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The experience of a neurocritical care admission and discharge for patients and their families: A qualitative analysis

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Abstract

INTRODUCTION: A qualitative assessment of discharge resource needs is important for developing evidence-based care improvements in neurocritically ill patients. We hypothesized that standardized, open-ended assessments of patients or caregivers after neurocritical care would result in themes that reflect post-intensive care concerns.

METHODS: We conducted a quality improvement initiative at an academic hospital and included all patients admitted to the Neurosciences Intensive Care Unit (NSICU) over an 18-month period. Telephone assessments were made at 3–6 months following admission. Patients or caregivers were asked if they had adequate resources upon discharge and if they had any unanswered questions. The content of responses was reviewed by a neurointensivist and neurocritical care nurse practitioner. A structured codebook was developed, organized into themes, and applied to the responses.

RESULTS: 61 patients or caregivers responded regarding access to resources at discharge with 114 individual codable responses. Responses centered around five themes with 23 unique codes: satisfied, needs improvement, dissatisfied, poor post ICU care, and poor health. The most frequently coded responses were that caregivers believed their loved one had experienced an

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unclear discharge (n=11) or premature discharge (n=12). 204 patients or caregivers responded regarding unanswered questions or additional comments at follow-up, with 516 codable responses. These centered around six themes with 26 unique codes: positive experience, negative experience, neutral experience, medical questions, ongoing medical care or concern, or remembrance of time spent in the ICU. The most frequent response was that caregivers or patients stated that they received good care (n= 115). Multiple concerns were brought up, including lack of follow-up after hospitalization (n=15), and dissatisfaction with post-ICU care (n=15).

CONCLUSIONS: Obtaining qualitative responses after discharge provided insight into the transition from critical care. This could form the basis for an intervention to provide a smoother transition from the ICU to the outpatient setting.

Keywords

neurocritical care; post ICU syndrome; caregiver support

Introduction

As the field of neurocritical care continues to grow, patient centered outcomes need to be studied in addition to crude survival and functional outcomes. Critical care-based societies have recommended prioritizing research that encourages survivor focused outcomes.¹ Cohort studies from the Neuroscience Intensive Care Unit (NSICU) have often focused on functional outcomes alone.^{2–5} Resources necessary for transitioning out of the critical care setting is a unique outcome metric that has been previously highlighted as an important unmet need in general critical care.⁶ To understand how neurocritical care can be improved for survivors, a qualitative assessment of transition needs following discharge is necessary.

Although there have been previous studies to determine needs related to post-ICU care transitions, none have been well studied in the neurocritical care patient population.⁷ For instance, patients with acute respiratory distress syndrome (ARDS) have been described previously as having many hurdles in transitioning out of the ICU, moving from a critically ill state into a rehabilitative state, integrating back into society, and frequently struggling with their new life outside of the ICU.⁸ Discharge checklists, education, and tip sheets have been developed based on input and qualitative interviews from stroke survivors and stroke caregivers, although a limited proportion of stroke patients require the provisions of critical care.^{9,10}

We performed a quality improvement initiative to follow patients with critical neurological injuries¹¹ using a nursing-led strategy to obtain qualitative data pertaining to 1) unmet resources and 2) unanswered questions post-ICU discharge by asking open-ended questions. We hypothesized that by using established thematic content analysis techniques, we would find areas that may be targets for improvement in the discharge and care-transition processes.

Methods

This was a quality improvement initiative to understand post-discharge outcomes and qualitative unmet needs and concerns of critically ill patients or their informal caregivers admitted to the neuroscience intensive care unit (NSICU) at the University of Cincinnati, which is a Level 1 trauma center, comprehensive stroke center, and quaternary referral center. Our retrospective reporting of these data were approved by the Institutional Review Board (IRB) of the University of Cincinnati with waiver of informed consent. Data collection for this project has been previously described.¹¹ Once neurocritically ill survivors were identified and verified, we performed a scripted telephone assessment between 3–6 months following admission. Data was entered using REDCap (Research Electronic Data Capture), a secure, web-based application.¹² We preferentially requested to speak to the patient, but then asked if the primary caregiver would answer on the patients' behalf if the patient was not able to speak. We did not query if the caregiver was a care partner, although it is possible some of the participants may have had formalized care partner relationships. Patients or caregivers were specifically asked 1) if they had adequate resources upon discharge and 2) if they had any unanswered questions or comments. If they answered these open-ended questions, they were encouraged to expand on their responses.

