The Center for Trauma Survivorship: Addressing the great unmet need for posttrauma center care

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BACKGROUND: Returning patients to preinjury status is the goal of a trauma system. Trauma centers (TCs) provide inpatient care, but postdischarge

treatment is fragmented with clinic follow-up rates of <30%. Posttraumatic stress disorder (PTSD) and depression are common, but few patients ever obtain necessary behavioral health services. We postulated that a multidisciplinary Center for Trauma Survivorship (CTS) providing comprehensive care would meet patient's needs, improve postdischarge compliance, deliver behavioral

health, and decrease unplanned emergency department (ED) visits and readmissions.

METHODS: Focus groups of trauma survivors were conducted to identify issues following TC discharge. Center for Trauma Survivorship el-

igible patients are aged 18 to 80 years and have intensive care unit stay of >2 days or have a New Injury Severity Score of ≥16. Center for Trauma Survivorship visits were scheduled by a dedicated navigator and included physical and behavioral health care. Patients were screened for PTSD and depression. Patients screening positive were referred for behavioral health services. Patients were provided 24/7 access to the CTS team. Outcomes include compliance with appointments, mental health visits, unplanned ED

visits, and readmissions in the year following discharge from the TC.

RESULTS: Patients universally felt abandoned by the TC after discharge. Over 1 year, 107 patients had 386 CTS visits. Average time for each

appointment was >1 hour. Center for Trauma Survivorship "no show" rate was 17%. Eighty-six percent screening positive for PTSD/depression successfully received behavioral health services. Postdischarge ED and hospital admissions were most often for infections or unrelated conditions. Emergency department utilization was significantly lower than a similarly injured group

of patients 1 year before the inception of the CTS.

CONCLUSION: A CTS fills the vast gaps in care following TC discharge leading to improved compliance with appointments and delivery of phys-

ical and behavioral health services. Center for Trauma Survivorship also appears to decrease ED visits in the year following discharge. To achieve optimal long-term recovery from injury, trauma care must continue long after patients leave the TC. (J Trauma

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LEVEL OF EVIDENCE: Therapeutic, Level III.

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Trauma centers (TCs) save lives, but the real goal of a trauma system is to return the injured back to their lives as functioning members of their families and communities. Trauma centers were created to provide high-quality acute care with survival as the metric of success. Currently, even patients with severe (Injury Severity Score [ISS], <25) or life-threatening (ISS, ≥25) injuries have a case fatality rate of only 5% and 20%, respectively, resulting in large numbers of patients discharged alive. However, the long-term outcome and fate of these survivors are much less clear.

In the recent National Academy of Science Engineering and Medicine report describing a model for a national trauma care system, the primary focus is on achieving zero preventable deaths.² The document articulates that, in the continuum of trauma care, any breaks along the chain lead to preventable morbidity and mortality. There is only a cursory mention of rehabilitation as an important factor in leading to recovery and reentry into society but this states that, because of a paucity of data, this component is the weakest link in the chain. What is missing from this "chain of care" is any description of how a patient actually transitions from inpatient TC care to recovery.

One of the earliest studies examining the fate of trauma patients was by Gissane et al.³ in 1970. They followed 1,265 road traffic victims and found that 21% were permanently

disabled, 50% of the disabled were younger than 30 years, and 22% required considerable rehabilitation. They also identified a large need for social workers and help with financial difficulties as a result of their injury.

In a study of severely injured trauma patients evaluating outcomes at 3.3 years following discharge, almost two thirds were less active and only 50% were back to work or school.⁴ Gabbe et al.,⁵ followed 2,424 trauma survivors at 3 years following injury and identified serious limitations in all domains: mobility, self-care, pain, anxiety, and depression as well as the ability to perform their usual activities. These data demonstrate that life-long disabilities persist after discharge from the TC.

The impact of posttraumatic stress disorder (PTSD) and poor long-term outcomes following civilian trauma was initially identified in the 1990s. The impact of pain and behavioral health on outcomes has been subsequently confirmed by others. Recently, the Functional Outcomes and Recovery after Trauma Emergencies project identified that 62% of patients had significant physical limitations, 37% had difficulty with $1 \ge$ activity of daily living, and 20% suffered from PTSD at 12 months following injury. In this modestly injured group, only 59% had been able to return to work. Identifying PTSD and depression as predictors of poor outcomes is only part of the battle, and because of a multiplicity of barriers, only a small percentage of patients ever receive treatment for PTSD and depression.

