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1

**Development and Pilot Implementation of a Patient Oriented Discharge Summary for Critically Ill Patients**

ICU Discharge Summary for Patients

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## **Abstract**

### **BACKGROUND**

Patients leaving the intensive care unit (ICU) often experience gaps in care due to deficiencies in discharge communication, leaving them vulnerable to increased stress, adverse events, readmission to ICU, and death. To facilitate discharge communication, written summaries have been implemented to provide patients and their families with information on medications, activity and diet restrictions, follow-up appointments, symptoms to expect, and who to call if there are questions. While written discharge summaries for patients and their families are utilized frequently in surgical, rehabilitation, and pediatric settings, few have been utilized in ICU settings.

### **AIM**

1) To develop an ICU specific patient-oriented discharge summary tool (PODS-ICU), and 2) pilot test the tool to determine acceptability and feasibility.

### **METHODS**

Patient-partners (i.e., individuals with lived experience as an ICU patient or family member of an ICU patient), ICU clinicians (i.e., physicians, nurses), and researchers met to discuss ICU patients' specific informational needs and design the PODS-ICU through several cycles of discussion and iterative revisions. Research team nurses piloted the PODS-ICU with patient and family participants in two ICUs in Calgary, Canada. Follow-up surveys on the PODS-ICU and its impact on discharge were administered to patients, family participants, and ICU nurses.

### **RESULTS**

Most participants felt that their discharge from the ICU was good or better ( $n = 13$ ; 87.0%), and some ( $n = 9$ ; 60.0%) participants reported a good understanding of why the patient was in ICU. Most participants ( $n = 12$ ; 80.0%) reported that they understood ICU events and impacts on the patient's health. While many patients and family participants

indicated the PODS-ICU was informative and useful, ICU nurses reported that the PODS-ICU was “not reasonable” in their daily clinical workflow due to “time constraint”.

## CONCLUSION

The PODS-ICU tool provides patients and their families with essential information as they discharge from the ICU. This tool has the potential to engage and empower patients and their families in ensuring continuity of care beyond ICU discharge. However, the PODS-ICU requires pairing with earlier discharge practices and integration with electronic clinical information systems to fit better into the clinical workflow for ICU nurses. Further refinement and testing of the PODS-ICU tool in diverse critical care settings is needed to better assess its feasibility and its effects on patient health outcomes.

**Key Words:** <sup>1</sup> Discharge tool; patient discharge summary; patient communication; family communication; transitions in care; intensive care unit

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**Core Tip:** Critically ill patients face a difficult transition when moving home from an intensive care unit (ICU). In order to ease this transition, we developed and pilot tested a patient-oriented discharge summary tool that included information about medications, activity and diet restrictions, follow-up appointments, symptoms to expect, and who to call if there are questions. We found that critically ill patients and their families found the tool to be very informative. However, nurse practitioners found the discharge tool to be time consuming to complete and a poor fit into their clinical

workflow. Further revision and testing of the tool is needed to better assess its feasibility and determine any impact it may have on patient health outcomes.

## **INTRODUCTION**

The discharge of patients from the intensive care unit (ICU) is a challenging transition period that leaves patients particularly vulnerable to heightened stress<sup>1</sup> and increases their chances of experiencing adverse events,<sup>2</sup> being readmitted to ICU,<sup>3</sup> and dying.<sup>4</sup> Many patients who report experiencing gaps in care during their transition from the ICU are dissatisfied with the quality of care they received.<sup>5</sup> They cite confusion due to poor communication with their healthcare team as a major contributing factor to their dissatisfaction.<sup>6,7</sup> Failures to effectively communicate information such as diagnoses, tests, treatments, and goals of care to patients and their family-caregivers result in poorly executed transitions in care, and impede continuity of care.<sup>8-10</sup> Deficiencies in communication can be further worsened by any combination of patient factors such as lack of understanding of medical terms,<sup>11</sup> limited fluency in English,<sup>12,13</sup> difficulty retaining verbal instructions<sup>14</sup>, or inability to absorb critical information due to stress.<sup>15,16</sup> While patient-centered summary tools to communicate critical information to patients and family-caregivers (i.e., family members or close friends of the patient) at discharge have been implemented, many of these tools vary in their applicability to diverse care settings and are not standardized across healthcare systems.<sup>17</sup>

