

Noncompliance With Medical Follow-up After Pediatric Intensive Care

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ABSTRACT. *Objectives.* To describe the medical follow-up ordered, the health care utilization, the appointment compliance, and the risk factors associated with noncompliance in patients who are discharged after a pediatric intensive care unit (PICU) stay.

Methods. A prospective, analytic, cohort study of 111 critically ill children, age 1 day to 16 years, who were admitted to a 30-bed PICU in an urban, tertiary-care, pediatric teaching hospital compared children who were compliant with medical follow-up with those who were not. The main outcomes measured were emergent and unscheduled physician visits during the first 6 weeks after hospital discharge; compliance with ordered medical follow-up after hospital discharge; and comparisons of socioeconomic, demographic, and medical need factors between compliant and noncompliant children.

Discharge orders for follow-up appointments with general pediatricians and subspecialists were collected from the chart at hospital discharge. Patients were contacted after hospital discharge to determine whether and when they received medical follow-up; 28% were found to be noncompliant. Risk factors associated with noncompliance were evaluated. Emergent and unscheduled physician visits were tracked during the first 6 weeks after hospital discharge.

Results. Lack of follow-up orders at hospital discharge did not affect the frequency of emergent visits. Children fell into 2 groups: those who were 100% compliant and those with $\leq 67\%$ compliance. No socioeconomic or demographic risk factors could be identified between the 2 groups. Compared with the 100% compliant patients, patients who were compliant with $\leq 67\%$ of appointments were more severely ill, as defined by higher peak pediatric risk of mortality scores during their PICU stay (11.5 vs 8.4), longer PICU length of stays (10.1 days vs 4.6 days), and longer hospital length of stays (25.5 days vs 14 days). Most predictive of noncompliance was the number of medical appointments ordered by physicians. Patients with 3 or more appointments were less likely to be compliant with follow-up. After hospital discharge, children were more likely to visit a primary care physician compared with a subspecialist (95% vs 82%). When patients were ordered to see a specialist, scheduled appointments were much better attended than the recommended appointments (92% vs 67%).

Conclusions. Lack of ordered medical follow-up did not affect emergent visits. In this group of critically ill children, a significant percentage (28%) did not receive timely medical follow-up. No socioeconomic or demographic risk factors were identified in noncompliant children. However, severity of illness (higher peak pediatric risk of mortality score, longer PICU stay, and longer hospital stay) and the number of follow-up appointments ordered were predictors of noncompliance. Potential exists for implementing strategies to improve compliance in identified populations. *Pediatrics* 2002;109(6). URL: <http://www.pediatrics.org/cgi/content/full/109/6/e94>; compliance, follow-up, predictors, pediatrics, PICU, appointments.

ABBREVIATIONS. PICU, pediatric intensive care unit; ED, emergency department; PRISM, pediatric risk of mortality score; LOS, length of stay; PCP, primary care provider.

The care of critically ill children in pediatric intensive care units (PICUs) consumes a significant amount of health care resources¹⁻³; however, little is known about the long-term outcomes of this environment. A few studies have reported long-term health outcomes and quality of life in children after discharge from a PICU.⁴⁻⁶ Tracking children after hospital discharge to determine their need for medical care and compliance with ordered medical follow-up is an additional step in investigating PICU outcomes.

Studies of follow-up compliance in adult populations have been reported in the outpatient clinic setting⁷⁻¹¹; however, no studies have reported follow-up compliance after an ICU stay. Similarly, no studies of follow-up care after PICU stays have been reported. Of the few pediatric follow-up studies reported, all have dealt with well children in outpatient clinics and have shown that these children demonstrate poor compliance with follow-up appointments with nonattendance rates of 16% to 49%.¹²⁻¹⁶

Two of these pediatric studies identified factors associated with noncompliance. McClure et al¹⁶ identified 1) older age (78 vs 64 months), 2) caregiver perception of a significantly more severe illness, 3) use of public transportation to reach the clinic, and 4) more appointments scheduled in the previous 12 months in noncompliant patients. Cooper and Lynch¹² identified 4 common risk factors among nonattendees: 1) initial referral from an emergency department (ED), 2) hospital admission before the first appointment, 3) recognition of multiple medical problems, and 4) family social problems.

