all transcripts. Second, analysts grouped similar codes into overarching themes. Analysts discussed and reached consensus regarding all codes and themes.

**Other Data Analysis.** Additionally, we examined frequency of unique medical problems treated during the ICU stay and the common plans/interventions associated with each medical problem.

## RESULTS

### Participant Characteristics

Between August 2018 and April 2019, there were 155 patients who received at least four days of mechanical ventilation in the medical ICU. We approached a convenience sample of 32 surrogates during this time period, of whom 30 provided consent to participate. Most participating surrogates were female ( $n = 22, 73\%$ ) with the majority of these surrogates also being children of the patients ( $n = 17, 57\%$ ) followed by spouses ( $n = 9, 30\%$ ), siblings ( $n = 3, 10\%$ ), and parents ( $n = 1, 3\%$ ). The average age of the respective patients was 61 years (SD, 13). There were 14 patients who were male (47%) and 16 who were female (53%). The

### Participant interview prompts

1. Overall, can you tell me how you used the Written Summary?
  - a. When did you last read the Written Summary? Why?
  - b. What elements of the summary stood out to you? Why?
2. Did you have any problems/issues understanding the summary?
  - a. Can you describe the issue(s)?
3. Did you find any information missing?
  - a. Did you find any information superfluous?
4. Verify usage pattern – When do you usually read the Written Summary?
  - a. If you do not read the summary, why not?
  - b. Can you tell us about what are you looking for in terms of information or update?
  - c. Can you elaborate on why you would continue (or not continue) to use the summary?
  - d. Did you use it differently initially versus now – now that you have been seeing it for some days?
5. Go over the Written Summary and ask questions about each element on the summary:
  - a. Content personalization and quantity: Is the summary giving you the information you need?
  - b. How would you describe this summary: enough information, not enough information or too much information? Why?
  - c. Does the summary help you communicate the status of you (or your patient) with other people?
6. Depending on what patient or their surrogates mention, the following can be asked selectively.
  - a. If there is one or two things that could make this Written Summary better, what could they be?
  - b. Would you recommend to others in a situation like yours to look out for the summary and use it in certain way?
  - c. What would that recommendation be?

**Figure 2.** Interview guide for determining the effect of the ICU summary on participant experience.

racial and ethnic breakdown was White, non-Hispanic ( $n = 12$ , 40%), Black, non-Hispanic ( $n = 8$ , 26%), Hispanic ( $n = 5$ , 17%), and Asian ( $n = 5$ , 17%).

### Written Summary Description and Characteristics

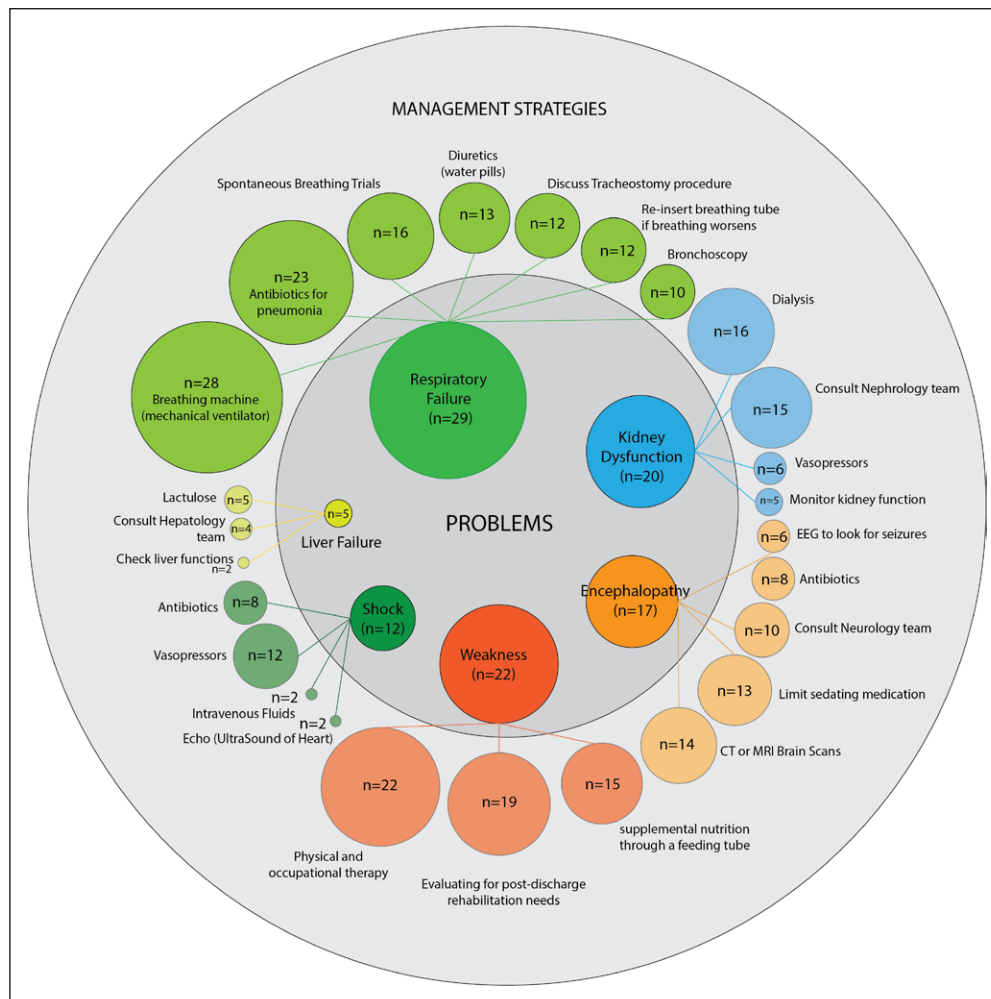
The median number of summaries each participant received was 6 (range, 3–15). The most common management approaches for summaries created for participants in this study are displayed in **Figure 3**.