There have been a number of initiatives to improve patient and family-caregiver communication during transitions in care using written communications that facilitate and support the exchange of information from clinicians to patients and their families.<sup>18-20</sup> Among these are patient- and caregiver-centered discharge summaries that include information on medications, activity and diet restrictions, follow-up appointments, symptoms to expect, and who to call if there are questions.<sup>21,22</sup> Most patient- and caregiver-centered discharge summary tools use evidence-based techniques such as plain language, large fonts,<sup>23</sup> pictograms,<sup>24</sup> and teach-back components<sup>25,26</sup> to ensure patients are engaged and develop a strong understanding of their health.<sup>27</sup> While

written patient-centered discharge tools have become commonplace in surgical,<sup>28</sup> rehabilitation,<sup>29</sup> and pediatric settings,<sup>30</sup> few have been employed in critical care settings.<sup>31</sup>

To address the need for a standardized, written, patient-centered discharge tool suitable for use in the ICU, our team of patient partners (i.e., previous patients and family-caregivers who now represent patients' interest in research), clinicians, and researchers aimed to incorporate ICU-specific elements into the Patient Oriented Discharge Summary (PODS) tool co-developed by patients, the Toronto Central Local Health Integration Network, and OpenLab (Toronto, Canada). Specifically, our objectives were to: (1) adapt the content of the PODS to the ICU context based on input from key stakeholder groups including patient partners, clinicians, and researchers (PODS-ICU); (2) pilot test the adapted PODS-ICU in the ICU to determine its acceptability and feasibility; and (3) gather patient, family-caregiver, and clinician perspectives on the usability of the tool and quality (e.g., comprehensiveness) of information provided to patients and family-caregivers during a discharge from the ICU.

## **MATERIALS AND METHODS**

### **Setting**

We conducted this study in two ICUs in Calgary, Alberta, Canada. ICU A, Foothills Medical Centre, is a 28-bed medical-surgical ICU in a tertiary level academic hospital and ICU B, South Health Campus, is a 10-bed medical-surgical ICU in a community-based hospital (collective catchment population 1.4 million). Both hospitals use the same patient information systems which house ICU patients' demographics along with key clinical, healthcare service, and health outcome data.<sup>32</sup>

### **Design**

We designed our study as a collaborative quality improvement research project that adhered to the internationally recognized Revised Standards for Quality

Improvement Reporting Excellence (SQUIRE) 2.0 guidelines for reporting new knowledge on improving healthcare.<sup>33</sup> We executed the study in two distinct phases:

Development of the PODS-ICU and

Pilot testing of the PODS-ICU in two ICUs (ICU A and ICU B)

### **Development of the PODS-ICU**

To create a workable PODS-ICU tool and a standardized implementation process, we formed a working group of stakeholders with diverse backgrounds and extensive critical care experience. The working group included two patient partners (1 patient, 1 family-caregiver), four bedside registered nurses (RNs), two nurse practitioners (NPs), one physician, one clinical nurse specialist, a quality improvement lead, and a researcher. The working group was tasked with producing a printable (i.e., not handwritten) PODS-ICU template for patients who were being discharged from the ICU to a hospital ward or directly into community settings (i.e., their home). The working group met monthly to discuss and reach consensus on the content and the format for the PODS-ICU (i.e., electronic *vs* paper-based templates) and to complete iterative revisions of the tool. After each meeting, minutes were circulated by email to working group members. The researcher incorporated feedback into the tool, circulating documents that mapped out the revised content areas back to the group by email. This process led to agenda building for the next working group meeting and was repeated until a consensus was reached on the PODS-ICU. In order to maximize efficient completion of the PODS-ICU, the working group decided to make the tool easily accessible to clinicians, and to permit editing of its content until it was deemed ready for pilot testing. The group agreed that the PODS-ICU should be paired with effective education methods such as teach-back, which has been shown to optimize communication between clinicians, patients, and family-caregivers.<sup>34</sup>

### **2.4 Pilot test of the PODS-ICU tool**

#### *Sample and Recruitment*

Between August 12<sup>th</sup> and November 5<sup>th</sup>, 2019, we recruited a sample of patients and family-caregivers transitioning from the ICU to the hospital ward from ICU A. Between January 5<sup>th</sup> and March 1<sup>st</sup>, 2020 we recruited a sample of patients and family-caregivers transitioning from ICU to home from ICU B. Trained team members (RNs and NPs) were tasked with piloting the PODS-ICU in the participating sites.