Qualitative responses were analyzed using thematic content analysis, using inductive and deductive coding to identify, analyze, and report overarching patterns (*themes*) and nuanced patterns (*codes*) across a dataset. Two researchers (NK and KR) independently coded the responses, then met weekly to work through each transcript together. A directed content analysis approach was used to interpret the transcribed data.¹³

A codebook for each of the two questions was developed collaboratively through discussions among our research team to ensure consistent application of codes. For each code, we included a long definition, short definition, when to use, when not to use, and an example of each code. The code books were agreed on by all team members prior to coding, and inductive changes were made by NK and KR during the formal coding period. When changes to the code book were made, the coders reviewed previously coded interviews with the revised code book to make certain that no previously coded segments were mislabeled. The abbreviated code books are included as Tables 1 and 2.

Both coders generated new emergent codes as needed, and later compared and discussed until consensus in coding styles was reached. If the two coders were unable to reach agreement, a third-party adjudicator was used (BF). Throughout the process of coding, emergent patterns, themes, and noteworthy statements were documented, as a way to provide analytical depth, identify illustrative quotes, and highlight points for further discussion. The proportion of themes for each major neurocritical care diagnosis, length of stay, and discharge destination were examined.

Results

Patient identification:

A total of 1324/2163 patients fulfilled our inclusion criteria (see Figure, Supplemental Digital Content 1, which describes study flow). Of those, a total of 365/1324 (27.6%) died in the hospital whereas another 150 died after discharge for a follow-up mortality of 515/1324 (38.9%). Of 959 hospital survivors, 557 were reached by the study team at 4.4 +/– 0.8 months after their initial admission. 232 provided a qualitative response to open ended questions. Demographics of those who provided qualitative responses were compared to those who did not (see Table, Supplemental Digital Content 4). The two groups were similar in proportions of race, primary diagnosis, hospital length of stay, discharge destination, and whether the responses were from the survivor or a caregiver. The two groups were significantly different in that male patients or caregivers of male patients were more likely than female patients or caregivers of female patients to provide a qualitative response, and patients with an ICU stay of <72 hours were less likely to provide a qualitative response compared to those with an ICU stay of >72 hours.

Qualitative Analysis:

Resources at discharge—Comments regarding patient resources at discharge fell into five major themes: 1) satisfied 2) it was okay, but something happened that could be improved 3) dissatisfied with ICU and discharge 4) post-ICU care was bad 4) and ongoing health concerns. Each of the themes contained more specific, targetable codes. There was 94.7% agreement for codes in patient resources at discharge. The most commonly described theme for patient resources at discharge was, “**It was okay.**” This theme broadly described caregiver responses that pointed out specific areas upon discharge where their needs were not met. This included several codes such as patients reporting *no home care, no appointment, unclear discharge instructions, or insurance issues*. The most commonly coded unmet need overall for discharge was *premature discharge* (n = 12). Additional commonly coded responses to the open-ended question about resources upon discharge were *unclear discharge* (n = 11), *poorly prepared* (n = 9), and *ghosted* (n = 9).

The most commonly coded theme regarding resources at discharge (based on percent of total codes within each diagnosis) for all major diagnoses is included in Supplemental Digital Content 2. Individuals who were admitted for a subarachnoid hemorrhage (SAH) or seizures/status epilepticus reported poorer ICU discharge processes when compared to other major diagnoses. Additionally, only individuals with acute ischemic stroke (AIS) reported any satisfaction with the discharge process. Patients with an ICU LOS >72 hours had a higher proportion of responses reporting a poor discharge process, less satisfaction, and poor post-ICU care compared to those in the ICU < 72 hours. Patients who were discharged from the hospital to a skilled nursing facility (SNF) were most likely to report poor post-ICU care, and those who were discharged to inpatient rehabilitation were least likely to report poor post-ICU care (Supplemental Digital Content 5).

Unanswered Questions—Unanswered questions or comments after discharge fell into six themes, 1) **neutral** 2) **positive**, 3) **negative**, 4) **medical questions**, 5) **ongoing medical**

concern or questions, or 6) **remembrance**. There was 99% agreement in coding the unanswered questions or comments. Within these themes, several common codes emerged. The most common codes for unanswered questions after discharge were in the theme title, “**positive care**,” which included *Good care in the ICU*(115), *Enthusiasm for institution* (33), and *Grateful* (31). The most common theme in response to unanswered questions (based on percent of total codes that occurred for each diagnosis) for each major diagnosis is listed in Supplemental Digital Content 3. Commonly coded responses within the theme of “**areas of improvement**” were *bad post-ICU care* (n = 15), *lacking follow up* (n = 15), *recovery needs* (n = 15), *disease complication* (n = 14), and *got info* (n = 14).