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The purpose of this study was to determine health care utilization, describe the medical follow-up ordered by physicians, and investigate predictors of noncompliance for children discharged from a PICU. This study investigates the hypothesis that a significant number of children who are discharged after a PICU stay do not receive the ordered medical follow-up after hospital discharge because of identifiable factors that lead to the failure of guardians to seek medical care. We attempted to identify and investigate prospectively socioeconomic, demographic, and medical need factors that could predict which children are at risk for delayed or lack of medical follow-up.

METHODS

As randomization of subjects was not feasible, an observational prospective cohort design was used. The cohort of children was obtained in the PICU at Texas Children's Hospital (Houston, TX) between February 2000 and August 2000. This protocol was approved by the institutional review board at Baylor College of Medicine.

Subjects

Eligible patients included all patients who were admitted to the PICU up to 18 years of age and did not live in a chronic care facility. Patients were excluded from the study when they were transferred from another inpatient unit for a brief period of monitoring for an isolated procedure or when their PICU admission was <8 hours. Of the patients who were enrolled, those who were transferred to another inpatient facility and those who died were considered "withdrawals." Patients who were readmitted to a hospital during the study period and families who were failed telephone contacts were considered study "dropouts."

Study Protocol

Enrollment and Baseline Data

Patients' guardians were approached for enrollment after a minimum 24-hour hospital stay. After a guardian (eg, parent, grandparent, foster parent) signed a consent, they listed contact preferences: time of the day (morning, evening, night) and location (eg, work, home). At the time of enrollment, families were verbally encouraged to remember the date of all follow-up appointments kept. Participation entailed an initial interview that consisted of 12 demographic/social questions and 1 brief telephone call after hospital discharge. Patients' admission pediatric risk of mortality score (PRISM), a recognized and validated measure of pediatric severity of illness,¹⁷ was collected on enrollment.

Tracking and Discharge Data

Continued hospitalization was verified daily on the hospital inpatient roster. Peak PRISM score, PICU length of stay (LOS), hospital LOS, and orders for medical follow-up were collected after hospital discharge. Discharging physicians ordered medical follow-up appointments at their discretion, and these data were obtained from the medical record at discharge. Ordered follow-up appointments that were scheduled for a specific date and time were considered "scheduled," and appointments that were recommended within a time frame (eg, 2 weeks) were considered "recommended" for study purposes. Discharge instructions such as "follow-up with Dr _____ ASAP" (as soon as possible) were considered as recommended orders for follow-up within 1 week of discharge. Ordered testing, such as a hearing or eye examination, was considered subspecialty follow-up for study purposes. Instructions to follow-up "prn," or "as needed," were not considered an order for follow-up for study purposes and were not included for compliance analysis.

Follow-up

At the time of hospital discharge, patients were entered into a follow-up calendar that was checked weekly to determine which families should be called. Appointments kept within a window of

150% of the length of time the appointment was ordered by the physician were considered "on time" and recognized as compliant with follow-up. For example, patients who were instructed to follow-up in 10 days were considered compliant when they were seen within 15 days after discharge. Six weeks after hospital discharge, initial telephone contact was attempted to determine whether and where the patient had received any medical care. The 6-week interval was chosen after a preliminary chart review demonstrated that the vast majority of appointments were ordered within 4 weeks of hospital discharge, and this time frame would allow appointment attendance within the defined 150% time interval. A maximum of 4 telephone contact attempts per patient was made during a 2-week period. If the child received medical care, then the location and provider of care were recorded (eg, pediatrician's office, local ED, subspecialty office visit.)

Caregivers of children who did not receive follow-up were asked an open-ended question about why they failed to make each scheduled or recommended visit. Parents were also asked whether their child had received any emergent care or unscheduled health care during the study period, and the location and provider of care for the emergent or unscheduled visit were recorded.

Sample Size

Planned analysis included binary logistic regression analysis. On the basis of data from previous studies,^{12,15,16} 14 variables (age, race, income, insurance, number of caregivers, caregivers' employment status, transportation, established primary care provider [PCP], last PCP visit, diagnosis, PICU LOS, hospital LOS, and PRISM scores [admission and peak]) were selected for evaluation. Of these, it was anticipated that only 6 to 8 variables would achieve significance in the final model. For each of the 6 to 8 variables expected to achieve significance, we chose to collect 15 samples; therefore, 90 to 120 patients were needed to complete the study. A total of 160 families were enrolled to accommodate anticipated deaths, readmissions, and failed contacts and achieve a study completion rate of approximately 110 families.

