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Protective and Unequal? Caregiver Presence During Pediatric Hospitalizations

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Abstract

OBJECTIVES: Describe the association between caregiver presence on hospital day 1 and outcomes related to readmissions, pain, and adverse events (AE).

METHODS: Caregiver presence during general pediatrics rounds on hospital day 1 was recorded, along with demographic data and clinical outcomes via chart review. AE data were obtained from the safety reporting system. χ^2 tests compared demographic characteristics between present and absent caregivers. Background elimination determined significant predictors of caregiver presence and their association with outcomes.

RESULTS: A total of 324 families were assessed (34.9% non-Hispanic white, 41.4% Black,17% Hispanic or Latinx, 6.8% other race or ethnicity). Adolescents (aged ≥14 years) had increased odds of not having a caregiver present compared with 6- to 13-year-olds (36.2% vs 10%; adjusted odds ratio [aOR] 5.11 [95% confidence interval (CI) 1.88–13.87]). Publicly insured children were more likely to not have a caregiver present versus privately insured children (25.1% vs 12.4%; aOR 2.38 [95% CI 1.19–4.73]). Compared with having a caregiver present, children without caregivers were more likely to be readmitted at 7 days (aOR 3.6 [95% CI 1.0–12.2]), receive

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The data that support the findings of this study are available on request from the corresponding author, Dr Lin. The data are not publicly available because they contain information that could compromise the privacy of patients.

opiates for moderate/severe pain control (aOR 11.5 [95% CI 1.7–75.7]), and have an AE reported (aOR 4.0 [95% CI 1.0–15.1]).

CONCLUSIONS: Adolescents and children with public insurance were less likely to have a caregiver present. Not having a caregiver present was associated with increased readmission, opiate prescription, and AE reporting. Further research is needed to delineate whether associations with clinical outcomes reflect differences in quality of care and decrease barriers to caregiver presence.

Parents and guardians (caregivers) play a critical role in the care of children in the hospital. When caregivers are actively engaged in their children's care, it leads to improved shared decision-making, satisfaction, identification of medication issues, and provision of information missing from the medical chart.[1-4] Further, family participation in a child's hospitalization can improve health outcomes such as increased child comfort, lower risk of adverse events (AEs), and shorter length of stay.[5,6] However, many caregivers are unable to be present with their child in the hospital because of complex and intersecting social, financial, and emotional factors.[5,7,8]

Several obstacles make it difficult for caregivers to be present during their child's hospitalization including the need to work, travel expenses, and food expenses. These costs disproportionately affect socioeconomically disadvantaged families and lead to cumulative social and financial burdens.[7,8] Hospitalization itself may trigger food insecurity,[9] and only 39% of hospitals in Canada and the United States provide free meals to parents with financial need or who are breastfeeding.[10] Despite evidence that hospitalizations are particularly burdensome for families with lower socioeconomic status (SES), few have investigated inequities related to caregiver presence in the hospital.

Noting the potential for disparities in caregiver presence in the hospital, the objectives of this study were to determine:

1. patient sociodemographic characteristics associated with caregiver presence at the bedside during rounds on hospital day 1; and
2. the association of caregiver presence with clinical outcomes.We hypothesized that caregivers with higher SES were more likely to be present during rounds on day 1 of hospitalization compared with caregivers of lower SES, and that caregiver presence is associated with improved outcomes related to readmissions, pain, and AEs.

METHODS

Study Population

This report is a secondary analyses of a cross-sectional survey study of caregiver presence during family centered rounds (FCR) on their child's first hospital day (within 24 hours of admission) on the general pediatrics floor at a tertiary care center in Durham, NC. FCRs consist of a multidisciplinary medical team that reviews subjective and objective patient data, elicits questions or concerns from the patient and family, and presents the daily plan. We identified caregivers through daily monitoring of the inpatient general pediatric team

admissions using the electronic health record (EHR) (Monday through Friday, August 2020 through June 2021). Caregivers of children undergoing evaluation for child abuse/neglect and those admitted for a primary psychiatric condition were excluded. Eligible caregivers were approached in the morning, before the start of FCR, to participate in the study. If caregivers were not present in the hospital room, the team checked with the bedside nurse if they were expected back at the bedside. If they were not, caregiver was recorded as not present. Caregivers were recorded as present if they were in the hospital room with their child, regardless of their decision to participate in the survey study. The hospital's institutional review board approved this study.

