

# Characteristics of Long-Stay Patients in a PICU and Healthcare Resource Utilization After Discharge

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**OBJECTIVES:** To examine the characteristics of long-stay patients (LSPs) admitted to a PICU and to investigate discharge characteristics of medical complexity among discharged LSP.

**DESIGN:** We performed a retrospective cohort study where clinical data were collected on all children admitted to our PICU between July 1, 2017, and January 1, 2020.

**SETTING:** A single-center study based at Erasmus MC Sophia Children's Hospital, a level III interdisciplinary PICU in The Netherlands, providing all pediatric and surgical subspecialties.

**PATIENTS:** LSP was defined as those admitted for at least 28 consecutive days.

**INTERVENTIONS:** None.

**MEASUREMENTS:** Length of PICU stay, diagnosis at admission, length of mechanical ventilation, need for extracorporeal membrane oxygenation, mortality, discharge location after PICU and hospital admission, medical technical support, medication use, and involvement of allied healthcare professionals after hospital discharge.

**MAIN RESULTS:** LSP represented a small proportion of total PICU patients (108 patients; 3.2%) but consumed 33% of the total admission days, 47% of all days on extracorporeal membrane oxygenation, and 38% of all days on mechanical ventilation. After discharge, most LSP could be classified as children with medical complexity (CMC) (76%); all patients received discharge medications (median 5.5; range 2–19), most patients suffered from a chronic disease (89%), leaving the hospital with one or more technological devices (82%) and required allied healthcare professional involvement after discharge (93%).

**CONCLUSIONS:** LSP consumes a considerable amount of resources in the PICU and its impact extends beyond the point of PICU discharge since the majority are CMC. This indicates complex care needs at home, high family needs, and a high burden on the healthcare system across hospital borders.

**KEY WORDS:** children with medical complexity; discharge; long-stay patients; pediatric intensive care unit; transitional care units

Improvements in pediatric critical care have led to the very low mortality rate seen today, of approximately 3% in PICUs (1–3). However, an earlier study performed at our PICU 15 years ago showed that the mortality of long-stay patients (LSPs;  $\geq 28$  d) was significantly higher (22%) than the average PICU patient (4). These LSP accounted for 3% of total admissions and occupied 63% of total admission days. Furthermore, it is known that unfavorable outcomes are associated with LSP, including acquired moderate-to-severe disabilities, poorer reported quality of life and high consumption of healthcare resources (5–7). Over the past 10–15 years, critical care for children has

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## KEY POINTS

**Question:** What are the characteristics of long-stay patients (LSPs) admitted to a PICU during their hospital stay and at discharge?

**Findings:** This retrospective cohort study showed that—similar to 15 years ago—LSP, consume a considerable large amount of resources in the PICU and this does not end at PICU discharge since most LSP had a prolonged hospital stay. Consequently, many LSP could be classified as children with medical complexity, needing complex care at home, and posing a significant burden on healthcare resources.

**Meanings:** There is a need to have a clear picture of the patient characteristics of long-stay care-intensive pediatric patients to shape targeted and tailored healthcare services.

rapidly evolved, in part because of more complex surgical procedures for all kinds of congenital malformations as well as advances in life-sustaining treatments. Children may therefore survive formerly lethal conditions and/or malformations due to the advances in life-sustaining treatments. Consequently, increasing numbers of children survive with chronic comorbidities and technological dependencies, requiring recurrent and sometimes prolonged PICU stays (8, 9). This may increase (multi)morbidities, leading to children with medical complexity (CMC). CMC is defined as children having a chronic condition, high family needs, functional limitations, and requiring significant healthcare resource utilizations (10). Medical complexity potentially affects the length of PICU stay, the total hospital stay, and the need for care after discharge. Van de Riet et al (11) showed that LSP has more complex chronic conditions compared with non-LSPs. However, no study has examined other discharge characteristics concerning medical complexity in the LSP population. This is important to identify to organize the care needed optimally because caregivers of CMC often have to learn complex nursing and intensive care techniques carrying a tremendous amount of responsibility, stress, and financial burden.

Therefore, the aim of the study was: 1) to examine the change in characteristics of LSP admitted to the

PICU, and 2) to investigate discharge characteristics concerning medical complexity.