We used eCritical MetaVision Alberta to identify patients who were expected to leave the study ICUs within the next 24-48 h. A patient partner and a research assistant from our study team approached patients if they were I) cleared for discharge II) over 18 years of age III) able to provide written informed consent and IV) able to communicate in English. Family-caregivers, defined as any individuals providing physical or emotional support to a patient (e.g., a relative, friend or a formal caregiver) who had knowledge of the patient before the ICU admission, were also approached to participate in the study. Family-caregivers were eligible to participate if they were: I) over 18 years of age II) able to provide informed consent and III) able to communicate in English. A recruitment script [**Additional File 1**] was used to ensure patients and family-caregivers (i.e., collectively referred to as participants) were provided adequate information about the study, and understood the role of study participants. Written informed consent was collected from all participants. Participants were enrolled as dyads (i.e., a patient and a family-caregiver) for this study.

#### *PODS-ICU Implementation*

Patient partners informed select RNs/NPs (ICU nurses who had agreed to administer the PODS-ICU to participants) when a patient and family-caregiver had been enrolled. RN/NPs then completed the PODS-ICU tool and conducted a teach-back education session with the recruited participant(s) (i.e., patient and/or family-caregiver) prior to the patient's discharge from the ICU. The RN/NP then completed a brief online questionnaire (via Qualtrics, Provo, Utah) [**Additional File 2**] to provide feedback on their experience completing the PODS-ICU (e.g., ease of access, ease of use, time required to review the tool with a patient or family-caregiver) and its perceived impact on their workflow.

### *Participant Questionnaires*

The patient partner followed up with study participants, regardless of whether the PODS-ICU was successfully delivered, within one week after patient discharge from ICU to administer questionnaires assessing the quality of the discharge process. Patients and family- caregivers received separate versions of the feedback questionnaire. The follow-up was done in person for patients still present in the hospital, and over the phone for those patients who had left the hospital. Participants were administered questionnaires that inquired about how well they understood their (or the patient's) care trajectory as they were discharged from the ICU [Additional Files 3, 4, 5]. Participants who did not respond were contacted by the patient partner up to two additional times.

### *PODS-ICU Acceptability and Feasibility*

We measured the acceptability of the PODS-ICU by calculating the proportion of eligible patients and family-caregivers who consented to participate in the study. The feasibility was assessed by calculating the proportion of consented participants who received the PODS-ICU prior to discharge.

### **Data analysis**

We conducted data analysis as per the standard recommendations for design and analysis of pilot studies<sup>35</sup> in Microsoft Excel v16.0 (Microsoft Corporation, Redmond USA). Given that our study did not involve hypothesis testing, no power analysis was conducted, and no inferential statistics were calculated. We used descriptive statistics (mean, median) to summarize participant characteristics and questionnaire data (from patients, family-caregivers, and clinicians).

## **RESULTS**

### **3.1 Development of PODS-ICU**

The working group held 7 meetings between December 2018 and July 2019. After drafting an initial PODS-ICU template, the working group determined that patients discharged from the ICU to another inpatient care unit differed clinically (i.e., were

sicker) from patients discharged from the ICU directly to the community. Hence, the two patient groups required different post-discharge information. As such, the working group developed two different versions of the PODS-ICU. Following two rounds of major revisions and multiple rounds of minor revisions, the working group standardized written content where possible to improve efficiencies in completing the PODS-ICU, while still allowing for tailoring of patient-specific information. The working group first developed the PODS-ICU tool as a Microsoft Word (2019, Redmond, USA) template accessible through the hospitals' internal Website. The final template was subsequently developed alongside an in-house collaborator and embedded into a locally developed customized software program that could be run off an encrypted USB or a desktop local drive. A side-by-side comparison of the PODS-ICU Word versions for patients being discharged from the ICU to another care unit, and PODS-ICU for patients being discharged from ICU directly home in the community is shown in **Figure 1**.

