

Impression of Primary Care Follow-Up After a PICU Admission: A Pilot Survey of Primary Care Pediatricians

OBJECTIVES: The majority of PICU general follow-up occurs with primary care providers. Our objective was to investigate primary care pediatricians': 1) comfort with and barriers to caring for children after a PICU admission, 2) knowledge of and screening for post-intensive care syndrome in pediatrics (PICS-P), and 3) resource needs.

DESIGN: Pilot cross-sectional survey study.

SETTING: Metropolitan Detroit, Michigan from September 2022 to March 2023.

SUBJECTS: Primary care pediatricians.

MEASUREMENT AND MAIN RESULTS: The survey included 15 questions on provider demographics, comfort with and barriers to caring for children after a PICU admission, knowledge of and screening practices for PICS-P, and resource needs. The median values for continuous data and frequencies for categorical data were calculated. The survey response rate was 17% (26/152). The median age was 38.5 years (interquartile range 34–52 yr) and 19 of 26 (73%) were female. In case studies, 26 of 26 (100%) were “very comfortable” resuming care for a patient with a straightforward bronchiolitis PICU admission while 8 of 26 participants (31%) were “somewhat uncomfortable” and 1 of 26 (4%) was “not at all comfortable” with caring for a patient after a complex acute respiratory distress syndrome PICU admission. Seven of 26 participants (27%) were familiar with the term “post-intensive care syndrome in pediatrics.” Over 50% screened for four of five PICS-P domains. Key barriers were care coordination with specialists, discomfort or difficulties with managing new home equipment, and inadequate or missing documentation.

CONCLUSIONS: In this pilot study, approximately one-third of primary care pediatricians had knowledge of PICS-P. Participants experienced numerous care barriers. Our findings suggest future research could engage improved study methods and designs, and focus on interventions to support primary care-provided PICU follow-up.

KEYWORDS: pediatric intensive care units; post-intensive care syndrome pediatrics; primary care providers

Post-intensive care syndrome in pediatrics (PICS-P) is the constellation of physical, cognitive, social, and emotional impairments experienced by patients and their caregivers after a PICU admission (1). Although PICU follow-up clinics have begun to be established to identify and treat PICS-P (2), the majority of general PICU follow-up occurs with primary care providers (2–5). Prior studies have shown that up to 80% of patients are recommended to follow-up with a primary care provider after a PICU admission (3, 4).

Pediatric primary care providers are uniquely poised to help screen and coordinate the management of PICS-P because they are often the medical home

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KEY POINTS

Question: Our objective was to investigate primary care pediatricians': 1) comfort with and barriers to caring for children after a PICU admission, 2), knowledge of and screening for post-intensive care syndrome—pediatrics (PICS-P), and 3) resource needs.

Findings: In this pilot cross-sectional survey study, we found that participants noted decreased comfort in providing care to children after a complex PICU admission, and only 27% had knowledge of PICS-P.

Meaning: Our findings suggest future research could engage improved study designs and focus on interventions to support primary care-provided PICU follow-up.

that provides primary care and care coordination (6). However, primary care pediatricians' knowledge of PICS-P and the barriers experienced by primary care pediatricians in caring for children after a PICU admission remain poorly understood. In addition to an improved understanding of PICS-P components and management strategies, improving PICS-P management requires an improved understanding of the barriers experienced by pediatric primary care providers.

Our study objective was to survey primary care pediatricians in Metro Detroit, Michigan concerning: 1) comfort with and barriers to caring for children after a PICU admission, 2) knowledge of and screening for PICS-P, and 3) resource needs.

MATERIALS AND METHODS

We performed a pilot cross-sectional study of primary care pediatricians in Wayne, Oakland, and Macomb counties in Michigan. We sampled community pediatricians and pediatricians affiliated with a quaternary care pediatrics hospital. Surveys were sent as a Research Electronic Data Capture Database survey via email from September 2022 to March 2023 using a contact list from the Director of Physician Relations at the Children's Hospital of Michigan. If the survey was not completed within 2 weeks of initial contact, a reminder email was sent. This study was approved by Central Michigan University (institutional review

board [IRB] number 2022-963) and Detroit Medical Center (20027) IRBs. The procedures were followed in accordance with the ethical standards of the Central Michigan University IRB and the Helsinki Declaration of 1975. Participants were emailed an information sheet describing the study and provided informed consent, which was indicated by completing the survey. Participants received a \$20 gift card.

Participants completed a survey of 15 questions on provider demographics, comfort with and barriers to caring for children after a PICU admission, knowledge of and screening for PICS-P, and resource needs (**Supplemental Digital Content, Appendix A**, <http://links.lww.com/CCX/B315>). Fourteen of the main questions were closed-ended (multiple choice, 8; Likert scale, 3; numerically answered, 3) and one was open-ended (free response, 1). Two questions had branching logic, whereby selecting an answer prompted a follow-up question with a Likert scale or free response question. Questions were generated by a multidisciplinary research group based on definitions of PICS-P and research on intensive care follow-up practices (1, 2, 7, 8). The research group included a primary care pediatrician, a pediatric critical care physician, two pediatric residents, and the physician director for Physician Relations. Missing and inconsistent data were handled as described in **Supplemental Digital Content Appendix B** (<http://links.lww.com/CCX/B315>). All surveys with greater than 80% quantitative data present were analyzed. Quantitative survey results were analyzed using median values for continuous data and frequencies for categorical data using STATA, version 14 (StataCorp, College Station, TX). Qualitative questions were analyzed by identifying themes using conventional qualitative content analysis.

