

Aging and Post-Intensive Care Syndrome–Family (PICS-F): A Critical Need for Geriatric Psychiatry

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ABSTRACT

Post-intensive care syndrome–family (PICS-F) describes the psychological symptoms that affect the family members of patients hospitalized in the intensive care unit (ICU) or recently discharged from the ICU. Geriatric psychiatrists should be concerned about PICS-F for several reasons. First, ICU hospitalization in older adults is associated with higher rates of cognitive and physical impairment, compared to older adults hospitalized in non-ICU settings or dwelling in the community. This confers a special burden on the caregivers of these older ICU survivors compared to other geriatric populations. Second, as caregivers themselves age, caring for this unique burden can be more challenging compared to other geriatric populations. Third, evidence for models of care centered on patients with multimorbidity and their caregivers is limited. A deeper understanding of how to care for PICS and PICS-F may inform clinical practice for other geriatric populations with multimorbidity and their caregivers. Geriatric psychiatrists may play a key role in delivering coordinated care for PICS-F by facilitating timely diagnosis and interdisciplinary collaboration, advocating for the healthcare needs of family members suffering from PICS-F, and leading efforts within healthcare systems to increase awareness and treatment of PICS-F. This clinical review will appraise the current literature about the impact of critical illness on the family members of ICU survivors and identify crucial gaps in our knowledge about PICS-F among aging patients and caregivers.

INTRODUCTION

Approximately 1.4 million older adults in the United States survive an episode of critical illness each year. As the intensive care unit (ICU) population ages and survival rates from critical illness improve, a growing number of older patients are suffering from long-term cognitive, psychological, and physical impairments known as post-intensive care syndrome (PICS).¹⁻³ Witnessing critical illness and ICU hospitalization along with caring for patients with PICS may cause family members to experience psychological symptoms, such as depression and anxiety. In 2012, the Society of Critical Care Medicine formally recognized these psychological symptoms experienced by family members of ICU patients as post-intensive care syndrome–family (PICS-F).³

Geriatric psychiatrists should be concerned about PICS-F for several reasons. First, ICU hospitalization in older adults is associated with higher rates of cognitive and physical impairment compared to older adults hospitalized in non-ICU settings or dwelling in the community.⁴ This confers a special burden on the caregivers of these older ICU survivors compared to other geriatric populations. Second, as caregivers themselves age, caring for this unique burden can be more challenging compared to other geriatric populations. Third, evidence for models of care centered on patients with multimorbidity and their caregivers is limited.⁵ A deeper understanding of how to care for PICS and PICS-F may inform clinical practice for other geriatric populations with multimorbidity and their caregivers. In this review, we will examine symptoms, epidemiology, and risk factors for PICS-F; evidence-based recommendations for the detection, prevention, and management of PICS-F; and the impact of aging on both patients and caregivers in the context of PICS-F. Finally, the unique role that geriatric psychiatrists could play in delivering clinical care, conducting research, and creating public policy focused on PICS-F will be discussed.

POST-INTENSIVE CARE SYNDROME–FAMILY

Symptoms and epidemiology of PICS-F

Studies of PICS-F have primarily focused on depressive, anxiety, and trauma-related symptoms. Depression is the most common symptom of PICS-F. The prevalence of depression then decreases to 5–36% six months after ICU discharge. Although one study found the prevalence of depression at the time of ICU admission or during the ICU stay to be as low as 16%, it is most frequently reported to be quite high, in the range of 70.3 to 90%.⁶ The prevalence of depression then decreases to 5–36% six months after ICU discharge.⁷ Anxiety is the second most prevalent symptom in PICS-F. The prevalence is 42–80% during the ICU stay and then decreases to 15–24% six months after ICU discharge.⁷ Trauma-related symptoms include acute stress disorder and post-traumatic stress disorder (PTSD). The prevalence of acute stress disorder is 32–33%.³ The prevalence of PTSD is 30–42% at 3 months after ICU discharge and 35–57% at 6 months.⁷ In summary, depression, anxiety, and trauma-related symptoms are highly prevalent in caregivers.