## MATERIALS AND METHODS

The PICU of the Erasmus MC Sophia Children's Hospital, Rotterdam, is a level III interdisciplinary ICU for children in The Netherlands, providing all pediatric and surgical subspecialties. All patients admitted from July 1, 2017, to January 1, 2020, were retrospectively identified using the computerized patient data management system. LSP was defined as those admitted for at least 28 consecutive days at the PICU.

The following patient characteristics were collected: age, sex, reason for admission, length of PICU stay (LOS), diagnosis at admission, length of mechanical ventilation, need for extracorporeal membrane oxygenation (ECMO), and mortality. The following discharge characteristics were collected: discharge location after PICU and hospital admission, medical technical support, amount of medications, and involvement of allied healthcare professionals after hospital discharge.

The diagnoses were categorized into six groups: disorders of the respiratory system, cardiac vascular disease, gastrointestinal disorders, multiple congenital abnormalities, neurologic disorders, and others.

At discharge, LSP patients were classified according to the model of Cohen concerning CMC (10). Although abundant literature exists on CMC, a uniform classification system is lacking (12). In this study, a child was classified as CMC when it met all four of Cohen's domains: having a chronic condition, high family needs, functional limitations, and high healthcare use (**eTable 1**, <http://links.lww.com/CCX/B242>). The chronic condition domain was met if the child was diagnosed with a complex chronic condition according to the model of Feudtner et al (13, 14), and/or if there was (an expected) continuous dependence on technology for at least 6 months after discharge. The functional limitation domain was met if patients were discharged with one of the following technological devices; a tracheostomy, mechanical ventilation, oxygen therapy, airway clearance intervention techniques, monitoring of oxygen saturation, IV therapy medications (total parenteral nutrition, medication through central or PICC line), feeding tube (nasogastric tube, gastrostomy, and jejunostomy), and

colostomy. The domain of high family needs was met if patients were discharged with more than three different types of medications and/or if more than two allied healthcare professionals were kept involved in primary or outpatient care (rehabilitation physician, dietician, physiotherapist, occupational therapist and, speech therapist). All LSP met the domain for high healthcare use since they had a length of stay (LOS) greater than or equal to 28 days at the PICU.

This study has been approved by the ethics review board of the Erasmus Medical Center, Rotterdam, the Netherlands (MEC-2020-0568).

## Analysis

The analysis was performed using IBM SPSS Statistics, version 28. For patients who were readmitted to the PICU, only data on the first admission were included. However, when it came to resource use (admissions days, days on mechanical ventilation, and ECMO), all admission data of prolonged stays greater than or equal to 28 days was included. Whenever LSP had multiple admissions of greater than or equal to 28 days at the PICU, only data from the last discharge were included in the section to analyze discharge characteristics.

Variables were summarized as frequencies and percentages and/or medians. Nonparametric tests were used. A Mann-Whitney *U* test was used to analyze continuous data, such as LOS, age, days on mechanical ventilation, or ECMO between non-LSP and LSP. The chi-square test was used to compare nominal data, such as diagnosis groups, gender, and mortality

between non-LSP and LSP. A *p* value of less than 0.05 was considered significant.