RESULTS

The survey response rate was 17% (26/152). All participants completed greater than 80% of the 14 main quantitative questions, with less than 1% of responses missing (**Supplemental Digital Content, Appendix B**, <http://links.lww.com/CCX/B315>). Of survey respondents, 19 of 26 (73%) were females, with a median age of 38.5 years (IQR 34–52 yr), and 11 of 26 (42%) were White/Caucasian (**Table 1**). The median years in practice was 6.5 (IQR 3.5–23), the median practice size was 7 (IQR 5–10), and 19 of 26 (73%) had greater than or equal to five patients return to their care after a PICU admission in the last year (**Table 1**).

TABLE 1.
Pediatric Primary Care Provider
Demographics and Practice Characteristics

<i>n</i> = 26	
Pediatric primary care provider demographics	
Age, median (IQR)	38.5 (34–52)
Gender, <i>n</i> (%)	
Female	19 (73)
Male	6 (23)
Prefer not to answer	1 (4)
Race, <i>n</i> (%)	
American Indian/Alaska Native	0 (0)
Asian	7 (27)
Black/African American	4 (15)
Multi-racial	1 (4)
White/Caucasian	11 (42)
Other	1 (4)
Prefer not to answer	2 (8)
Ethnicity, <i>n</i> (%)	
Hispanic	0 (0)
Non-Hispanic	23 (88)
Prefer not to answer	3 (12)
Years in practice, median (IQR)	6.5 (3.5–23)
Pediatric primary care practice characteristics	
Number of patients per year who have returned to provider's care following PICU admission, <i>n</i> (%)	
0	1 (4)
1–2	2 (8)
2–5	4 (15)
>5	19 (73)
Number of providers in practice, median (IQR)	7 (5–10)

IQR = interquartile range.

The survey findings are reported in **Table 2**. Twenty of 26 participants (77%) “strongly agreed” that primary care provider follow-up is important after a child’s PICU admission. In case studies of former PICU patients, 26 of 26 participants (100%) were “very comfortable” resuming care for a patient with a straightforward bronchiolitis PICU admission. Eight of 26 participants (31%) were “somewhat uncomfortable” and 1 of 26 (4%) were “not at all comfortable” with caring for a patient after a complex acute respiratory distress syndrome PICU admission. The

greatest barriers reported were care coordination with specialty providers (18/26, 69%), discomfort or difficulties with managing new home equipment (18/26, 69%), and inadequate or missing documentation (15/26, 58%). Seven of 26 participants (27%) were familiar with the term PICS-P and the level of familiarity ranged from “somewhat familiar” to “not at all familiar.” Over 50% of participants screened for four of five PICS-P domains. Participants noted, in free response fields, that screening was done with history and physical or the pediatric symptom checklist. Eighteen of 26 participants (88%) identified education about the specific care needs of children after a PICU admission as a resource need. Over 50% of participants noted additional resource needs included timely delivery of patient records, and case management, social work, and psychology resources. In response to the free response question on what else would be helpful when caring for children who have had a PICU admission, the main themes were timely and complete medical documentation from the hospital stay, details on managing equipment and devices, improved care coordination from inpatient to outpatient providers and with specialists, and documenting and scheduling follow-up appointments before discharge.

DISCUSSION

In this pilot study, approximately one-third of primary care pediatricians had knowledge of PICS-P. Over half of the participants screened for nearly all PICS-P domains, often through history and physical examination. Participants noted decreased comfort with the care of children with a complex PICU admission and reported numerous care barriers. Nearly all participants identified a need for further education on post-PICU care.

The findings and limitations in this pilot study are similar to a recent study of primary care PICU follow-up in Australia (9). Both studies reported low awareness of PICS-P, with only 20% aware in the Australian study (9). Both studies noted follow-up barriers. Some barriers, such as care coordination, were similar, but each study also identified unique barriers (9). Both studies also noted PICS-P screening challenges, with the Australian study championing an online parent-completed PICS-P screening tool (9). Regarding limitations, both studies had low survey response rates of less than 20% (9). Both studies also likely oversampled

TABLE 2.
Comfort, Barriers, and Post-intensive Care Syndrome in Pediatrics Screening Practices of Primary Care Providers in Care of Children After a PICU Admission