Data Collection and Measures

Using the EHR, we collected demographic data including age, race, ethnicity, sex, insurance type, and address. Caregivers were asked to self-identify their child's race and ethnicity on admission. We defined children as "Latinx" regardless of race if caregivers reported Latinx/Hispanic ethnicity for their child. If a caregiver identified >1 race for their child, we classified them as "other race and ethnicity." Insurance status was categorized into private (including military insurance), Medicaid, and uninsured. Home addresses were geocoded in ArcGIS Pro 2.5.0 (Esri, Redlands, CA) and Origin Destination Cost Matrix Analysis used to calculate shortest travel time between patient residential address and the tertiary care center in Durham, NC.

We obtained unplanned, 7-day and 30-day readmission and pain control score during the first 24 hours of hospitalization through review of the child's medical record. From our institutional safety repository, we obtained AE and severity of AE data. Our institution classifies the initial event severity using the National Coordinating Council for Medication Error Reporting and Prevention classification system for both medication and nonmedication events.[11] All events are reviewed by the operational leaders of the location, as well as the patient safety leadership team to determine the actual event severity. Medical complexity was determined using a previously published point-of-care algorithm assessing number of subspecialists, medical–technology dependency, and high-resource utilization.[12] We adapted 3 measures of pain control to measure pain management for children with a pain score of 3 or more documented in the EHR during the first 24 hours of admission.[13] The 3 measures included:

1. any opiate given within the first 24 hours of admission (excluded opiates given in the emergency department);
2. reduction in pain score by 2 or more points within 24 hours of maximum pain score; and
3. optimal pain control defined as scores of 0 to 3 within 24 hours of maximum pain score.

Analyses

To compare pairwise, demographic characteristics between present and absent caregivers, we used χ^2 tests (Table 1). A multivariate logistic regression model was performed using Stata. We examined a set of clinically relevant variables, including age, medical complexity,

race, and ethnicity, for association with clinical outcomes (Table 2). Backward selection was used to determine predictors in a predictive model with a *P* value <.05 (Table 2).

RESULTS

Study Sample Description

A total of 341 families met inclusion criteria on hospital day 1 on the basis of EHR review. Among these families, 18.5% (*n* = 63) of the children had no caregiver present, 73.9% (*n* = 252) had a caregiver present, and 7.6% (*n* = 26) were unavailable (eg, off the floor for procedures/imaging or not approached because of infectious risk [eg, coronavirus-positive]) on the first day of their child's hospitalization. The 26 children that were unavailable on hospital day 1 were excluded from this study for a final sample size of 315 caregivers/children. Demographics of the included children are described in Table 1.

Predictors of Caregiver Absence

Adolescents (aged ≥14 years) had increased odds of no caregiver present compared with children aged between 6 and 13 years (36.2% vs 10%; adjusted odds ratio [aOR] 5.11 [95% confidence interval (CI) 1.88–13.87]) (Table 1).

Females were more likely to have no caregiver present compared with males (24.8% vs 15.2%; aOR 1.85 [95% CI 1.05–3.25]). Additionally, publicly insured children were more likely to have no caregiver present versus privately insured children (25.1% vs 12.4%; aOR 2.38 [95% CI 1.19–4.73]). Child race, medical complexity, and travel time were not significant predictors of caregiver absence.