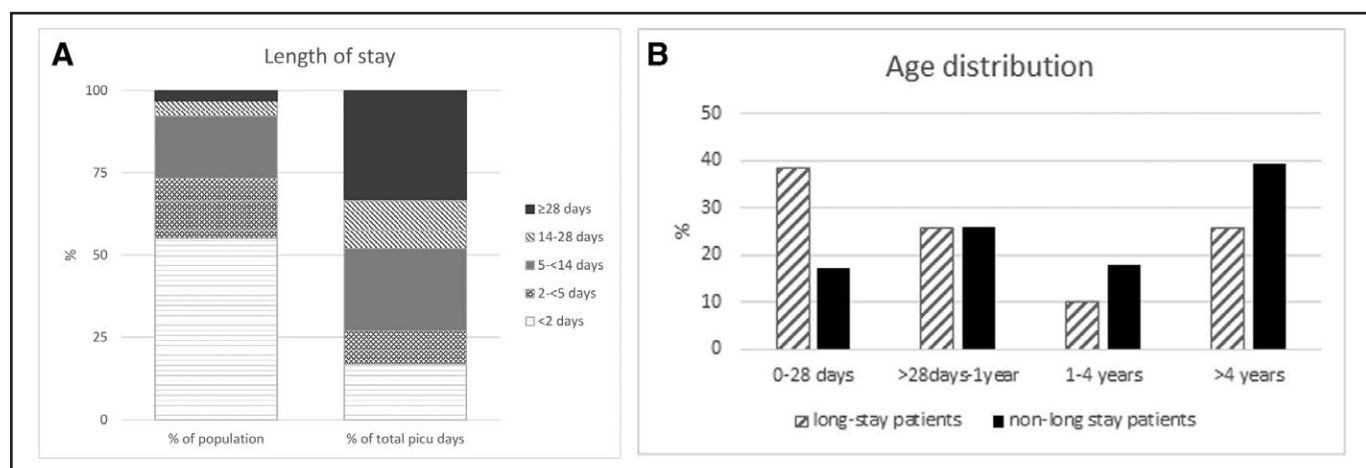
## RESULTS

### Overall Demographics

During the study period, 3,370 admissions were registered from 2,496 individual patients. They accounted for a total of 20,338 admission days at the PICU. The median stay on the PICU was 2 days with an upper 95th percentile of 21 days. In total, there were 108 admissions (3.2% of all admissions, **Fig. 1A**) with a LOS greater than or equal to 28 continuous days at the PICU from 101 individual patients (median 48 d, range 29–311 d). Ninety-five patients were admitted once for a period greater than or equal to 28 days, five patients had twice a prolonged stay at the PICU, and one patient was admitted three times for an extended period. These LSPs had a total LOS of 6,735 days, accounting for 33.1% of all admission days. Overall mortality was 4.2% (106/2,496 patients), and 16.8% (17/101) of the LSP died during their stay in the PICU.

In **Tables 1** and **2** and **Figure 1B** the characteristics of the LSP are shown, compared with non-LSPs (<28 d admission). A more specific overview of the diagnosis of LSP at first admission is presented in **eTable 2** (<http://links.lww.com/CCX/B242>).

Not only on admission days the LSP consumes a higher proportionally amount of care, the same observation is seen on ventilation days and days on ECMO. In total, 69 patients received ECMO for a total of 649 days. Of these, 308 d (47.4%, range of



**Figure 1.** Length of PICU stay, total PICU days and age distribution. **A**, Percent of admissions (*left column*) by five groups based on length of stay vs their corresponding percentage of total PICU days (*right column*). **B**, Age distribution of the long-stay patients (LSPs) (*gray-shaded filling pattern*) vs the non-LSPs (*black pattern*).

**TABLE 1.**  
Patient Demographics Based on Their First PICU Admission

Patient Characteristics Upon First PICU Admission	Non-Long Stay Patients (<28 d) <i>n</i> = 2395	Long-Stay Patients (≥28 d) <i>n</i> = 101	<i>p</i>
Age in months (median) <sup>a</sup>	21.6	2.0	< 0.001
< 1 mo at admission, <i>n</i> (%)	414 (17.3)	39 (38.6)	
Female, <i>n</i> (%) <sup>b</sup>	1,044 (43.6)	57 (56.4)	0.014
Diagnosis, <i>n</i> (% in group) <sup>b</sup>			
Respiratory	377 (15.7)	21 (20.8)	0.21
Cardiovascular	552 (23)	33 (32.7)	0.031
Gastrointestinal	52 (2.2)	2 (2.0)	1
Multiple congenital abnormalities	132 (5.5)	24 (23.8)	< 0.001
Neurologic disorders	330 (13.8)	13 (12.9)	0.883
Others	952 (39.7)	8 (7.9)	< 0.001
Mortality, <i>n</i> % <sup>b</sup>	89 (3.7)	17 (16.8)	< 0.001
Readmission, <i>n</i> (%) <sup>a</sup>	431 (17.99)	59 (58.41)	< 0.001

Demographics of patients based on their first admission at our PICU, subdivided between long-stay patients (≥ 28 d) and non-long-stay patients (< 28 d). Readmissions are only counted within the study period (from July 2017 to January 2020) and independent of duration of admission.

<sup>a</sup>A Mann-Whitney *U* test was used to analyze continuous data.

<sup>b</sup> $\chi^2$  was used with nominal data.