Studies have also examined the quality of sleep in caregivers and its effect on caregiving. About 54–64% of caregivers had impaired sleep while patients were hospitalized in the ICU.^{8–9} Sleep deprivation resulted in acute impairment of functioning and sustained attention. Two months after ICU discharge, more than half of caregivers reported impaired sleep. Caregivers who were responsible for decision making about patients' care were more likely to have more impaired sleep and poorer sustained attention.

Risk factors for PICS-F

Potential risk factors for PICS-F can be categorized into caregiver-related factors, patient-related factors, and healthcare-system-related factors. Studies have consistently shown that caregiver-related factors play a major role in the development of PICS-F.³ Caregiver-related factors include female gender, caring for a spouse, low level of education, preexisting mental or physical illness, family history of mental illness, lack of social and professional support, and caregiving for more than 100 hours per month.^{3,10} On the other hand, patient-related factors do not appear to play a role in the development of PICS-F. The RECOVER study found that patients' severity of illness, physical functioning, need for assistance with activities of daily living (ADLs), and subjective ratings of cognitive symptoms were not associated with caregiver outcomes.¹¹ Finally, healthcare-system-related factors may be important—and potentially modifiable—contributors to PICS-F. ICU-related factors associated with a higher risk of PICS-F include limited ICU visiting hours, perception of patients being near death, and poor communication with ICU physicians.^{10,12}

Unique Challenges for Caregivers of Older ICU Survivors

Caregiving for older ICU survivors is unique in two important ways. First, older adults hospitalized in the ICU have higher rates of multidomain functional impairments and frailty compared to older adults hospitalized in non-ICU settings and living in the community.⁴ This risk largely derives from the high prevalence of ICU delirium and excessive immobilization associated with mechanical ventilation. The prevalence of delirium in older adults hospitalized in the ICU is 70–80%, compared to 33% of older adults hospitalized on the general medical unit. ICU delirium is a major risk factor for long-term cognitive impairment after ICU discharge.¹³ The prevalence of long-term cognitive impairment in older ICU survivors can be as high as 70% one year after ICU hospitalization, with an estimated 10% suffering from incident dementia.¹⁴ Immobilization in mechanically ventilated patients increases the risk of ICU-acquired weakness, which, in turn, can lead to physical impairment. Older adults who were mechanically ventilated

were 30% more likely to need assistance with ADLs compare to hospitalized older adults who were not mechanically ventilated.¹⁵ Second, caregiving for older ICU survivors is uniquely challenging because functional impairments develop acutely, are initially managed by hospital staff during the hospitalization, and then suddenly have to be managed primarily by caregivers after discharge. Caregivers often receive little preparation for these unexpected responsibilities of caring for such complex needs.

EVIDENCE-BASED RECOMMENDATIONS FOR PICS-F

Screening and assessment

The SCCM recently highlighted the importance of family empowerment and engagement in its ABCDEF Bundle of Care (the “F element”) of ICU care.¹⁶ Additional work is needed, however, to transform our current ICU and post-ICU models from providing patient-centered care for critical illness and (to a lesser degree) PICS to delivering patient- and family-centered care for critical illness, PICS, and PICS-F. For example, although the recent guidelines on the F component of ABCDEF provided detailed recommendations on how to involve families in the care of ICU patients, the guidelines did not include screening tools for depression, anxiety, and trauma-related symptoms for PICS-F; specific points of time to administer these screening tools to family members; or the responsible disciplines for assessing and managing PICS-F. While more research is needed to validate screening tools for PICS-F, clinicians should consider using widely accepted screening tools for depression, anxiety, trauma-related symptoms, and sleep deprivation to assess family members for PICS-F (Table 1). Ideally, the assessment of the caregiver should also include the examination of relevant biopsychosocial aspects, which may worsen PICS-F. These aspects include a sense of caregiver mastery (*i.e.*, sense of control), caregivers’ perception of their support network, and the effect of caregiving on the caregivers’ lives.¹¹ Clinicians should be especially vigilant about ensuring that family members and

caregivers who have risk factors for PICS-F or display symptoms suggestive of PICS-F are provided with psychoeducation about PICS-F and, if indicated, referrals to mental health treatment.