Trauma centers provide total comprehensive care during the inpatient stay, but the system often breaks down and fragments upon discharge. Navigating postdischarge care is difficult even for the most health literate. Poor communication at multiple levels has been identified as a significant barrier to a successful discharge of the trauma patient. We postulated that the model of multidisciplinary, coordinated, inpatient TC care needs to be continued long after discharge. Thus, we created the Center for Trauma Survivorship (CTS) with a philosophy of care that mirrors that of the TC and fills this missing vital gap in health

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care delivery to maximize recovery and reintegration into work, school, and the community. These data report on the first year of CTS operation. We postulated that a multidisciplinary CTS providing comprehensive care would meet unmet patient needs, improve postdischarge compliance, deliver behavioral health services, and decrease unplanned ED visits and readmissions.

PATIENTS AND METHODS

Patient Population

Because increasing injury burden and intensive care unit (ICU) admission have been previously identified as factors associated with worse outcomes, we chose to focus our efforts on that patient population. Patients eligible for the CTS were adults aged 18 to 80 years who were admitted to the ICU for >2 days or had an overall injury burden reflected in a New Injury Severity Score (NISS) of ≥16 and survived to discharge. The NISS was chosen rather than ISS because ISS fails to account for the long-term morbidity of multiple fractures.

Focus Groups

Three focus groups were held for former trauma patients and caregivers. Patients who would have met CTS eligibility requirements were chosen. The patients were at least 1 year from their injury. The goals of these focus groups were to understand the needs that were both met and failed to be met during TC admission and especially during and after the TC discharge. Qualitative and quantitative data were obtained during these focus groups.

Center for Trauma Survivorship

In response to the needs identified in the focus groups, the CTS was developed to provide coordination and holistic physical and behavioral health care for all patients meeting eligibility criteria. The CTS interdisciplinary team is composed of a dedicated nurse practitioner, social worker, and health care navigator supplemented with a trauma physiatrist and trauma surgeon. We have already documented the importance of a dedicated trauma physiatrist in the acute care of our patients, 13 and we believe having the same individuals involved and helping to coordinate their care in the outpatient are vitally necessary to achieve optimal long-term outcomes. Patients are identified during their initial hospitalization and approached before discharge by the CTS staff. Patients are specifically scheduled for the CTS and not the routine trauma clinic. All appointments and transportation for CTS appointments are coordinated by the patient navigator. When necessary, Uber Health is provided for the patients to ensure that they make their appointments. The CTS visit is comprehensive and includes a complete assessment of physical, emotional, and behavioral health. This includes but is not limited to complete evaluation of current medication usage, pain management, need and compliance with needed subspecialist appointments, rehabilitation needs, and discussion of long-terms outcomes and plans. Patients are seen and evaluated by more than one health care provider in the same setting.

During the first CTS visit, patients are screened for PTSD (PCL-5 [PTSD Checklist for DSM-5]) and depression (Beck Depression Inventory). Patients who screen positive are referred for behavioral health services. Patients who screen negative but

during the course of their visit in the opinion of the CTS staff require further behavioral health services are also referred. Patients are provided 24/7 access to the CTS team through email and a dedicated cell phone. The primary outcomes during this first year were compliance with CTS appointments, percent of patients successfully obtaining behavioral health services, unplanned ED visits and hospitals readmissions.

ED Visits and Readmissions

The electronic medical record on all CTS patients was searched for all ED visits and readmissions in the 12 months following discharge from the TC. The reasons for the visits and any subsequent admissions were evaluated and classified as a new condition, a postoperative or postinjury complication requiring emergent care, or potentially avoidable (e.g., something that could have been managed in the CTS). To compare the effectiveness of the CTS in decreasing these unplanned returns, the trauma registry was queried for all patients who met CTS eligibility for the 1 year preceding the initiation of the CTS. The number of ED visits and readmissions in the year following discharge was identified. These charts were also reviewed for the number and timing of any trauma clinic visits after discharge.