**TABLE 2.**  
Characteristics of All PICU Admissions

All PICU Admissions	Non-Long Stay Admissions (< 28 d), <i>n</i> = 3,262	Long-Stay Admissions (≥ 28 d), <i>n</i> = 108	<i>p</i>
Length of stay (median) <sup>a</sup>	2	48	< 0.001
% of total admissions	96.8	3.2	
% of total days	66.9	33.1	
Admissions with mechanical ventilations use	<i>n</i> = 1,076	<i>n</i> = 84	
Ventilation days (median) <sup>a</sup>	2 (range 1–26)	26 (range 1–129)	< 0.001
% of all ventilations days	63.4	36.6	
Admissions with ECMO use	<i>n</i> = 48	<i>n</i> = 21	
Days on ECMO (median) <sup>a</sup>	6 (range 1–24)	11 (range 3–56)	< 0.001
% of all ECMO days	52.6	47.4	

ECMO = extracorporeal membrane oxygenation.

<sup>a</sup>A Mann-Whitney *U* test was used to analyze continuous data.

Resource use of admission days, days on mechanical ventilation and on ECMO, subdivided by non-long-stay admissions and long-stay admissions. In this section, every admission is counted as a single event, despite readmission of the same patient.

3–56 d) were used by LSP (*n* = 21). Consequently, LSP used 36.6% of all days on mechanical ventilation (in total 6,981 d in 1,160 patients; LSP *n* = 84, 2,557 d) in the PICU.

### Discharge and CMC Characteristics

Of the 84 LSP who survived the PICU, 13 were discharged directly home, and six were transferred to



a rehabilitation center (Fig. 2). Of the other 65 children, 49 had a prolonged stay at the general ward in the hospital with a median of 16 days (range 1–123), and 16 children had a prolonged stay in another (non) academic hospital with a median of 40 days (range 8–189). Four patients were sent from the general ward in the hospital to another hospital, and three patients were lost to follow-up. After discharge from the PICU, three deceased in the general ward, and four were discharged with palliative care. In terms of the final discharge location, most children were sent home ( $n = 59$ ), to a rehabilitation center ( $n = 11$ ), or to a medical day care center ( $n = 4$ ). These 74 LSP were classified according to the CMC model.

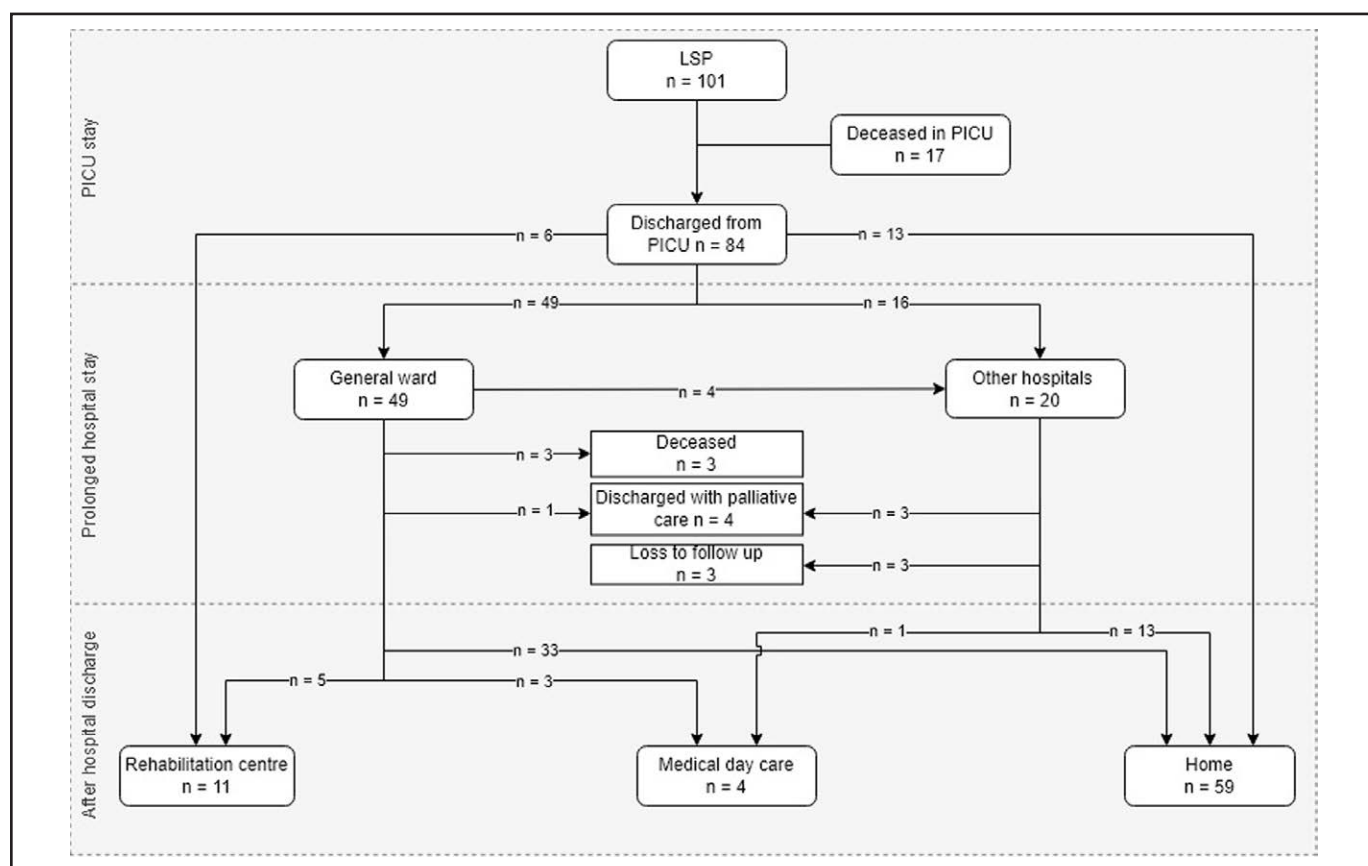
In total, 56 children (76%) could be classified as CMC (Table 3). More specifically, of the LSP, 89% suffered from a chronic condition, and 82% left the hospital with one or more technological devices (Table 3). Almost all children met the criteria for the high needs domain (95%), where all children needed medications (median 5.5; range 2–19) and/or greater than or equal to two allied healthcare professionals were involved