### Overarching Themes

Overall, surrogates who were provided with daily written summaries indicated that the summaries were of

use to them and their families. Participants described the summaries as “easy to understand,” “detailed,” and “very helpful.” Participants indicated that the summaries bolstered their understanding of the care being given to their loved ones and complemented communication with the ICU team. In sum, participant interviews illuminated four overlapping themes.

**First Theme: Written Summaries Provided Clarity to Participants Regarding the Patient’s Condition.** Daily written summaries made the patient’s medical problems and management approach easier for participants to understand. One participant stated, “It clarifies the names and conditions and is more specific and is actually more memorable than what you tell us in person.” Several participants had commented that



**Figure 3.** Frequency of ICU problems and management strategies. EEG = electroencephalogram.

the language in the summaries was understandable, “There’s not a lot of medical jargon, so it’s [the summary is] easy to understand.” Participants could refer to summaries at their own convenience, giving them more time to process medical information, and leading to an improved understanding of the patient’s condition. As stated, “So with the rounding summary I’m able to go over it on my own later as well.” Some commented on the efficiency of the approach, “It was very detailed and it was so much of a time saver and helpful to go back and reference those notes [summaries].”

**Second Theme: Written Summaries Facilitated Participant Understanding of the Patient’s Course.** Daily written summaries helped participants understand if medical issues were responding to treatment or if new issues were developing. One participant said, “I do have them all printed off at home to compare them.” Another commented, “I noticed that the underlined stuff is the stuff that was different than

the last day, so that stood out to me and that helped.” Participants often used the daily written summaries to create a timeline of the patient’s hospital course. As stated, “I look at all of the summaries and go back and then go forward. Even though it says what’s new with the underlined, but I go back and try to compare.”

**Third Theme: Written Summaries Facilitate Communication Between Participants and Medical Providers.** Because participants perceived that they had a better understanding of the patient’s condition after reading the daily summary, they felt that it was easier to communicate with the patient’s medical team. One participant said, “I think [the summaries] may have helped because I have a better understanding of what’s going on, and I feel like I know exactly what they’re [the medical team] talking about while they’re talking about it because I had seen it before in the email so it’s not the first time I’m hearing about a certain problem or issue.” Another participant stated, “In

fact, it has improved our communication because in the moment I don't always know what they're [the medical team] talking about."

**Fourth Theme: Written Summaries Facilitated Communication Between Participants and Other Family Members.** The written format was easily shareable among families and all family members were able to view the same, consistent information. As one participant said, "You can forward those [summaries] to relatives and friends so you don't have to explain to everybody what's going on." Others had family members who lived in a different city and were unable to visit, "I share the summary with my mom, brother, sister, and other people who don't live here. And it's sometimes hard to communicate because not everyone lives here, so I automatically forward it on and they are able to read what's going on so I don't have to call and update them."

## DISCUSSION

In this pilot study, we determined that providing families of ICU patients with daily written summaries of ICU rounds was feasible and appreciated by participants. Families are often invited to be present for daily medical rounds to improve their understanding of the patient's medical problems and to facilitate communication between clinicians and families (11). We found that written summaries of rounds had similar benefits to physical presence during rounds with regard to the family experience. Written communication also facilitated tracking of patient progress and exchange of information among families. Importantly, families did not feel overwhelmed or stressed by receiving information in a written format.

Studies have demonstrated that by providing written information to patients and their family members both during and after hospital ICU admission, rates of comprehension and overall satisfaction can be improved. These studies have predominantly focused on the availability of leaflets, designed to provide general information during the ICU stay or after discharge (12–14). The distinguishing features of the daily written summary in this study were that the information was patient-specific and was updated daily. These features were viewed as beneficial by participants.