### **3.2. Pilot test of the PODS-ICU tool**

#### *3.2.1 Participant Enrolment*

<sup>5</sup> During the study period, 319 patients were discharged alive from the two study ICUs. <sup>4</sup> Of these, 42 patients were potentially eligible for the study. Participant recruitment and reasons for exclusion are shown in **Figure 2**. The most common reasons for patient exclusion were ICU stays less than 24 h in duration ( $n = 181$  patients) and discharges on weekends when the study team (i.e., patient partners) was unavailable to approach patients ( $n = 57$ ). A number ( $n = 39$ ) of patients were excluded based on recommendations of the clinical team to not approach for clinical or psychosocial reasons (i.e., stress, family not available). Forty-two patients were approached for participation into the study, of which 10 were excluded due to inability to communicate in English and/or provide consent, and 1 for being enrolled in another study. Of the 31 eligible patients, 28 (90.3%) consented to be part of the study. Patients who declined to participate in the study indicated that they felt too overwhelmed to participate ( $n = 2$ ;

9.70%) or that their family was not present at the time they were approached ( $n = 1$ ; 6.70%). Nine (32.1%) of the consented patients were administered PODS-ICU by the ICU research team nurses, while 19 (68.0%) patients did not receive PODS-ICU because there was either no research team nurse available to administer the tool ( $n = 11$ ; 40.0%), or there was insufficient time for the research team nurse to complete the PODS-ICU ( $n = 8$ ; 28.6%) prior to discharge. Twenty-one (75.0%) family-caregivers for the 28 participating patients consented to participate in the study.

The nine patients who received the PODS-ICU were primarily female ( $n = 6$ ; 66.7%) with a mean age of 63 years with at least some post-secondary education ( $n = 6$ ; 66.7%). Family-caregivers were primarily women ( $n = 55.6\%$ ) with a mean age of 62 years, and most had some post-secondary education ( $n = 55.6$ ). Of the 21 family-caregivers that consented to participate in the study, 6 caregivers (66.7%) for the 9 patients who were administered the PODS-ICU received information about the patient's transition from the ICU. Once enrolled, no patients or family-caregivers withdrew from the study. Demographic characteristics of participating patients and family-caregivers are listed in **Table 1**.

### 3.2.2 Participants' Reported Experiences

Of the 15 participants (9 patients and 6 family-caregivers) who received the PODS-ICU, 13 felt that their discharge from the ICU was good ( $n = 4$ ; 30.1%), very good ( $n = 5$ ; 38.5%), or excellent ( $n = 4$ ; 31.0%) (**Figure 3A**). Over half of participants ( $n = 9$ ; 60.0%) felt they were moderately, very, or completely engaged in thinking about the ICU transition process (**Figure 3B**). Most participants stated they had a good or better understanding of the medical condition that brought the patient to the ICU ( $n = 11$ ; 73.3%) and that they understood the events that happened in the ICU and the impact of the ICU stay on the patient's health ( $n = 11$ ; 73.3%) (**Figure 3C**). When asked about the ICU discharge, most participants ( $n = 12$ ; 80.0%) said they had a conversation with the ICU team to discuss the transition and next steps (**Figure 3D**).

### 3.2.3 Clinician Reported Experiences

Participating nurses completed the feedback questionnaire for 10 (66.7%) of the 15 patients who had a PODS-ICU completed. It took the study nurses an estimated 45 minutes on average to complete the PODS-ICU tool (median 25 minutes) and an additional 30 minutes on average to review it with the patient and/or family-caregiver (median 15 minutes). Key data from the survey (which included closed and open-ended questions) are displayed in **Table 2**.