Intra-ICU prevention and management

In 2017, a multidisciplinary international expert panel conducted an exhaustive review of more than 450 studies about family-centered care in the ICU.¹¹ Based on the findings of these studies, the panel developed comprehensive evidence-based guidelines on how to deliver family-centered care in the ICU. These guidelines, which were published by the SCCM, focused on how to encourage family presence in the ICU and how to engage and empower family members to participate in ICU care. Four major recommendations shown to improve both patient and family outcomes included the creation of “open” ICUs, family witnessing of resuscitation efforts, ICU diaries, and proactive engagement of family members in patients’ care (Table 2).^{8,10,17,18} The concept of “open” ICUs was designed to increase family presence in the ICU and also address healthcare system factors associated with poorer patient and family outcomes.¹⁹ Characteristics of an open ICU include a flexible visitation policy in terms of hours, number of visitors, and age of visitors; daily meetings with family; healthcare providers performing tasks in front of family members; and redesign of units to ensure the family's comfort and sleep needs. In addition to improving patient outcomes, open ICUs are associated with higher levels of family satisfaction and decreased family anxiety.¹⁹

Incorporating family members into ICU care and having them present during medical procedures is another major emphasis of the SCCM guidelines. For example, ICU staff should encourage family members to witness codes. Family members who witnessed codes were shown to have fewer depressive and PTSD symptoms 3 and 12 months later.²⁰ Finally, studies strongly support the use of ICU diaries to improve both patient and caregiver outcomes.¹⁸ ICU

diaries document the medical events and experiences during the patient's ICU stay. Potential diary entries include a calendar of events, photographs of patients and the ICU, and entries from ICU staff and family members. Interestingly, one study found that ICU diaries did not improve PTSD-related symptoms in relatives at 3 months, but did decrease PTSD-related symptoms, most notably in the domains of avoidance and intrusion, 12 months after ICU discharge.^{18,21–23}

Communication between the ICU team and family members is also vital, as family members can share their knowledge about patients' previous levels of cognitive, psychological, and physical functioning.¹⁹ Family members and other primary caregivers should be involved in daily ICU rounds and empowered to participate in medical decision making with appropriate support and information.^{12,24} Finally, ICU physicians and staff should discuss with patients and families the anticipated post-ICU trajectory, especially in patients who are likely to have PICS.

Post-ICU prevention and management

The evidence for post-ICU interventions for PICS-F is considerably less than that of intra-ICU interventions. As part of the standard of care, healthcare professionals should ensure that caregivers have access to appropriate resources, such as home health services. Web-based tools for caregivers are available from the SCCM and Healthtalk in the UK.^{25,26} However, there is little to no rigorous evidence demonstrating that specific post-ICU interventions can prevent or decrease the symptoms of PICS-F.²⁷ One major barrier to conducting large-scale, multisite studies of post-ICU interventions of PICS-F is the lack of a centralized process for post-ICU follow-up. Frequently, patients and caregivers, particularly in rural and underserved areas, follow up at different hospitals or even healthcare systems from where they received their ICU care. The SCCM, through the THRIVE initiative, has encouraged the creation of a network of post-ICU clinics in the US.²⁸ To date, however, there is limited evidence demonstrating that

post-ICU clinics improve long-term patient outcomes.²⁷ Furthermore, although post-ICU clinics may represent a potential opportunity to deliver interventions for the prevention and management of PICS-F, family-centered care is not consistently part of the standardized care delivered in these clinics. Finally, there are few to no formal guidelines clarifying which healthcare professionals have the primary responsibility of caring for PICS-F in the post-ICU setting and how to deliver such care. Given that the effects of PICS-F can last years and profoundly impact the quality of life of these caregivers, there is an urgent need to develop guidelines on the care of PICS-F in the post-ICU setting.

IMPLICATIONS OF CAREGIVING LITERATURE FOR PICS-F

Theories of caregiving

Theories of caregiving identify the broad range of barriers and facilitators of the caregiving role; its impact on the physical, mental, and financial well-being of caregivers; and the causal mechanisms that link these factors. The selection, optimization, and compensation (SOC) model and the stress-coping model for caregiving can be adapted and used to guide PICS-F interventions.^{3,29} According to the SOC model, older adults select personal goals on which to focus their resources to optimize their well-being and compensate for physical decline and other losses.³⁰⁻³³ Thus, successful aging requires the development and maintenance of primary control throughout the course of life, which is disrupted both by caregiving (which is an externally imposed goal) and by caregiving stress (which depletes available resources). The stress-coping model for caregiving focuses heavily on how caregivers perceive stress and methods to support their coping.³⁴⁻³⁶ Both predict that caregivers are vulnerable to decline in their physical, psychological, and cognitive health, mediated by their caregiving burden, social support, and other resources.³⁶ Even this simple illustration of these two theories points to future areas of study for PICS-F: the physical and cognitive impacts of caregiving, caregivers' sources

and needs regarding social support, and other resources accessed or needed during the course of ICU recovery.