after discharge (outpatient and primary). In addition, home care was arranged at discharge for 31%, and 7% of patients were referred to a medical daycare unit.

## DISCUSSION

This study shows that a small percentage of LSPs consume a considerable proportion of resources in the PICU in terms of LOS, ECMO, and ventilation days. Furthermore, we show that many of these patients need an extended hospital stay after PICU discharge and that most LSP is CMC have (complex care) needs at home. Although the findings that LSP consumes considerable levels of resources have been recognized for decades (4, 5), there is a need to have a clear picture of the patient characteristics to identify how care could be organized differently (15, 16).

To assess whether the rapidly evolving PICU care has led to differences in the patient population, we compared our results with data from 15 years ago. Analysis of these data showed a much lower percentage (33% instead of the former 63%) of PICU-admission days for



**Figure 2.** Discharge location of long-stay patients (LSPs) ( $\geq 28$  d) after their last admission at our PICU, with or without an intermediate stay at our general ward. \*No further information known due to lost in follow-up.

**TABLE 3.**  
**Discharge Characteristics of Long-Stay Patients Based on Their Last Discharge**

	Patients Discharged to Home, Revalidation, or Medical Day Cares (n = 74)
Children with medical complexity, n (%)	56 (76)
Chronic condition, n (%)	66 (89)
Functional limitations, n (%)	61 (82)
Technical devices, n (%)	
Monitor	34 (46)
Tracheostomy	15 (20)
Mechanical ventilation/oxygen therapy	17 (23)
Coughing device	3 (4)
Central line	1 (1)
Gastrostomy	17 (23)
Nasogastric tube	40 (54)
Nutrition, n (%)	
Only tube/gastrostomy feeding	35 (47)
Tube/gastrostomy with oral feeding	22 (30)
Only oral feeding	17 (23)
High needs, n (%)	70 (95)
Medication, median (range)	5.5 (2–19)
Allied healthcare professionals, n (%)	69 (93)
Dietician	66 (89)
Physiotherapist	56 (76)
Speech therapist	52 (70)
Occupational therapist	6 (8)
Revalidation physician	20 (27)
High healthcare use, n (%)	74 (100)
≥28 d length of stay PICU, n (%)	74 (100)
Home care, n (%)	23 (31)
Medical day care, n (%)	5 (7)