**Participating RNs and NPs reported, that: 1) patients and family-caregivers appreciated the information the tool provided, 2) discharge timing often did not allow for an opportunity to complete and teach-back the PODS-ICU, or to do it well, and 3) the process of filling out the PODS-ICU was too time-consuming and did not fit well into the clinical workflow. Select comments received from research team RNs/NPs are shown here:**

## **DISCUSSION**

We designed and pilot tested the PODS-ICU, a patient- and family-caregiver- focused written discharge summary tool to provide critically ill patients and their family-caregivers with key information on the patient's stay in ICU, transition (i.e., discharge) from the ICU, and what to expect post-ICU. Our pilot study showed that the PODS-ICU was well accepted and participants viewed their discharge from the ICU positively when it was used. However, the pilot study also showed that while the tool had high acceptability, it was not feasible to administer in the ICU settings as: 1) the time to discharge varies for each patient and current clinical practices did not allow for the tool to be consistently delivered, and 2) clinicians found the PODS-ICU to be time consuming and fit poorly within their clinical workflow.

The practice of providing written information to patients and/or their family-caregivers at the point of discharge from the ICU remains uncommon,<sup>36</sup> with very few existing tools to aid in that process.<sup>31</sup> Previous evaluations of written discharge communications for patients and family-caregivers in ICU have shown that these tools

can improve family-caregiver satisfaction with care in the ICU,<sup>37</sup> decrease family-caregiver 'transfer' anxiety around transitions from the ICU,<sup>38,39</sup> help patients and families understand and accept ICU events,<sup>40,41</sup> help 'fill in the gaps' for patients with memory lapses,<sup>42,43</sup> and improve longer term patient outcomes.<sup>44</sup> In developing the PODS-ICU tool, we relied on the pre-existing OpenLab PODS tool<sup>21,27,45</sup> and input from patient-partners to ensure the tool addressed specific informational needs of patients in the ICU (e.g., summary of ICU events, medications, upcoming tests and appointments, what to expect during recovery, resources for help). This allowed the PODS-ICU to support reliable delivery of essential information from clinicians to patients and family-caregivers at discharge from the ICU, whether the patient was being transferred to a ward in the hospital or directly home. In our study, clinicians reported the PODS-ICU tool to generate comprehensive and beneficial summaries. Interestingly, previous evaluations of summary tools have reported similar challenges to those we observed in implementing the PODS-ICU, such as varying clinician motivation to complete the tool due to lack of time, competing priorities, and/or negative perceptions of the tool's utility.<sup>40</sup> Due to these limitations, clinicians in our study struggled with the feasibility of incorporating this tool into their workflow.

Outside of ICU settings, patient-centered discharge communications (both written and oral) have shown benefit in cardiovascular,<sup>46-48</sup> maternity and neonatal,<sup>49,50</sup> and surgical<sup>51</sup> settings. Like the PODS-ICU, discharge communications in other settings have aimed to convey information on next steps (e.g., what to expect),<sup>52</sup> identification and management of risk factors and complications (e.g., when to seek care, pain management)<sup>53,54</sup>, and medications<sup>47,55,56</sup> from healthcare providers to patients and their families. Similarly to the PODS-ICU, many discharge communications from various acute care settings have been reported as time consuming and adding to healthcare provider workload.<sup>40,45,57,58</sup> However, they have also been reported to reduce hospital readmissions, improve treatment adherence, and enhance patient satisfaction and can be considered important to successful transitions in care.<sup>40,57,58</sup> This suggests a high value to improving upon ICU discharge tools (like the PODS-ICU), which could be

expected to have cost-savings comparable to discharge communications between hospital and community-based healthcare providers.<sup>59</sup>