Association With Clinical Outcomes

Caregiver presence was found to be associated with clinical outcomes related to readmission, pain treatment, and AEs (Table 2). Not having a caregiver presence was associated with higher rates of 7-day readmission (aOR 3.6 [95% CI 1.0–12.2]). A subset of 61 children had moderate/severe pain documented (47 with caregiver present and 14 without a caregiver). Children without a caregiver present were associated with increased odds of receiving opiates for moderate to severe pain scores (aOR 11.5 [95% CI 1.7–75.7]). Compared with children with caregivers present, children with absent caregivers were more likely to have an AE reported in the institutional safety repository (aOR 4 [95% CI 1.0–15.1]).

DISCUSSION/CONCLUSIONS

In our study, nearly 1 in 5 caregivers were not present for rounds on the first day of their child's hospitalization. Not having a caregiver present was associated with worse hospital outcomes, including increased risk of an AE occurring and readmission. Children with public insurance, >14 years of age, and female gender were less likely to have a caregiver present. Given the association between caregiver presence and health outcomes, supporting families, particularly those with lower SES, so they can be present with their children may be an important target for achieving health equity in the inpatient setting.

When caregivers are present and engaged, they can help prevent medical errors, assert preferences for analgesic decision-making,[14] and participate in shared decision-making around discharge.[15] It is possible that poorer communication and lack of advocacy because of caregiver absence contributed to some of the disparate outcomes we observed.[15-18] Although caregivers may assume that their adolescent is able to advocate for themself, literature suggests most do not participate meaningfully in conversations with health care providers and may feel anxious or fearful during family-centered rounds.[19,20]

This study has several limitations. We only measured caregiver presence for family-centered rounds on hospital day 1. Caregivers may have been present on subsequent days or arrived after rounds. However, communication on hospital day 1 may be particularly important for preventing medical errors and identifying children at risk for decompensation.[21-23] An additional limitation stems from hospital incident reporting because it is both voluntary and suffers from underreporting, thereby only capturing a subset of errors and AEs.[24] We did not collect data asking why caregivers were not present, which may have been because of unmeasured confounders, including but not limited to principal diagnoses. Further studies are needed to understand barriers to caregiver presence to target interventions. Lastly, this study represents a small sample size at a single institution and may not be generalizable to other settings.

In this study, we found that having a caregiver present for rounds on the first hospital day was an independent predictor of health outcomes. Structural and institutional practices that communicate the importance of rounds, orient families to their role during an admission, and address barriers to caregiver presence may improve health outcomes. Further research is needed to describe how caregiver presence on rounds may impact clinical outcomes and delineate whether associations with clinical outcomes reflect differences in quality of care.

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TABLE 1

Demographic Characteristics of Patients With Caregivers Present or Not Present

	n	Caregivers Present, *n* (%), Total *n* = 252	Caregivers Not Present, *n* (%), Total *n* = 63	aOR (95% CI)[a]
Age, y, %				
< 1	111	86 (77.5)	25 (22.5)	2.62 (1.01–6.79)*
1–5	86	75 (87.2)	11 (12.8)	1.32 (0.46–3.88)
6–13	60	54 (90.0)	6 (10.0)	Ref
14 y or more	58	38 (63.8)	21 (36.2)	5.11 (1.88–13.87)*
Sex, %				
Male	158	134 (84.8)	24 (15.2)	Ref
Female	157	118 (75.2)	39 (24.8)	1.85 (1.05–3.25)*
Race and ethnicity, %				
Black or African American	130	101 (77.7)	29 (22.3)	1.47 (0.76–2.82)
Hispanic or Latinx	53	41 (77.4)	12 (22.6)	1.50 (0.66–3.34)
Non-Latinx white	110	92 (83.6)	18 (16.4)	Ref
Other race and ethnicity[b]	22	18 (81.8)	4 (18.2)	1.14 (0.34–3.75)
Insurance, %				
Private	97	85 (87.6)	12 (12.4)	Ref
Medicaid	191	143 (74.9)	48 (25.1)	2.38 (1.19–4.73)*
Uninsured	23	20 (87.0)	3 (13.0)	0.60 (0.07–5.07)
Travel time from tertiary care center in Durham, NC, %				
<30 min	122	101 (82.8)	21 (17.2)	Ref
30–59 min	89	69 (77.5)	20 (22.5)	1.39 (0.70–2.76)
60 or minutes	96	74 (77.11)	22 (22.9)	1.43 (0.73–2.79)
Mode of admission, %				
Direct admit	47	40 (85.1)	7 (14.9)	0.78 (0.32–1.87)
OSH transfer (ED or inpatient)	43	34 (79.1)	9 (20.9)	1.17 (0.52–2.66)
Tertiary care center ED	184	150 (81.5)	34 (18.5)	Ref
ICU transfer	35	23 (65.7)	12 (34.3)	2.31 (1.105–5.08)*