Variables

The Behavioral Model of Health Services Utilization considers 3 components of the population at risk: need, predisposing, and enabling variables.¹⁸ "Need" refers to the health status or degree of illness, perceived by the patient or provider, that prompts utilization of health service. In this study, needs were 1) an illness requiring a hospital admission, 2) PRISM scores, 3) PICU LOS, and 4) hospital LOS. Predisposing variables, demographic and social/structural, describe the propensity of individuals to use health services. In this study, predisposing variables were 1) age, 2) race, 3) income, 4) number of adult caregivers, 5) last PCP visit, and 6) caregivers' employment. Finally, enabling variables describe the resources available to individuals that promote access to health care. In this study, enabling variables were 1) type of insurance, 2) mode of transportation, and 3) identification of a PCP.

Analysis

Binary logistic regression was used to determine which variables predicted compliance. χ^2 , Fisher exact test, and 2-sample *t* tests were used for comparisons between the study cohort and withdrawals, comparison of individual variables between compliance groups, and comparisons of compliance between different types of appointments.

RESULTS

Patients Enrolled

A total of 160 patients were enrolled during the 6-month study period. Of these patients, 7 died before hospital discharge and 10 were transferred to another hospital, yielding 17 patients in the "withdrawal" group. Twenty-seven patients were readmitted during the study period, and 5 patients were failed telephone contacts, composing the "dropout" group. The 111 patients who completed the study composed the health care utilization cohort. Six pa-

tients were discharged from the hospital without any type of follow-up ordered, yielding a separate compliance cohort of 105 children with ordered follow-up appointments (Fig 1). χ^2 testing, Fisher exact testing, and 2-sample *t* tests demonstrated that there were no differences in demographic characteristics between the compliance cohort and all other patients (Table 1).

Emergent Visits

Of the 111 patients in the utilization cohort, families of 23 children (21%) reported a total of 36 emergent medical visits during the 6- to 8-week period immediately after hospital discharge. The 2 most common reasons listed by parents for these emergent visits were fever ($n = 7$) and respiratory issues ($n = 7$). Patients without orders for medical follow-up were equally as likely to have emergent or unplanned physician visits as patients with follow-up orders (33% vs 22%; $P = .62$). Lack of instructions for a PCP visit did not result in more emergent visits compared with patients with PCP follow-up instructions (57% vs 43%; $P = .19$).

Instructions for Follow-up Appointments

All patients were discharged from the inpatient ward and follow-up appointments were ordered at the discretion of the discharging physician. The compliance cohort of 105 patients had a total of 186 follow-up appointments ordered by physicians at the time of hospital discharge: 57 PCP appointments and 129 subspecialist appointments. Only 1 appointment

was for subspecialty testing; the remaining 185 appointments were with physicians. There was considerable variability in medical follow-up instructions with only 57 children (51%) receiving instructions to see their PCP. More children were sent home with subspecialist follow-up instructions than PCP follow-up instructions (92 vs 57; $\chi^2 = 28.3, P < .001$).

Compliance With Follow-up Instructions

The compliance cohort was created from the 105 patients with ordered follow-up appointments. After preliminary data analysis, compliance fell into clearly defined groups of 100% and $\leq 67\%$. No patients attended between 68% and 99% of their appointments. Differences between groups were analyzed using binary logistic regression. Compliance did not vary on the basis of any predisposing or enabling factors (Table 2).

Thirty-nine appointments (21%) met the study definition of noncompliance. Of these appointments, 26 were missed and an additional 13 appointments were delayed 150% beyond the ordered time. Twenty-nine children (28%) met the study definition of noncompliance. Of these children, 20 missed appointments and 9 other children attended very delayed appointments 150% beyond the ordered time.

Table 3 lists reasons cited by parents for failure to attend follow-up appointments. The most common reasons that parents listed for missing appointments were logistic and communication errors ($n = 14$), citing difficulty with scheduling appointments with physician offices, lack of telephone numbers for spe-

Fig 1. Outcome of all patients enrolled in the study.