RESULTS

Focus Groups

Three focus groups were held with 27 trauma patients and 9 caregivers. The time from injury ranged from 1 to 18 years. Focus groups were facilitated by one of the authors (C. Castellano). The top five themes identified in these focus groups were: (1) abandonment by TC, (2) need for mental health and addiction services, (3) inadequate pain management, (4) physical limitations, and (5) general support for daily living (e.g., transportation, financial hardships). Further exploring the top theme of abandonment, the majority of patients and caregivers related that they felt "let down" by the TC up to three times during their overall experience. The first was when the patient transferred out of the ICU to the ward. The second was upon discharge. This second event was not dependent upon whether the patient was discharged to rehabilitation or home. In fact, those patients who were discharged to rehabilitation, felt even more removed from the TC. At rehabilitation they described problems with follow-up appointments, surgical and trauma related wounds, and having a new health care team that did not fully appreciate and understand their posttraumatic issues. This group, when they were discharged from rehabilitation, often related further difficulty accessing care at the TC and felt abandoned for the third time.

Patient Population

From August 1, 2018, to July 31, 2019, 137 eligible patients were discharged alive from the TC. Of these, 107 patients (79%) were seen at least once in follow-up in the CTS. Reasons for not being seen varied but included discharge outside the trauma catchment area, inability to contact the patients or caregivers, unwillingness to participate, or insurance issues requiring them to follow-up elsewhere. The demographic data for the CTS participants are shown in Table 1.

TABLE 1. CTS Patient Demographics	
Number	107
Age (mean \pm SD), y	39 ± 15
Sex	83% Male
	17% Female
Race/ethnicity	
African American	60
Hispanic (all)	25
Caucasian	17
Asian	2
Other	3
Mechanisms of injury	
Gunshot wound	25
Stab wound	2
Motor vehicle	22
Pedestrian	25
Fall	25
Assault	6
Other	2
ISS (mean \pm SD)	21 ± 11
NISS (mean \pm SD)	31 ± 13
ICU admission, %	93
ICU LOS (mean \pm SD), d	16 ± 14
Hospital LOS (mean \pm SD), d	28 ± 22
Discharge disposition	
Home	49
Rehabilitation	
Acute	43
Subacute	14
Nursing home	1
LOS, length of stay.	

Access to CTS Care

Over the 12 months, the 107 patients underwent a total of 386 CTS visits. The average time for each appointment was >1 hour. The overall CTS "no show" for the year was 17%. In latter half year of CTS operations, this rate decreased to <15%. Uber Health provided 100 individual ride segments for patients. Patients who were discharged to rehabilitation returned using medical transport coordinated by the CTS staff and not the sending facility. Over the study period, there were more than 1,000 phone calls and 1,500 text messages between CTS staff and patients or caregivers.

The dedicated nurse practitioner is the primary provider for 100% of the patients. Because of the colocation of practices,

TABLE 2. Behavioral Health Services (February 2019 to August 2019)

No. patients	37
No. total visits	136
1 Session	55 Patients
2 Sessions	24 Patients
3 Sessions	21 Patients
≥4 Sessions	31 Patients
No show rate	21%

approximately 80% of patients are also seen either formally or informally by our trauma physiatrist (P.Y.). This synergy has realized improvements in pain management, mobility, and specialized rehabilitation needs including TBI neuropharmacology, nerve injury, and complicated musculoskeletal injuries as well as directing and supervising ongoing physical and occupational therapy. To attempt to decrease the number of follow-up appointments, patients are sometimes seen during subspecialty appointments (e.g., orthopedics), and if possible, we arrange for subspecialists to see patients during scheduled CTS appointments. Lastly, about 25% are also seen by a trauma surgeon (D. H.L.) for complex decision making in overall care, wound management, or scheduling and counseling for additional surgery.

Behavioral Health

During their initial visit, 32% of patients screened positive for PTSD alone, 32% were positive for depression alone, and 23% were positive for both. Eight-six percent of those screening positive successfully received behavioral health services. Despite initially screening negative, an additional five patients were referred for behavioral health services when, during their CTS visit, they related symptoms of PTSD or depression. Early in the development of the CTS, we had difficulty ensuring access to behavioral health services. The ability to have patients receive behavior health resources markedly improved following the hiring of a dedicated behavioral health worker 6 months into CTS operations. Since that time, compliance and ability to provide long-term behavioral health care have greatly improved. The presence of the behavioral health social worker has also empowered the CTS nurse practitioner and physiatrist to prescribe appropriate antidepressants in select patients. The number of behavioral health visits is shown in Table 2.