Written summaries share some features of ICU diaries. ICU diaries are a written record of the patient's

ICU stay. However, the primary purpose of ICU diaries has been to fill in the gaps in memory of ICU survivors after hospital discharge and to improve long-term psychological outcomes for patients (15, 16). In contrast, the purpose of the written summary was to provide information to surrogates of incapacitated patients to improve their experience and comprehension in real time. Although both ICU diaries and written summaries keep a record of ICU events, written summaries also provided insight into the medical team's decision-making process. Further study could investigate whether providing patients with written summaries after the ICU stay reduces symptoms of postintensive care syndrome (17).

At our institution, ICU progress notes are typically not written or formatted to be easily understood by nonclinicians. In this study, the transformation process from daily ICU notes to written summaries involved defining medical terminology, interpreting the results of tests or procedures, summarizing the recommendations of consulting services, and explaining the thought process of the ICU clinicians. "OpenNotes" is an initiative whereby clinicians are encouraged to share clinical notes directly with patients (18). The results of our study support the notion that families of ICU patients would appreciate reading notes written by ICU clinicians if the notes are understandable. Future study should examine the feasibility and acceptability of sharing ICU progress notes directly with families.

Participants did not view daily written summaries as a replacement to direct communication with the ICU team. Family presence and verbal communication are essential for building rapport and a trusting relationship between the ICU team and patient's family. However, the findings from our study demonstrate that written communication can enhance a surrogate's understanding of verbal communication. Currently, numerous clinical settings outside the ICU use clinical summaries to facilitate a patient's understanding of his or her health, to encourage more active participation in medical decision-making, and to help limit issues related to patient recall (19, 20). Studies have shown that these tools are a valuable means of communication from both the patient and provider point of view.

This pilot study is limited by its small sample size. It was conducted at a single center where participants were enrolled based on the availability of the investigators. The study population within this report may

not be representative of that in other clinical settings. Another limitation is that the template developed to create written summaries was based on a small number of participants. The template we designed to create daily summaries may not be applicable to other ICU settings. However, the most common ICU problems we identified were similar to those described by other investigators (18). In addition, the process we used to develop summaries could be replicated in ICUs that care for a different patient population. Third, we did not elicit feedback from clinicians on the ICU team. Members of the patient's medical team were aware that the patient's surrogate was participating in the study and often provided information to the investigators regarding the patient's treatment plan. Feedback from participating surrogates confirmed that the information in the written summaries matched and clarified the information they received from the primary team. Fourth, we were not able to determine whether participant characteristics (i.e., race/ethnicity and educational background) were associated with their experience of being provided with a written summary. Finally, this study was not designed to determine the effect of written summaries on important surrogate outcomes such as satisfaction, psychologic symptoms, and decisional certainty. Further study will be needed to determine the impact of daily written summaries on the surrogate experience.

## CONCLUSION

Surrogates of critically ill patients deemed daily written summaries of care acceptable and feasible. The summaries helped surrogates understand information and communicate with providers and families; these are important aspects of the ICU experience. Although the daily summary was conceived as a way to supplement the experience of participating in ICU rounds, written communication may also have a distinct role during times of restricted visitation (21, 22). Using this kind of written communication in general ICU practice may be difficult because it takes time to create the summary and to ensure consistency among different providers. Our findings support the sharing of ICU clinical notes with families if the notes are written and formatted in an understandable way. Although this process may initially increase the amount of time clinicians spend with documentation, there could be time saved throughout the ICU stay if families have

an improved understanding of the patient's condition and have an easier time making medical decisions. Use of templates could decrease the time it would take to a clinician write an ICU progress note that could be shared with the patient's family. An automated process to create summaries could further enhance the viability of this communication tool. Eventually, written summaries could be generated directly from existing electronic medical records and delivered to families via a smartphone app. Further adaptation and evolution of the written summary should be undertaken to see if improvement in interface between provider and family member can further enhance communication.

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*Dr. Bulger, Quinn, and Greenberg contributed to the conception and design of the study, data collection, data analysis, and drafting, critical revision, reading, and approval of the article. Dr. Greenberg is the guarantor of the article, taking responsibility for the integrity of the work as a whole, from inception to published article. Dr. Glover contributed to data analysis, and drafting, critical revision, reading, and approval of the article. Dr. Basapur contributed to the conception and design of the study, data collection, data analysis, and critical revision, reading, and approval of the article. Dr. Shah contributed to the conception and design of the study, and critical revision, reading, and approval of the article.*

*The authors have disclosed that they do not have any potential conflicts of interest.*

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