	<i>n</i> (%)
Importance of primary care follow-up after PICU admission	
Agreement with the statement “I believe follow-up with a primary care provider is important after a child’s admission to PICU”	
Strongly agree	20 (77)
Agree	6 (23)
Neutral	0 (0)
Disagree	0 (0)
Strongly disagree	0 (0)
Case studies of comfort level with providing post-PICU care	
9-mo-old child, full term and previously healthy, admitted to the PICU due to viral bronchiolitis, intubated × 3 d, discharge home at prehospital baseline functional and health status	
Not at all comfortable	0 (0)
Somewhat uncomfortable	0 (0)
Neutral	0 (0)
Somewhat comfortable	0 (0)
Very comfortable	26 (100)
9-mo-old child, full term and previously healthy, admitted to the PICU due to acute respiratory distress syndrome, required extracorporeal membrane oxygenation support × 14 d, unable to wean from ventilator, discharge home with tracheostomy, ventilator, and gtube	
Not at all comfortable	1 (4)
Somewhat uncomfortable	8 (31)
Neutral	2 (8)
Somewhat comfortable	14 (54)
Very comfortable	1 (4)
Barriers to caring for patients following PICU admission	
Inadequate or missing documentation from the hospital stay	15 (58)
Care coordination with specialty providers	18 (69)
Discomfort or difficulties with managing new home equipment	18 (69)
Discomfort or difficulties with managing increased medical complexity	14 (54)
Discomfort or difficulties in discussing new medical complexities with child’s caretakers	5 (19)
Lack of ancillary supports—social work, care management	11 (42)
Knowledge of post-intensive care syndrome in pediatrics	
Familiar with term “post-intensive care syndrome in pediatrics” ^a	7 (27)
Level of familiarity with the term “post-intensive care syndrome in pediatrics” ^a	
Not at all familiar	18 (69)
Slightly familiar	3 (12)
Somewhat familiar	5 (19)
Moderately familiar	0 (0)
Extremely familiar	0 (0)

(Continued)

TABLE 2. (Continued)**Comfort, Barriers, and Post-intensive Care Syndrome in Pediatrics Screening Practices of Primary Care Providers in Care of Children After a PICU Admission**

	<i>n</i> (%)
Screening for post-intensive care syndrome in pediatrics domains after PICU admission	
General assessment of child	23 (88)
Child's physical and functional status	20 (77)
Child's emotional and mental health	17 (65)
Child's social functioning	7 (27)
Child's return to school or educational concerns	16 (62)
Caregiver's emotional and mental health	15 (58)
Resource needs in caring for patients following PICU admission	
Education about specific care needs of children after PICU admission	23 (88)
Timely delivery of patient records from PICU admission	17 (65)
Care management resources	18 (69)
Social work resources	15 (58)
Psychology resources	14 (54)

^aThese represent questions 11 and 12. Question 11 asked "Are you familiar with the term 'Post-Intensive Care Syndrome in Pediatrics (PICS-p)'?" with a "yes/no" response. Question 12 asked "How familiar are you with 'Post-Intensive Care Syndrome in Pediatrics'?" with a Likert scale. One participant answered with inconsistent results: they responded "no" to question 11 but "slightly familiar" to question 12.

providers who regularly saw post-PICU patients and were likely motivated to participate (9). Further, both studies were single-centered survey studies, which only provided narrow data on local follow-up needs (9).

The limitations and findings of this pilot study and prior work highlight three areas that could enhance future research on primary care PICU follow-up (1, 2, 7–9).

The first area, low survey response rates, could be addressed with novel participant engagement approaches. Continuing this work, we could seek feedback on how to improve survey responses from participants who did and did not complete the pilot survey. Future studies could recruit from captive audiences including primary care providers of patients with a recent PICU discharge or providers at primary care education events. Future projects could also be developed with a collaborative group of PICU and primary care pediatricians, which could aid in participant engagement.

The second area, study design limiting broad data applicability, could be tackled with alternative study approaches. A future single-centered or multicenter survey study could aim to recruit the varied providers involved in primary care PICU follow-up, including community, academic, rural, and urban/suburban pediatricians, family practitioners, and advanced

practice providers. These findings could inform a primary care PICU follow-up guideline. Another approach is to conduct in-depth local studies using qualitative interviews with primary care providers, which could provide detailed data on local needs.

The third area, supporting primary care providers' needs, could be addressed by system-based interventions (1, 2, 7–10). Post-PICU knowledge gaps could be tackled with PICS-P education programs that are codeveloped with primary care providers. PICS-P screening gaps could be addressed by validating a PICS-P screening tool. The recently published PICU Core Outcome Measurement Set, which identified quantitative measures of PICS-P outcomes, could be used to develop a PICS-P screening tool (10). A guideline on PICS-P screening and management could be codeveloped with primary care providers. System barriers could be tackled through interventions to improve coordination across the continuum of care.

CONCLUSIONS

In this pilot study, approximately one-third of primary care pediatricians had knowledge of PICS-P. Participants noted decreased comfort in providing

care to children after a complex PICU admission and experienced numerous care barriers. Our findings suggest future research could engage improved study designs and methods, and focus on interventions to support primary care-provided PICU follow-up.

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