Pilot implementation of the PODS-ICU highlights important opportunities to improve clinician-patient communication during a discharge from the ICU. These include: 1) earlier discharge planning (i.e., preparation for discharge begins as soon as a patient is admitted), 2) integration of discharge communication with electronic clinical information systems, and 3) regular incorporation of teach-back into clinician-patient communications. At a practical level, earlier discharge planning could prompt clinicians to begin completing parts of the discharge summary as soon as a patient is admitted, perhaps fitting better into their workflow. Electronic clinical information systems provide the potential to partially automate the population of patient data into discharge summaries, a time-consuming aspect of the PODS-ICU. Pre-population of discharge summaries with patient data can increase efficiency and potentially reduce the risk of human transcription error.<sup>60,61</sup> Finally, incorporating the teach-back method into clinician-patient and clinician-family-caregiver communications, an important aspect of the PODS-ICU and recommended by the Agency for Healthcare Research and Quality (AHRQ),<sup>62</sup> has been shown to improve patients' understanding of their health information.<sup>63</sup> This could foster better connections between patients and clinicians,<sup>34</sup> further benefitting communication efforts. Apart from the above discussed methods to increase time efficiency of completing the PODS-ICU (i.e., earlier discharge planning, integration with electronic clinical information systems), further engaging patients and families to modify the PODS-ICU to only include information important to patients may be a valuable refinement to the tool.

<sup>3</sup> There are a number of limitations to consider when interpreting the results of our pilot study. First, only a small number of participants ( $n = 9$  patients and  $n = 6$  family-caregivers) received the PODS-ICU tool. Although we were able to ascertain some reasons for the low delivery of PODS-ICU (i.e., availability of research team nurses and time required to complete the tool), an assessment by more patients, family-caregivers and clinicians could provide more insights into the usability of the tool. Second, we

pilot tested the PODS-ICU in two study ICUs in a single city (Calgary) in Canada. We recognize that ICU populations differ in type and severity of illness and some ICU staff may have more capacity to implement the PODS-ICU. As the OpenLab's PODS has shown the potential to improve patient outcomes in various care settings,<sup>21,45</sup> the PODS-ICU may be more successful in settings where it is better integrated into clinician work flow.<sup>45</sup>

## **CONCLUSION**

We developed a written discharge summary tool (PODS-ICU) that provides patients and their family-caregivers with the essential information they need as they transition out of the ICU. While the PODS-ICU may require pairing with earlier discharge practices and integration with electronic clinical information systems to fit better into the clinical workflow, the tool has the potential to engage and empower patients and family-caregivers in ensuring continuity of care. Further refinement and testing of the PODS-ICU tool in diverse ICUs is needed to determine its broader feasibility and the effects on patient health outcomes as well as patient-centered care.

## **ARTICLE HIGHLIGHTS**

### ***Research background***

Gaps in discharge communication can leave critically ill patients vulnerable to stress, poor health outcomes, and death.

There are no standard written discharge summaries available for critically ill patients and their families.

### ***Research motivation***

Written discharge summaries can provide patients and their families with important information (e.g., medications, activity and diet restrictions, follow-up appointments, symptoms to expect, who to call if there are questions).

### *Research objectives*

We aimed to develop and pilot test a patient-oriented discharge summary tool for critically ill patients and their families.

### *Research methods*

We worked alongside former critically ill patients and their families, clinicians, and researchers to discuss patient needs and develop a written discharge summary tool.

Intensive care unit nurses piloted the tool in two intensive care units in Calgary, Canada.

Research team members administered follow-up surveys to patients, family participants, and ICU nurses on the impact of the summary tool on discharge.

### *Research results*

Most participants felt the discharge summary tool was useful and informative.

Most participants<sup>6</sup> reported that they understood intensive care unit events and impacts on the patient's health.

Participating intensive care unit nurses reported time constraint in completing the discharge summary tool and encouraged refinement of the tool.

### *Research conclusions*

The patient-oriented discharge summary tool could benefit from further refinement and testing in diverse critical care settings to better assess its feasibility and its effects on patient health outcomes.

### *Research perspectives*

Written discharge communication provides patients and their families with essential information as they discharge from the intensive care unit.

Future directions for a written patient-oriented discharge summary tool for critically ill patients include pairing the tool with earlier discharge practices and integrating the tool

with electronic clinical information systems to fit better into the clinical workflow for ICU nurses.

### **ACKNOWLEDGEMENTS**

We would like to thank the working group for their role in developing the PODS-ICU tool, the individuals involved in PODS-ICU testing, and the patient partners involved in participant recruitment for all their hard work on this project.

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