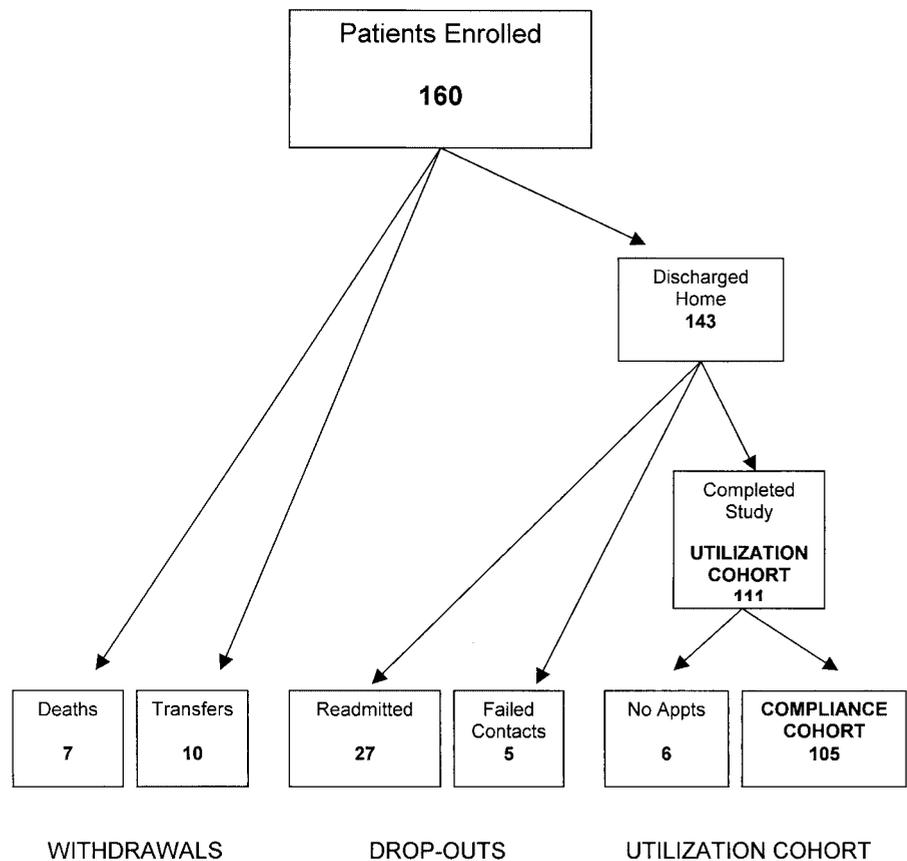


TABLE 1. Comparison of Patients Used in Final Compliance Analysis: Compliance Cohort Versus Withdrawals, Dropouts, and Children Without Appointments

	Withdrawals, Dropouts, and No Appointments (<i>N</i> = 55)	Compliance Cohort (<i>N</i> = 105)	<i>P</i> Value
Average age (mo)	70 (±73)*	49.5 (±55)*	.074
Race			.61
White	28 (51%)†	51 (49%)†	
Black	14 (26%)	20 (19%)	
Hispanic	13 (22%)	30 (29%)	
Asian	0	3 (2.9%)	
Other	1 (1.8%)	1 (0.9%)	
Average family income	\$33 000	\$38 000	.18
Type of insurance			.53
Traditional	4 (7%)†	3 (3%)†	
Managed care	27 (49%)	60 (57%)	
Medicaid	20 (36%)	36 (34%)	
Self-pay	4 (7%)	6 (6%)	
Transportation			.37
Private	52 (95%)†	95 (91%)†	
Family/friend	3 (5%)	9 (9%)	
Other	0	1 (1%)	
PICU LOS	7.9 days (±13.1)*	6.1 days (±8.3)*	.36
Hospital LOS	23.5 days (±27.4)*	17.3 days (±17.5)*	.13
PRISM Scores			
Admission	7.9 (± 5.7)*	7.5 (± 5.2)*	.68
Peak	9.5 (± 6.4)	9.5 (± 6.4)	.81
Average number of hospitalizations	0.58 (± 0.50)*	0.60 (± 0.49)*	.82

* Standard deviation.

† Percentage of total patients.

cialists, and lack of written instructions about when to call. (All parents were given a written discharge instruction sheet regarding the timing and names of the physicians they should see for follow-up with a copy placed in the medical record.) Noncompliant families also cited insurance issues as another major factor that contributed to missed appointments. Families who had undergone a recent change in insurance plan cited delays while waiting for approval or reported that the plan did not include certain physicians.