Individuals with TBI reported much fewer positive responses compared to other diagnoses, with only 5% of responses positive, compared to the next lowest, which was 39%. Patients discharged home had the highest proportion of positive comments about their ICU stay.

Discussion

Our study is the first to describe the neurocritical care discharge process. The use of open-ended post-ICU assessments such as this can inform iterative changes in practice that can be evaluated based on changes in the perception of needs with the potential to provide evidence for practices such as discharge education that are untestable via traditional clinical trial design.¹⁴ Our findings suggest that there are many unmet needs and concerns related to transition out of the ICU in a complicated neurocritically ill patient population for which we can develop further improvements in care.

The most common unmet need regarding resources after discharge was that caregivers perceived their loved one was prematurely discharged, or they felt unprepared to leave the ICU with their loved one. Patients who are *medically* not prepared for ICU discharge do have worse outcomes, but the *perception* that a loved one was prematurely discharged has not been associated with worse outcomes.¹⁵ It is likely that the sense of being prematurely discharged may be felt by caregivers of loved ones who received little information, education, or follow-up regarding the next phases of care after the ICU. It is also possible that during the time in ICU, patients and/or caregivers had difficulty receiving information due to low health literacy, cognitive or memory distortions due to stress or illness, or they were simply overwhelmed at the time. Patients and caregivers reported that home health services were challenging to obtain, and were expecting services beyond the scope of home health care, which is consistent with previous qualitative studies of discharged hospital patients.¹⁶ This may have contributed to the sense of premature discharge. Many patients and caregivers also spoke subjectively about how long it had taken them to recover, and that they were surprised by the amount of time they experienced residual neurologic deficits. Although this is consistent with published timelines of neuro-recovery, additional education at the time of discharge may have allowed patients and caregivers to develop a framework for the timing of recovery, and may have decreased the number who reported the perception of a premature discharge.¹⁷

We targeted the use of qualitative methods to study discharge unmet needs and concerns, as no other quantitative measure would be specific enough to obtain this information. One

similar prior systematic review of four qualitative studies of pediatric intensive care unit transitions has been published, describing that the period of ICU discharge was emotionally, physically, and socially challenging, with the perception of little targeted support for families during this vulnerable time.¹⁸ Future studies should seek to develop comprehensive discharge processes from the neuro ICU that incorporate family support and education.

We found that patients with a longer ICU stay (> 72 hours) had a higher proportion of responses that indicated a poor discharge process, and more frequently reported poor post ICU care, compared to those with a shorter ICU stay (<72 hours). Although this study was not designed to determine the reasons for this finding, it is likely that patients with a longer ICU stay are more medically complex, and require additional services and preparation prior to ICU discharge. Further, patients who were discharged to a SNF were more likely to report poor post-ICU care compared to other discharge destinations. Previously published evidence, however, has reported that satisfaction with SNF placement can be improved if patients and families are both educated and involved in the decision about location, type, and mobility goals of a skilled nursing facility stay.^{19–21}

Individuals with TBI reported the lowest levels of positive responses when asked about any concerns. While this study is unable to make inferences for why this was the case, many respondents with TBI described complex, hectic discharges with numerous specialists and ancillary providers necessary for their post-ICU care. However, some unmet needs were common in all groups of patients, such as financial counseling, neuro-recovery education, or increased access to home health services, and could be addressed within the larger neurocritical care cohort to streamline options for patients and caregivers in these realms.

Limitations:

Our study was limited in that it was a quality improvement initiative rather than a formal clinical observational cohort study. While one of the authors performed the majority of the data entry and quality (ELS) and another the majority of the phone call follow-up (OL), different personnel participated over time which may have altered the qualitative responses from caregivers and their willingness to speak with study personnel. There is risk of bias, as some patients/caregivers chose to not provide qualitative responses. However, those who did provide qualitative responses did not have significant demographic differences, other than gender, compared to those who did not provide responses. Our analysis only used patients within a single institution, so other institutions with differing discharge processes may have other findings. We used telephone contact as our method for follow up and qualitative assessments. Qualitative assessments may have been different if obtained in person. Also, our qualitative information was obtained 3–6 months after the hospitalization. While this allowed patients or caregivers to place their ICU discharge in perspective, it may have led to responses that were subject to recall bias due to the length of time that had passed, the neurologic injury itself, or post-traumatic stress.