Evidence-based guidelines for caregivers of older adults

The National Academies of Sciences, Engineering, and Medicine assembled an expert panel to report on the demographic trends about caregiving of older adults; the impact of caregiving on caregivers' physical, psychological, and financial well-being; and recommendations about public policies to reduce the burden of caregiving.¹⁰ Their findings were detailed in the 2016 publication, "Families Caring for an Aging America." While caregiving for ICU survivors was not specifically discussed in the publication, a number of the panel's recommendations can be useful for caregivers of ICU survivors, particularly in the absence of evidence-based guidelines for PICS-F.¹⁰ First, the assessment of caregivers should include the following aspects: (1) context and environment of the caregiver and patient, (2) caregiver's perception of the health and functional status of the patient, (3) caregiver values and preferences, (4) well-being of the caregiver, (5) consequences of caregiving, (6) skills/abilities/knowledge to provide the patient with needed care, and (7) potential resources available to caregiver. Caregiver interventions that have been shown to be effective include psychoeducation and skills training that focus on teaching caregivers to independently develop individualized strategies and an emphasis on practices to improve the caregivers' quality of life, such as counseling, self-care, relaxation training, and respite.¹⁰ Future studies will need to test whether psychoeducation and skills training can improve patient and caregiver outcomes in caregivers of older ICU survivors who have a low sense of mastery, a known risk factor for PICS-F.

The NASEM report on caregiving also raised another concern relevant to PICS-F—the recognition of certain populations of older adults who have different caregiving needs.¹⁰ Patients with dementia or who require assistance with two or more ADLs were defined as having "high

needs” in terms of caregiving. In light of the high prevalence of cognitive and physical impairment in older ICU survivors, research is needed to determine the prevalence of older ICU survivors who meet this definition of “high needs” and the potential implications for their caregivers and PICS-F. This is a crucial scientific and policy question because caregivers of ICU survivors who provide more than 100 hours of caregiving per month are at higher risk for PICS-F. It is not known, though, whether this level of caregiver burden is due to a high prevalence of patients with high needs, limited access to caregiving resources, or a combination of both factors. Studies need to examine whether programs which have been shown to be efficacious for caregivers of ADRD and other diseases of aging can be equally beneficial for caregivers of ICU survivors.

FUTURE DIRECTIONS

Because of the relatively recent recognition of PICS-F, there are very few evidence-based guidelines about the screening, assessment, and management of PICS-F in the ICU and post-ICU settings. Clinicians can use current screening tools to assess caregivers for depression, anxiety, and PTSD, but these still need to be validated in caregivers with PICS-F. The current NASEM report for caregiving provides useful recommendations on how to conduct caregiver assessment.¹⁰ Studies are needed, however, to develop and incorporate domains specific to PICS-F such as experiences and perceptions of patients’ care in the ICU and availability of resources specific to PICS and PICS-F. Current clinical guidelines for the treatment of depression, anxiety, and trauma-related disorders also need to be tested in caregivers with PICS-F. For example, how should patients’ or caregivers’ treatment plans be modified for caregivers with PTSD who have to bring patients to the hospital, a common trigger for their PTSD? Finally, clinical care guidelines need to clarify which healthcare professionals are responsible for screening, assessment, and management of PICS-F.

In order to create these evidence-based clinical care guidelines, researchers in geriatric mental health and critical care medicine need to collaborate to address crucial knowledge gaps about PICS-F. These studies need to examine how risk factors and management of PICS-F are different for older caregivers of ICU survivors and caregivers of older ICU survivors. Figure 1 outlines known and proposed risk factors for PICS-F at the caregiver, patient, social network, and healthcare system level. Detailed characterization of known risk factors and further examination of proposed risk factors for PICS-F, particularly potentially modifiable ones, will help guide the creation of risk factor models for PICS-F and, eventually, inform targeted development and testing of interventions of PICS-F for future clinical trials. Implementation science research can help design models of care to target healthcare-system-related risk factors for PICS-F at the local level. One major concern that models of care for PICS-F will need to address is how to improve access to mental health professionals who can provide diagnoses and treatment for these caregivers.