Overall, children were more likely to visit a PCP than a subspecialist (95% vs 82%; $\chi^2 = 5.19$, $P = .023$) after hospital discharge; however, many of these appointments were attended late. When evaluating timely attendance (ie, within the compliance window), there was no difference in follow-up with PCPs compared with subspecialty physicians (88% vs 78%; $\chi^2 = 2.3$, $P = .13$).

The 186 follow-up appointments were also assessed to determine whether scheduling the appointment for a specific date and time or recommending a time frame caused variation in attendance. Scheduling specific appointments versus recommending appointments in a time frame did not affect compliance with PCP visits (100% vs 86%; $\chi^2 = 1.12$, $P = .29$). However, subspecialist appointments were much better attended when they were scheduled as opposed to recommended (92% vs 67%; $\chi^2 = 11.8$, $P = .001$).

Most children were discharged with instructions for more than 1 follow-up visit. Figure 2 demonstrates that the on-time compliance rate dropped sharply with increasing numbers of appointments. Compliance with medical follow-up varied inversely

with the number of follow-up appointments (Table 4). As shown in Table 5, evaluation by Spearman's rank analysis determined that the number of follow-up appointments at hospital discharge directly correlated with acuity of illness as reflected by admission PRISM scores ($P < .001$), peak PRISM scores ($P < .001$), total PICU LOS ($P < .001$), and hospital LOS ($P < .001$), whereas the age of the patient did not ($P = .19$).

Compliance with medical follow-up was inversely related to medical need. Table 6 shows children who were sicker, as evidenced by higher peak PRISM scores and longer PICU and hospital LOS, were less likely to be compliant with medical follow-up. Again, variables between the 2 compliance groups were compared using binary logistic regression and compliance markedly decreased as the number of follow-up appointments increased. With each additional follow-up appointment ordered, children were 5.8 times more likely to be noncompliant.

Prediction Model

Four factors were found to be predictive of non-compliance: 1) high peak PRISM score ($P = .020$), 2) longer PICU LOS ($P = .012$), 3) longer hospital LOS ($P = .008$), and 4) total number of follow-up appointments ($P < .001$; Table 6). The PICU admission PRISM score approached significance for prediction at $P = .056$. These 5 variables were tested for interactions using binary logistic regression, and no interactions were found. A backward elimination process was applied to remove variables in order of least significant P values to yield the following prediction model (Table 7):

TABLE 2. Compliance Based on Predisposing and Enabling Factors

	100% Attendees (N = 75)	≤67% Attendees (N = 30)	P Values
Average age (mo)	47.3 (± 53)*	54.9 (± 61)*	.53
Average family income	\$37 000	\$39 000	.97
Caregivers/parents			.70
1	8 (11%)†	1 (3%)†	
2	57 (76%)	25 (83%)	
3	8 (11%)	4 (13%)	
>3	2 (3%)	0	
Caregivers employed			.83
0	11	2	
1	39 (52%)†	19 (63%)†	
2	11	9	
3	1	0	
>3	1	0	
Transportation			.90
Personal	67 (89%)†	28 (93%)†	
Family/friend	7	2	
Other	1	0	
Race			.86
White	34 (45%)†	17 (57%)†	
Black	16 (21%)	4 (13%)	
Hispanic	22 (29%)	8 (27%)	
Asian	2 (2.6%)	1 (3.3%)	
Other	1 (1.3%)	0	
Insurance			.78
Traditional	2 (2.7%)†	1 (3.3%)†	
Managed care	41 (55%)	19 (63%)	
Medicaid	28 (37%)	8 (27%)	
Self-pay	4 (5.3%)	2 (6.7%)	
Established PCP			.49
Pediatrician	65 (87%)†	23 (77%)†	
Family doctor	5	5	
Health clinic	0	0	
Other	2	1	
None	3	1	
Time since last PCP visit			.39
Never	4	4	
24 h	21	4	
1 wk	11	4	
2-4 wk	6	1	
1 mo	11	7	
>1 mo	22	10	
Previous hospitalizations	0.57 (± 0.50)*	0.60 (± 0.50)*	.80

* Standard deviation.

† Percentage of total patients.

TABLE 3. Reasons for Failure to Follow-up

Principal Reason Cited	Number of Appointments (N = 39)
Communication issues/could not get appointment	14
Insurance issues	6
Cancelled by another physician	4
Forgot	2
Transportation difficulties	1
Parent unable to miss work	1
Other/no reason	11

$$P(\text{noncompliance}) = 1 + e^{-1/[4.24+1.72(\text{total appointments})]}$$

Using the model, a prediction curve was created to demonstrate how noncompliance would sharply increase as the number of follow-up appointments increased (Fig 3).