LSP as a % of total PICU-admission days (see **eTable 3**, <http://links.lww.com/CCX/B242>) (4). We found an increase in the percentage of children diagnosed with congenital heart disease (CHD; 32.7% instead of the former 12% (4)). A factor contributing to this observation might be the fact that for CHD more advanced treatment options (such as sophisticated catheter intervention techniques, stents, and expanding possibilities and indications for ECMO support (17) have been developed and used in the past 15 years, resulting in treatment of formerly lethal conditions. This might also explain the observation that in more than half

of the LSP mortality occurred in patients with CHD (**eTable 4**, <http://links.lww.com/CCX/B242>). These two observations align with the trend described by Edelson et al (18) that children with CHD consume a disproportionate share of hospital resources, with a significant increase in admissions and an increasing proportion of pediatric in-hospital deaths. Also, patients with gastrointestinal disorders were less frequently observed in our cohort compared with 15 years ago (2% vs 18%, respectively) (4). We can only speculate on the reasons for this shift. For example, it might be because children suffering from congenital

gastrointestinal abnormalities, such as gastroschisis, remained longer in the PICU in the past, while today they are referred to a transition unit within our hospital. This in-hospital transition unit is specialized in caring for chronically ill children, who will need complex care at home (19). Here parents are trained to do this care at home.

The decrease in the percentage of LSP as a proportion of total PICU admissions (from 63% to 33%) might also be attributed to this transition unit. Marcin et al (20), showed that PICU patients discharged to intermediate care units most commonly had a prolonged stay in the PICU. In our hospital, the use of this unit may have led to a shorter PICU stay for this specific group of LSP, potentially alleviating the burden on PICU bed utilization. Literature that supports this hypothesis is limited. One multicenter retrospective study demonstrated that the implementation of an intermediate care unit was not associated with a reduced LOS for patients with complex chronic conditions (21). However, prospective randomized control trials or other evaluation studies of transitional units are lacking. Another explanation for LSPs shorter PICU stay might be the increased use of home nursing programs, home mechanical ventilation facilities, and other medical technical support.

This study is the first to identify the medical complexity and characteristics of PICU LSP patients at discharge. We showed that 76% of the LSP could be classified as CMC indicating high healthcare utilization after discharge. Classifying for CMC is important because CMC often require 24/7 expert nursing care and have prolonged (re)admissions to hospital (22, 23). Additionally, parents must be proficient in complex nursing care, deal with multiple healthcare providers, find a new balance in life, and need to be empowered (e.g., emotional support) (24–27). Therefore, identification of CMC is essential to understand patients' (recovery) trajectories better and organize appropriately the complex care needed for patients and families during and after hospital discharge.

A number of limitations have to be addressed. First, this single-center study reduces the generalizability of the results. Our findings may provide a reasonable approximation for other similar level III interdisciplinary PICUs. Second, our study does not include data on long-term follow-up. This information could be especially important in relation to the long-term functional

outcomes, quality of life for children and parents, and deferred mortality of LSP. Third, the involvement of allied healthcare professionals is evaluated upon hospital discharge using references in the discharge letters, leaving uncertainty about any subsequent changes in outpatient care. Lastly, there is no consensus on the classification of CMC, which may lead to variations in its categorizations.

Future research should not only focus on LSP utilization in the PICU and discharge characteristics but also investigate the events leading to admission. Additionally, future research is necessary to discern if other care models, such as transitional care units (28–30), might reduce PICU LOS, empower families, facilitate the transition to home, and prevent readmissions.

To conclude, this study demonstrates the significant burden that LSP has on the PICU and hospital resources, which do not end at the moment of discharge. This study shows the complexity of care for LSP and highlights the importance of developing and assessing specific pediatric transitional care units to improve healthcare outcomes and costs.

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Dr. Joosten had full access to all the data in the study and takes responsibility for the integrity of data and the accuracy of data analysis. Drs. Boerman and Haspels were involved in the drafting of the article. Dr. de Hoog and Joosten were involved in the critical revision of the article for important intellectual content. Drs. Boerman and Haspels were involved in statistical analysis. Dr. Joosten was involved in supervision. All authors were involved in concept and design, acquisition, analysis, or interpretation of data. All authors approved the final article as submitted and agree to be accountable for all aspects of the work.

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