Geriatric psychiatrists may be able to play a key role in creating guidelines for clinical care of PICS-F and help to provide a special emphasis on the needs of older caregivers with PICS-F and of caregivers of older ICU survivors. Creation of these guidelines may help to increase recognition of PICS-F among primary care and mental health professionals who are providing healthcare to these caregivers. In addition to addressing clinical needs of PICS-F, geriatric psychiatrists can also provide input on crucial public-policy decisions related to healthcare system barriers, especially in the post-ICU setting; limited access to caregiver resources; and barriers to caregivers receiving mental health treatment.

Evidence for models of care centered on patients with multimorbidity and how to address the needs of their caregivers is limited.⁵ Post-ICU clinics may represent an opportunity to test the idea of integrating care for patients and caregivers. Providing psychoeducation and skills

training, as well as screening and treating family members, may help them function as more effective caregivers and be more likely to engage in mental treatment. One potential model for how to deliver clinical care for PICS-F may be the Critical Care Recovery Center (CCRC) based at Indiana University, the first post-ICU clinic in the United States.³⁷ One of the important premises of the CCRC is to deliver family-centered care for PICS, which includes standardized screening, assessment, and management of caregiver stress and PICS-F. Whether or not this family-centered approach impacts long-term patient and caregiver outcomes needs to be examined in the future.

Guidelines about how to integrate clinical care for PICS and PICS-F as the standard of care in the ICU and post-ICU settings may require a large-scale collaboration between professional organizations of mental health professionals and critical care specialists. One example on how to incorporate PICS-F into ICU and post-ICU care may be to examine how the American Association of Pediatrics (AAP) has approached maternal depression.³⁸ The AAP has published guidelines for how to incorporate screening for maternal depression into standard pediatric follow-up visits and has also developed an online maternal depression toolkit for pediatricians.³⁹ These guidelines could provide a template with which to develop recommendations incorporating PICS-F in routine ICU and post-ICU care.

In summary, PICS-F describes the psychological symptoms that caregivers of ICU patients frequently suffer from after witnessing ICU hospitalization and coping with the burden of caring for patients with PICS. Future research is needed to understand how to create evidence-based clinical guidelines for PICS-F, how to identify groups at high risk for PICS-F to target appropriate interventions, and how to design models of care to effectively deliver care to these caregivers. Public policies are also needed to address limited access to caregiver resources and structural barriers in healthcare systems, including limited access to mental health treatment, which

increase caregiver burden. Geriatric psychiatrists can play a pivotal role in constructing these guidelines and policies and ensuring that special needs of aging caregivers and older ICU survivors are highlighted.

ACCEPTED MANUSCRIPT

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FIGURE 1. CONCEPTUAL RISK FACTOR MODEL FOR POST-INTENSIVE CARE SYNDROME-FAMILY

	Pre-ICU	Intra-ICU	Post-ICU
Caregiver	Female Spouse Low level of education Mental or physical illness Family history of mental illness Age High level of emotional expressivity Previous history of trauma Resilience*	Sleep deprivation Perception of patient being near death <u>Perception of quality of care received</u> <u>Perception of decision-making responsibilities</u>	High burden of caregiving (≥ 100 hours/month) Low sense of mastery <u>Expectations for post-ICU course</u> <u>Newly acquired physical illness</u> <u>Perception of quality of care received</u> <u>Perception of patient's post-ICU changes (cognitive, behavioral, physical)</u>
Patient	Age MCI or ADRD Level of ADL assistance	<u>Delirium including subtypes</u> <u>Behavioral disturbances</u> <u>Restraints</u>	<u>Ability to make decisions about post-ICU care</u> <u>Ability to accept caregiver assistance and other services</u> <u>MCI or ADRD (new or worsening)</u> <u>Level of ADL assistance (new or worsening)</u>
Social network and resources		Limited social and professional support	Limited social and professional support <u>Access to caregiving resources</u> <u>Socioeconomic loss</u>
Healthcare system		Visitor restrictions Quality of HCP communication about ICU care Inclusion of caregiver in ICU care <u>Quality of HCP communication expectations about post-ICU course</u>	<u>Fragmentation of post-ICU care</u> <u>Ease of access to post-ICU care</u> <u>Inclusion of caregiver in post-ICU care</u> <u>Resources specific to ICU survivors and their caregivers</u>