DISCUSSION

The main finding of this study is that critically ill children display only a 72% compliance with timely

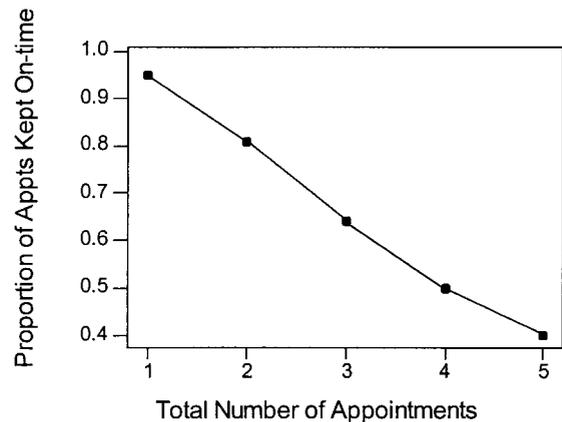


Fig 2. Proportion of appointments attended on-time on the basis of the total number of appointments at hospital discharge.

medical follow-up appointments after discharge from a hospital course that included a stay in the PICU. Although no studies have evaluated follow-up

TABLE 4. Number of Appointments and Compliance Rate

Total Number of Appointments	Number of Patients	Appointments Kept	Appointments Kept on Time
0	6	NA	NA
1	42	41 (98%)	40 (95%)
2	47	80 (85%)	76 (81%)
3	12	29 (81%)	23 (64%)
4	3	8 (67%)	6 (50%)
5	1	2 (40%)	2 (40%)
χ^2		14.65 ($P = .002$)	21.22 ($P = .001$)

NA indicates not applicable.

TABLE 5. Number of Appointments by Need Factors

	Total Appointments						Spearman's r (P Value)
	0	1	2	3	4	5	
Number of patients	6	42	47	12	3	1	
Hospital LOS (SD)	5.5 (2.4)	11.7 (9.3)	17.5 (19.6)	28.3 (20.7)	38.7 (25.7)	43.0	0.336 (<.001)
PICU LOS (SD)	3.0 (2.2)	3.7 (4.3)	6.9 (10.4)	10.5 (8.6)	3.3 (0.57)	17.0	0.327 (<.001)
Admission PRISM (SD)	5.2 (4.3)	5.3 (4.4)	8.4 (4.8)	10.5 (4.7)	9.3 (6.1)	24	0.409 (<.001)
Peak PRISM (SD)	5.2 (4.3)	6.4 (4.7)	10.5 (5.5)	12.6 (6.6)	10.0 (5.3)	26	0.383 (<.001)
Age (mo; SD)	95 (74)	54 (55)	45 (56)	32 (38)	120 (79)	53	-0.125 (.190)

SD indicates standard deviation.

TABLE 6. Compliance Based on Need Factors

	100% Compliance ($N = 75$)	$\leq 67\%$ Compliance ($N = 30$)	P Value	Odds Ratio (95% CI)
LOS (SD)				
PICU	4.7 (± 4.6)	9.5 (± 13.2)	.012	1.10 (1.02-1.18)
Total hospital	14.4 (± 14.9)	24.3 (± 21.6)	.008	1.03 (1.01-1.06)
PRISM score (SD)				
Admission	7.0 (± 4.9)	8.9 (± 5.8)	.056	1.09 (1.00-1.18)
Peak	8.5 (± 5.6)	11.1 (± 6.3)	.020	1.09 (1.01-1.18)
Diagnosis				
Medical	30	12		
Surgical	20	5		
Cardiac	24	13		
Trauma	1	0		
Average number of discharge appointments	1.53	2.45	<.001	5.80 (2.64-12.74)

CI indicates confidence interval; SD, standard deviation.

TABLE 7. Regression of Factors That Predict Compliance

Variable	Regression Coefficient	P Value	Odds Ratio (95% CI)
Hospital LOS	-0.0130	.55	0.99 (0.95-1.03)
PICU LOS	0.0799	.12	1.08 (0.98-1.20)
Admission PRISM	-0.0419	.63	0.96 (0.81-1.14)
Peak PRISM	-0.0257	.76	0.97 (0.93-1.15)
Total number of appointments	1.8357	<.001	6.27 (2.59-15.17)

compliance in similar children, this 28% overall patient noncompliance rate is similar to that reported in studies of well children with general outpatient follow-up appointments.^{12-14,16} The 22% appointment noncompliance rate with subspecialists in this study also compares to subspecialist appointment noncompliance in other studies.^{14,16} Also similar to a previous study,¹⁶ our study found that compliance inversely correlated with the number of follow-up appointments.