ED Visits and Readmissions

The number and indication for ED visits and unplanned admissions are shown in Table 3 and Table 4. These data demonstrate that these patients continue to have multiple medical and surgical issues following discharge and that, despite the CTS, they require considerable emergent care. The beneficial effect of the CTS can be observed when comparing postdischarge health care utilization with the pre-CTS patients (Table 3). Despite having similar demographics, NISS, and length of ICU and hospital stays, these patients had a considerably more ED visits.

In the CTS group, only five ED visits were considered avoidable and could have been handled by the CTS. Examining these five events, three occurred in the in the first 2 weeks of CTS operations over a holiday weekend. In the pre-CTS group,

TABLE 3. ED Visits and Readmissions: CTS Versus Pre-CTS Patients

	CTS	Pre-CTS
No. patients	107	177
Total ED visits (not admitted)	41	183
Avoidable no. ED visits	5	21
≥4 ED visits (no. patients)	2	16
≥4 ED visits (total visits)	8	110
Unplanned admissions (total number)	32	64

TABLE 4. Reasons for ED Visits and Readmission in CTS Patients

ED visits (not admitted; $n = 41$)	
Unrelated new condition	17
Posttrauma/operative infection	13
Related not infection	6
Medication related	5
Unplanned admissions $(n = 32)$	
Posttrauma/operative infection	17
Related not infection	10
Unrelated new condition	5

21 (11%) were avoidable and should have been treated in the trauma clinic (suture removal, minor wound checks, and medication refills). There were 7 patients in the pre-CTS cohort that resulted in 41% of the ED visits with 1 patient having 14 distinct ED encounters. In contrast, only two patients in the CTS groups were seen in the ED more than three times.³ One patient with a complex enteroatmospheric fistula and one patient with complicated decubiti after a spinal cord injury were each seen four times.

The increased ED utilization is likely due to a lack of coordinated trauma follow-up. In the pre-CTS cohort, only 41% of patients were ever seen by the trauma service following discharge. Of the patients who were seen in the trauma clinic, 33 (45%) only had 1 visit. The median time for that clinic visit was 11 days after discharge.

DISCUSSION

Severe traumatic injury is a sudden and unexpected life-altering event. It is a leading cause of psychosocial disruptions, stress, job loss, loss of relationships, and even personal bankruptcy. ¹⁴ Following discharge from the TC, patients and their caregivers often feel overwhelmed. Not only by the challenges of their own recovery but also by the challenges of navigating the health care system. Trauma centers provide total comprehensive inpatient care but little if any care following discharge. Coordination of aftercare, if it exists at all, is fragmented and often breaks down. Patients are burdened with a mountain of paperwork associated with the health care system and insurance demands and are often required to seek approvals for appointments, medications, and supplies that result in care that is delayed or denied. After identifying the many needs of our surviving patients, our program and data demonstrate the feasibility and success of a CTS to address these large gaps in health care delivery to potentially accelerate their recovery.

To better understand the patient's perspective, the use of patient-reported outcomes measure is emerging as critical to improve long-term outcomes and patient satisfaction. The health care infrastructure has most often "told rather than asked" patients what matters, and there are little data on patient's opinions following recovery from injury. ^{10–12} Gabbe et al. ¹⁰ interviewed 120 patients 12 to 24 months from their initial injury. While most patients felt grateful to be recipients of high-quality inpatient trauma care, they reported multiple deficiencies in communication especially during transitions of care. Most telling was that discharge from the TC was perceived as the most stressful event in their hospitalization with many patients feeling ill

prepared to go home or to rehabilitation. A consistent theme from these interviews was the sense of a lack of coordination of care after TC discharge and the inability to identify anyone who was in charge of their ongoing care. The clinic system was seen as ineffective and dysfunctional. Limited time with clinicians and the inability to see senior clinicians were also mentioned as negative factors in recovery. These data strongly parallel the themes that emerged from our focus groups; abandonment, difficulty in communicating with the TC, and a lack of ongoing care for physical and behavioral health issues. Similar to the experience in Victoria, discharge to rehabilitation was not as universally positive as most health care providers believe. The CTS was specifically designed to meet our patients' needs and mitigate these issues.