* = Protective factor
HCP = Health care professional

ICU = Intensive care unit
Underlined = To be tested

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Table 1. Symptoms and affected domains in PICS-F

Symptoms or caregiver-related domains in PICS-F	Prevalence or trend associated with PICS-F	Screening tools and psychological measures
Symptoms		
Depression	<ul style="list-style-type: none"> • 70–90% during ICU stay • 5–36% six months after ICU Discharge 	<ul style="list-style-type: none"> • Beck Depression Inventory (BDI)⁴⁰ • Patient Health Questionnaire-9 (PHQ-9)⁴¹ • Center for Epidemiologic Studies Depression Scale (CES-D)⁴²
Anxiety	<ul style="list-style-type: none"> • 42–80% during ICU stay • 15–24% six months after ICU Discharge 	<ul style="list-style-type: none"> • Beck Anxiety Inventory⁴² • Generalized Anxiety Scale (GAD-7)⁴³
Acute stress disorder and post-traumatic stress disorder	<ul style="list-style-type: none"> • 32–33% during ICU stay • PTSD 30–42% three months after ICU discharge • PTSD 35–57% six months after discharge 	<ul style="list-style-type: none"> • Primary care PTSD screen for DSM-5 (PC PTSD-5)⁴⁴ • Startle, Physiologic Arousal, Anger, Numb scale (SPAN)⁴⁵ • Short Post-Traumatic Stress Disorder (SPRINT)⁴⁶ • Trauma Screening Questionnaire (TSQ)⁴⁷
Sleep deprivation	<ul style="list-style-type: none"> • 80% with decreased sleep • 50% with poor quality of sleep 	<ul style="list-style-type: none"> • Epworth Sleepiness Scale (ESS)⁴⁸
Caregiver-related domains		
Sense of caregiver mastery	Lower sense of caregiver mastery	<ul style="list-style-type: none"> • The Mastery Scale⁴⁹
Caregiver perception of support network	Small support network or less assistance	<ul style="list-style-type: none"> • Caregiver Assistance Scale^{50,51} • Medical Outcomes Study Social Support Survey⁵²
Effects of caregiving on the caregivers' life	Higher stress level or negative impact	<ul style="list-style-type: none"> • Caregiver Impact Scale^{50,51}

Table 2. SCCM-recommended intra-ICU interventions for the management and prevention of PICS-F

Intervention	Described components
"Open" ICU	<ul style="list-style-type: none"> • Flexible visitation (minimal restrictions in terms of hours, number of visitors, and age of visitors) • Healthcare professionals willing to complete tasks in front of staff • Daily meetings with families to answer questions about care • Redesign of units to meet family's sleep and comfort needs
Incorporation of family members into the ICU culture	<ul style="list-style-type: none"> • Discussion with staff about current barriers and cultural attitudes of completing medical tasks in front of family • Education of staff about the potential benefits to patients and families • Training staff to invite family to witness medical procedures, particularly codes
ICU diaries	<ul style="list-style-type: none"> • Document describing medical events and experiences • Calendar of events • Photographs of patients and the ICU • Entries from ICU staff and family members
Proactive engagement of family members in patients' care	<ul style="list-style-type: none"> • Brochures that teach families how to participate in patients' care (e.g., talking to patients with simple words and soft voices, bringing in glasses and hearing aids, bringing in decorations from home, and participating in mobilizing the patient) • Invitation to give feedback during rounds about how to improve or change patients' care • Shared decision making, especially for end-of-life decision making • End-of-life conferences when clinically indicated • Encouragement of family to bring up safety concerns

	<ul style="list-style-type: none">• Discussion at discharge about expectations of patients' post-ICU course and PICS
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ICU = intensive care unit, PICS = post-intensive care syndrome

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