The critically ill children in the current study did demonstrate better compliance with follow-up than a

geographically similar group of hospitalized adults. A group of Houston adults had only a 50% compliance rate after hospital discharge.¹¹ However, unlike another adult study,¹⁰ the identification of a PCP before becoming ill did not improve the pediatric compliance with follow-up.

Only 1 previous study investigated severity of illness as a predictor of compliance with outpatient appointments.¹⁶ Using subjective parent and physician ratings, this study of well outpatients found that children who were perceived as being more ill by the caregivers were the least compliant with follow-up

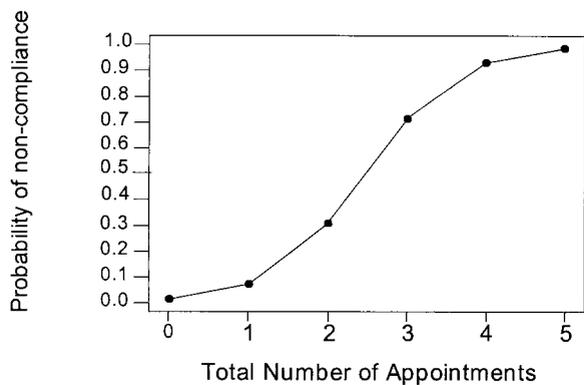


Fig 3. Binary logistic regression probability curve for appointment noncompliance on the basis of total number of appointments at hospital discharge generated by the prediction model.

appointments. Physicians' ratings of severity of illness did not vary between attendees and nonattendees. Utilization of medical services could be used to reflect the overall health status of the child. Cooper and Lynch¹² considered previous hospitalizations and recent ED visits as predictors of compliance and found no association between previous admissions or ED visits and outpatient clinic attendance. Our study found that the 28% of patients who were non-compliant had higher peak PRISM scores and longer PICU and hospital LOS, arguably making them more fragile from an objective medical perspective. Similar to the Cooper study, the number of previous hospitalizations did not differ between attendees and nonattendees in our study.

Three previous studies investigated socioeconomic and demographic factors in outpatient clinic nonattendees.^{12,15,16} Irwin et al¹⁵ found that lower social class was the single significant predictor of nonattendance among adolescents. Similarly, McClure et al¹⁶ also found lower social class as a predictor of nonattendance along with type of transportation used and presence of a single parent in the home. Cooper and Lynch¹² did not find social class as a predictor but did identify the presence of "social problems" with poor attendance. The authors did not clearly define "social problems." In our study, no demographic or socioeconomic risk factors were associated with noncompliance. Unlike previous studies,¹⁶ our study failed to identify age of the child or the use of public transportation as factors in determining whether families attended follow-up appointments. Although the McClure study showed that nonattendees were more likely to have single parents,¹⁶ our study found no difference in the number of caregivers or working caregivers between attendees and nonattendees.

Similar to outpatient studies of well children,^{14,16} the children in the current study were less likely to attend appointments with pediatric subspecialists compared with PCPs. The reason for this discrepancy in attendance is unclear. Pediatricians and family practitioners may be located closer to the families' home, making attendance of these appointments more convenient compared with traveling farther to a medical center for a subspecialist visit. Parents may

also believe that their child's PCP knows their child best and trust that physician's opinion. Finally, given that a significant number of missed appointments involved communication and scheduling issues, parents may find scheduling an appointment with their local PCP easier than scheduling appointments with subspecialists. However, a recent study of Kentucky managed care Medicaid patients found that healthy children missed 51% of subspecialist appointments despite the scheduling of appointments before the children left the PCP's office.¹⁹

In the current study, predictors of noncompliance were related to medical need as opposed to predisposing or enabling factors. Surprising is that there was an inverse relationship between medical need and follow-up compliance. Potential hypotheses include that a prolonged hospitalization may have desensitized the parents to the child's level of illness; a prolonged hospital stay may have been more stressful on the family, making the scheduling of additional time off work to attend follow-up appointments more difficult; or the education that the parent received while the child was hospitalized may have been so effective that the parent did not believe that the recommended follow-up was necessary.