Through a coordinated approach, more than 85% of CTS patients were successfully seen in follow-up. This is in stark contrast to the year prior when only 41% of patients followed up at all and only 22% were seen more than once. The poor rate of trauma follow-up has been reported previously. Stone et al. 15 found that only 31% of trauma patients discharged from an urban level I TC returned for follow-up. Of note, they identified that increasing age, presence of insurance, increasing length of stay, and discharge to rehabilitation facilities were associated with failure to follow-up at the TC. One hypothesis is that follow-up at the TC was too difficult and patients with resources sought follow-up care elsewhere. Overton et al. 16 demonstrated a significant increase in follow-up appointments in uninsured trauma patients enrolled into a dedicated local access to care program. Contact through other means (phone, telemedicine) than by follow-up visit has been suggested as a way to improve communication and return. 12 Malhotra et al. 17 used a dedicated telephone follow-up system to contact all trauma patients within 4 weeks of discharge. Telephone follow-up was still only able to be achieved in half, but during these calls, 17% were identified to have significant health care issues not addressed at the time of TC hospitalization. The ability of our patients to communicate 24/7 by text or email with the dedicated CTS staff and not an amorphous practice plan phone tree undoubtedly contributed to our improved retention rates.

Based upon our focus groups as well as the anticipated need for intake and screening, we scheduled a patient's initial CTS appointment for an hour, not expecting to use all of the allotted time. What was striking was that patients used all of the scheduled time and more. Subsequent appointments continue to last for about an hour. Time constraints in current medical practices and the drive for increased productively have made the 10-minute office visit unfortunately standard. While CTS patients may see more than one provider during this time, the complexity of care, pain management, psychosocial support, and coordination with other providers takes time and effort that is not available in the traditional clinic system. During appointments, it was only after a prolonged period with the patients and caregivers that additional and serious issues that required intervention became apparent. Simply put, it takes time to listen. In his landmark article from 1929, Francis Peabody¹⁸ stated, "The treatment of a disease may be entirely impersonal; the care of a patient must be completely personal. The significance of the intimate personal relationship between physician and patient cannot be too strongly emphasized, for in an extraordinarily

large number of cases both diagnosis and treatment are directly dependent on it, and the failure of the....physician to establish this relationship accounts for much of his ineffectiveness in the care of patients."

We also identified the disconnect between inpatient TC and outpatient providers, which further results in fragmentation and poor communication with follow-up care. The importance of having the CTS team know the patients and be familiar with their hospital course before coming to the CTS cannot be overemphasized. Similarly, Meltzer and Ruhnke¹⁹ in a study of medical hospitalists identified that spending more time with patients and improving communication between the outpatient and inpatient settings decreased readmissions. They found that increased time spent seeing patients actually improved value and health care quality not to mention patient satisfaction.²⁰

The negative impact of behavioral health sequelae following injury on outcomes has been documented. ^{6,9,21} More importantly, most patients' behavioral health needs go unmet.22 Posttraumatic stress disorder and depression are reported to effect between a 25% and 50% of survivors, but the true incidence is likely higher. The percentage of patients screening positive in this study falls within that range. We did identify several patients who initially screened negative for PTSD or depression, and it was only through prolonged and direct patient contact that the health care team discounted the screens and identified the need for a behavioral health referral. It was evident from subsequent treatment that these patients were emotionally shut down and despite in person screening. In addition, preexisting mental health problems may affect as many as 40% of the trauma population, and severe injury will likely exacerbate these underlying behavioral health disorders.²³ Lastly, access to behavioral health is even more problematic than standard medical care with exceedingly low rates of patients ever being successfully being treated.^{7,12} Bell et al.⁹ in a 500-person prospective study found that 70% of patients screened positive for depression and almost half screened positive for PTSD in the first year following injury, but only 22% of patients who screened positive actually received any behavioral health treatment. The hiring of a dedicated CTS behavioral health specialist, allowed the program to achieve an 85% first appointment rate for patients screening positive for PTSD or depression. The use of a navigator and transportation for behavioral health has kept the no-show rate low.