	n	Caregivers Present, *n* (%), Total *n* = 252	Caregivers Not Present, *n* (%), Total *n* = 63	aOR (95% CI)[a]
Medical complexity, %[c]				
Previously healthy	158	133 (84.2)	25 (15.8)	Ref
Child with special health care needs	125	96 (76.8)	29 (23.2)	1.61 (0.89–2.92)
Child with medical complexity	31	23 (74.2)	8 (25.8)	1.85 (0.74–4.60)

ED, emergency department; OSH, outside hospital; Ref, reference group.

[a] aOR of not having caregiver present.

[b] Other race and ethnicity encompasses American Indian or Alaskan Native, Asian, Native Hawaiian or Pacific Islander, and individuals identified as 2 or more race and ethnicities.

[c] Medical complexity determined using a previously published point-of-care algorithm.[12]

* $P < .05$.

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TABLE 2

Predictors of Health Outcomes using Multivariate Logistic Regression

	Length of Stay ≥72 h aOR (95% CI)	Readmitted Within 7 d aOR (95% CI)	Readmitted Within 30 d aOR (95% CI)	Any AE aOR (95% CI)	Received Opiate aOR (95% CI)
Caregiver not present	1.2 (0.7–2.3)	3.6 (1.0–12.2) *	2.1 (0.8–5.4)	4.0 (1.0–15.1) *	11.5 (1.7–75.7) *
Age, y					
<1	1.4 (0.8–2.5)	1.9 (0.4–9.1)	1.4 (0.5–4.3)	3.5 (0.6–21.8)	1.6 (0.1–31.5)
1–13	Ref	Ref	Ref	Ref	Ref
14 or more	2.0 (1.0–3.8) *	2.6 (0.5–13.1)	2.5 (0.8–7.5)	3.7 (0.8–18.4)	0.5 (0.1–3.8)
Medical complexity					
Previous healthy	Ref	Ref	Ref	Ref	Ref
Child with special health care needs	1.2 (0.7–2.1)	0.7 (0.2–3.1)	1.2 (0.4–3.5)	9.3 (1.0–88.1)	1.9 (0.3–10.1)
Child with medical complexity	3.3 (1.4–7.6) *	1.6 (0.3–10.1)	2.8 (0.8–9.9)	34.7 (3.0–398.9) *	13.6 (0.5–361.5)
Race and ethnicity					
Black race	1.3 (0.8–2.3)	1.3 (0.3–5.0)	0.9 (0.3–2.3)	1.3 (0.2–8.0)	1.4 (0.2–9.5)
Latinx ethnicity	1.2 (0.6–2.5)	0.9 (0.2–5.9)	0.5 (0.1–2.2)	6.1 (1.1–34.8) *	1.5 (0.2–13.8)
Other race/ethnicity	1.6 (0.6–4.3)	—	0.5 (0.1–4.5)	—	0.3 (0.1–6.1)
White race	Ref	Ref	Ref	Ref	Ref

Ref, reference group. —, no readmissions within 7 days for patients within the category “Other race/ethnicity” and No adverse events reported for patients within the category “Other race/ethnicity.”

* $P < .05$.

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