This study does allow the identification of patients at risk for inadequate or delayed follow-up. Critically ill patients with higher peak PRISM scores, prolonged PICU and hospital LOS, and 3 or more ordered follow-up appointments are at risk for non-compliance. Independent of PRISM scores and LOS, 3 or more follow-up appointments at the time of discharge is an independent indicator of the risk for noncompliance. Each follow-up appointment increased the risk of noncompliance almost 6-fold. This identification of patients at risk allows the opportunity to provide interventions that might improve follow-up compliance. The typical strategies to improve appointment compliance, such as mail or telephone reminders, are not practical from a hospital or institutional perspective. However, possible strategies to improve compliance on the basis of the above results include the scheduling of all follow-up appointments and improved discharge planning to clarify insurance before discharge.

Limitations

Potential limitations of this study include limited generalizability, as only patients at a single hospital and region were included. Health care utilization in rural areas or in populations with a higher percentage of indigent patients may be very different; although Texas Children's Hospital had 35% of its patients insured by Medicaid during the year of this study. All patients were enrolled and followed during the winter and spring months; however, given Houston's mild climate, seasonal and weather factors should be nominal components in medical follow-up.

The factors chosen to explain follow-up variability may not include all of the variables that affect whether children received their ordered medical care. For instance, the Behavioral Model of Health Services Utilization also includes the need for care as

perceived by the individual or, in this case, the parent.¹⁸ This study considered only need for care as perceived by the provider using a PICU admission and physician's discharge orders for follow-up. In their expanded behavioral model, Anderson and Aday¹⁸ included consumer satisfaction, whereas this study did not.

A third limitation might include the significant difference in total hospital LOS between the patients who completed the study and the withdrawals/dropouts (17 days vs 26 days; $P = .04$). However, the study completion group was used only for emergent visit analysis. Although their shorter hospital LOS could suggest that they were less ill than the withdrawal/dropout group, when severity of illness was considered, there was no difference in admission PRISM scores (7.4 vs 8.3; $P = .38$) or peak PRISM scores (9.0 vs 10.0; $P = .36$) between the 2 groups. Furthermore, the main focus of this study was patient compliance, and there were no differences in the total LOS between the final compliance cohort and all other enrollees (24 days vs 17 days; $P = .13$).

Another limitation involves potential for recall bias when parents were asked to remember the appointments kept during a 2-month period. A random selection of 15% of study subjects was tracked to investigate recall bias. The pediatric and subspecialist offices of these patients were called to confirm that the patients were indeed seen in the time frame reported. These telephone calls confirmed that the majority of parents were accurate in recalling their appointment attendance. Seventeen patients with 28 appointments were reviewed. Reporting discrepancies occurred with 7 appointments; however, the majority of these discrepancies were simply wrong attendance dates that still fell within the compliance window. One family actually attended an appointment that they forgot to report to the study coordinator. Most concerning was that 3 appointments that families reportedly attended were actually not confirmed by physician's offices. Given these false attendance reports, the 79% appointment compliance rate reported in this study could be an overestimation of actual appointment attendance. Nonetheless, the risk factors identified—higher peak PRISM scores, longer PICU and hospital LOS, and number of follow-up appointments at discharge—still allow predischARGE identification of patients for intervention strategies that could improve follow-up compliance.

CONCLUSION

This study provides a description of the instructions and compliance with pediatric medical follow-up after discharge from a PICU admission. A significant number of children (28%) were found to be at risk for inadequate medical follow-up after hospital discharge. Identifiable risk factors associated with noncompliance with follow-up include 1)

higher peak PRISM scores, 2) longer PICU and hospital LOS, and 3) the total number of follow-up appointments ordered at hospital discharge. Children were more likely to attend scheduled subspecialist appointments compared with recommended subspecialist appointments. There were no socioeconomic or demographic factors that predicted which children would miss follow-up appointments. The single most significant factor in predicting noncompliance was the number of follow-up appointments ordered at hospital discharge. Each additional appointment was associated with an almost 6-fold risk of noncompliance.

These findings support the hypothesis that a significant number of children do not receive the recommended medical follow-up after discharge from a PICU hospitalization. Although no socioeconomic or demographic risk factors could be identified in non-compliant children, some medical factors and certain discharge instructions were identified with decreased compliance rates.

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