Conclusions:

We found that the use of a qualitative assessment of unmet needs and concerns of survivors and caregivers regarding discharge from the NSICU was both feasible, and provided information that will allow us to make meaningful changes to the NSICU discharge process. Female survivors and caregivers of female survivors were less likely to provide qualitative responses, and future studies should explore if their needs differ. A neurocritical care intervention that entails a streamlined ICU discharge process that would ensure follow-up, provide education on post ICU care, and include a specific number to call in the event of questions may reduce problems that were brought up in this study. This intervention would provide a meaningful way for nurses to contribute to patient/caregiver wellness after a neurocritical illness, as well as provide a smoother transition from the ICU setting to the rehabilitation and outpatient settings. Although ICU discharge needs were apparent in all types of neurocritically ill patients, those who required a higher level of care after discharge or had a longer ICU stay reported more dissatisfaction with post-ICU care and the ICU discharge process, and may represent a population who would benefit from a tailored intervention to address discharge needs. In instances where the patient was not able to speak, caregivers provided valuable insight, and should be involved in future qualitative assessments of discharge processes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1:

Brief Description of Codes for “Patient Resources on Being Discharged”

Code	Description	Frequency
Satisfied, no complaints: 1		
Satisfied	All needs met after discharge.	3
It could be improved: 47		
No home care	Unmet home health care needs	6
New plan	The plan fell through after discharge.	1
Paperwork	Unmet paperwork completion	3
No appointment	Follow up not scheduled	6
Unclear discharge	Confusing information received at discharge	11
Insurance	Unmet discharge needs related to insurance	6
Non preferred follow up	Provider at discharge was non preferred one	6
Transportation	Unmet transportation needs after NSICU admission.	3
Medication issue	Unmet medication needs at discharge after NSICU admission.	4
Equipment problems	Unmet needs for equipment to care for NSICU patient post discharge	1
Poor discharge experience: 36		
Poor health care quality of life	Caregiver reports a poor quality of life for survivor, and not the outcome they were hoping for.	1
Poorly prepared	Unprepared to navigate the system post discharge	9
Ghosted	Perception of being pushed out of the system	9
Specific complaint	Specific instance of concern for caregiver	9
Poor quality	perceived poor quality of care in the ICU without more specific information.	4
Many unanswered questions	Many questions still at the time of discharge that were not answered.	4
Post ICU care was bad		
Simply not good	Nonspecific unmet post ICU needs	4
Premature discharge	Premature timing of discharge out of the ICU	12
Poor personnel	Personnel post ICU did not care appropriately for the patient.	1
Level or location of care	Unmet needs regarding level of care post discharge	3
Medical complications	Unmet medical needs at discharge	5
General medical complaint		
Poor health	Patient or caregiver describes that they are simply in poor health	3

Table 2:

Brief Description of Codes for “Any Unanswered Questions”

Code	Description	Frequency
Neutral		
Mostly Satisfied	Satisfied but some aspect could be improved upon	11
Positive		
Grateful	Grateful to staff	31
Liked staff	Satisfied with ICU care, good care	115
Healing	Patient is getting better or is cured	11
Enthusiasm for institution	Specifically reported that they felt appreciative of care provided in our institution	33
Got info they needed	Felt they received necessary information	14
Good Rehab	Description here	4
Family Support	A family/caregiver need was met	3
Negative		
Dissatisfied with staff	The hospital staff did a poor job	7
Bad rehab experience / bad post ICU care	Dissatisfaction or negative rehabilitation unit experience	15
Lacking information	Report a need for more education	10
Discharge disaster	Poor discharge experience	10
Lack of follow up	Appropriate follow up was not arranged	15
Medical questions		
Diagnosis related question	Caregiver still has question about primary diagnosis	5
Medication question	Question about a medication the patient was sent home with	4
Ongoing medical concern or care		
New complaint	Unanticipated issue has come up requiring them to seek care	6
Pain	Patient is having pain issues	6
Mental health	Caregiver describes that patient has depressive symptoms or anxiety related to hospitalization	10
Finances	Financial hardship surrounding hospitalization	3
Family needs	Family distress and methods family is coping with distress	4
Recovery	Caregiver comments on ongoing recovery or rehabilitation	15
Hospice	Patient now under hospice care	1
Disease complication	A complication has occurred	14
Level of care	Level of care after discharge was incorrect or suboptimal	1
Remembrance		
Event	Recall of a specific ICU event that is meaningful	5
Amnesia	Partial or total amnesia of hospitalization	11