Unnecessary ED utilization and readmissions within 30 days of discharge are currently used as quality metrics for the delivery of health care. Our data demonstrated that, even with the CTS, severely injured patients continue to require a long-term acute care with 41 ED visits and 32 readmissions over the 12 months following discharge, 50% being related to late infections. Many of these also occurred after 30 days, and it calls into question whether that metric is truly useful to measure quality of care in this cohort compared with patients undergoing elective surgical procedures. In comparison with the CTS patients, ED utilization but not readmissions, in the pre-CTS cohort were far greater. More importantly, more than 10% of those ED visits could have been addressed in a clinic or other outpatient setting. We postulate that the improved accessibility and the ability to contact the CTS staff kept patients out of the ED unnecessarily.

There are clearly limitations to the CTS model and analysis of its first year results. At the present time, we do not have sufficient data to determine if the CTS will improve important long-term outcomes as measured by back to work or school, nor do we have enough longitudinal data to assess whether improved access to behavioral health will improve the trajectory and outcome of our patients with PTSD, depression, and addiction. In addition, we do not have patient satisfaction or quality of life measures. Because we are treating all patients who meet the criteria, we have no comparator group to truly assess the efficacy of our program and will have to rely on historical and literature based controls. Nonetheless, from the qualitative data from own focus groups and those of Gabbe et al. 10 and Gotlib Conn et al., 11 the CTS is meeting many of the patient-centered complaints in the transition from lifesaving TC care to outpatient recovery and rehabilitative care. The CTS is also labor intensive, and there will always be the question of its fiscal solvency. A complete analysis of costs associated with the program is beyond the scope of this study; however, only 12% of CTS patients had no insurance and 45% were covered by a Medicaid product. Thus, increased appointments and patient retention would generate a source of revenue for the facility and the program. Center for Trauma Survivorship did require the hiring of a navigator and behavioral health specialist. The use of patent navigators is becoming increasingly standard in health care systems, and any health care provider would also generate revenue to offset their salary. Given the tremendous health care expenditure to create these trauma survivors, the dollars to create the CTS is modest.

In summary, we strongly believe that CTS is a model of care delivery that can expand the ability of the TC to meet the needs of our patients over time. This extension of the TC concept is in keeping with the philosophy of the American College of Surgeons to provide high-quality long-term care for our trauma patients. It is also in line with the recommendations in the National Academy of Science Engineering and Medicine report. Center for Trauma Survivorship represents the last link "in the chain of survival with communication and coordinated efforts across all providers and levels of care being essential to maximize outcome for injured patients."²

AUTHORSHIP

D.H.L. contributed to the literature search. All authors contributed to the study design. D.S., S.L., and C. Cho contributed to the data collection. D.H.L., A.C.M., D.S., P.A.W., C. Castellano contributed to the data analysis and interpretation. All authors contributed to the critical revision.

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DISCLOSURE

For all authors, no conflicts are declared.

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CRITIQUE

Dr. Livingston and colleagues have continued to advance our field by expanding the chain of trauma survival from injury through integration back to society. They have explicitly acknowledged an often unspoken fact that we struggle to comprehensively navigate the final steps of our patient's journey in the post-discharge period; falsely believing that successful discharge is an adequate goal for trauma center performance. Their center for trauma survivorship utilizes a multidisciplinary team to facilitate post-discharge care. Utilizing focus groups and a before and after analysis, they found that many at-risk patients and families perceive abandonment, mired in challenging attempts to navigate a complex healthcare system.

Keys to their success included a dedicated nurse practitioner, healthcare navigator, and engaged trauma surgeon. Further, asynchronous and synchronous communication via texts and phone calls helped bridge the abandonment gap through this team approach. The Rutgers group should be applauded for their demonstration of a post-implementation ED utilization reduction and an increased proportion of patient follow-up appointments. In a changing healthcare landscape, this is an important example of value based care that has implications for future trauma center benchmarking. Centers could frame the need to invest in these team resources based on overall improved patient and system value.

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