

Children's Drawings With Narratives in the Hospital Setting: Insights Into the Patient Experience

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ABSTRACT

OBJECTIVES: To explore PICU patients' experiences and perceptions through their drawings with explanatory narratives.

METHODS: Single-center prospective study in a 14-bed PICU in a tertiary care, academic-affiliated hospital. Pediatric patients age 6 to 17 years admitted to the PICU were approached to participate within 12 hours of transfer out of the PICU. Patients completed a brief study interview to identify the best and worst things about their PICU experience. Patients were asked to draw a picture of their experiences and then explain their drawings to study staff.

RESULTS: Forty patients (median age 11 [6–17] years) agreed to participate. The median length of PICU stay was 2 days. The best aspects of the PICU stay included staff (25%), entertainment devices (15%), and food (13%). The worst aspects of the PICU stay that were reported were the intravenous line (25%), alarms (10%), and physical discomfort (10%). The most common elements in drawings were self-depictions (88%), monitors (53%), the intravenous line (50%), registered nurses (35%), and television (33%). Patient narratives related to their drawings provided additional insights regarding patient experiences in the PICU and identified various coping mechanisms used by patients to adapt to their experiences.

CONCLUSIONS: Drawing, along with explanation, enables patients admitted to a PICU to disclose additional unique descriptive information about their experiences as patients. Facilitating this mode of communication may increase providers' awareness of positive and negative aspects of a PICU admission and may be used to improve pediatric patients' experiences in the hospital setting.

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Ms Clark designed the study and the data collection instruments, collected data, drafted the initial manuscript, conducted the analyses, and revised the manuscript; Ms Carleton designed the study, conducted the analyses, and reviewed the manuscript; Dr Cummings conducted the analyses and reviewed and revised the manuscript; Dr Noviski conceptualized and designed the study, drafted the initial manuscript, and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.



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Admission to a PICU can be traumatic, emotional, and overwhelming for patients and their families. Many factors lead to stress and apprehension for patients and their families, including unfamiliar people, painful and anxiety-producing procedures, not having one's own space, inadequate rest periods, and interruptions of routine.^{1,2}

Although patient surveys are the current standard method to assess patients on their experiences in pediatric as well as adult settings, alternative methods may provide additional opportunities to improve care. In different practice areas in pediatrics, art has been used to provide patients with a method of communication to express emotions and has been used as an opportunity to identify issues and to problem solve potential issues in their recovery.³⁻⁸

Few researchers have examined the patient experience of PICU hospitalization through patient drawings. Insight gained from pediatric patients' illustrations and descriptions of their PICU experiences may provide information for PICU staff to modify the care provided or explain its necessity. Additionally, understanding how pediatric patients perceive a PICU admission may be used to formulate and implement different interventions to improve the overall experience of a patient admitted to a PICU and, in a larger sense, any pediatric patient admitted to the hospital. We describe insights into the patient experience learned from providing PICU patients with the opportunity to draw and explain their experience from their pictures.

METHODS

We prospectively enrolled eligible patients admitted to a single-center, 14-bed PICU in a tertiary care, academic-affiliated hospital over a 6-month period. The study was approved by the Partners Human Research Committee (PHRC).

Per the PHRC, the researchers were asked to obtain consent from the patient's parent or guardian. If consent was obtained, the researcher was allowed to approach the child and read a script to the child, briefly describing the study. The script was approved by the PHRC, and the child's

willingness to draw was considered as implied assent. If the parent provided consent and the child objected for any reason, no further discussion took place. The lead investigator conducted all of the interviews with the patients who agreed to participate. The lead investigator was not known to the patients before approaching the children and their families regarding participation, nor was she part of the patient's clinical team.

Eligibility included PICU admission for at least 24 hours, and the interview was performed within 12 hours of transfer or discharge out of the PICU, which implied that the patients were no longer critically ill and were well enough to be considered for discharge. Predefined exclusion criteria included age <6 or >17 years, objection to the study by the patient or parent or guardian, patient inability to draw (ie, severe developmental delay or patient was mechanically ventilated), and the attending physician feeling that study participation would interrupt the care of the patient.

Patients were asked to answer the following 2 questions: (1) "What was the best thing about your PICU experience?" and (2) "What was the worst thing about your PICU experience?" They were then asked to draw a picture of what it was like to be a patient in the PICU. Patients were informed that their anonymity would be maintained and that no study information would be shared with any of the clinical staff caring for them; therefore, they could choose to draw or speak about positive and negative aspects of their admission. If a patient did not provide an answer, that patient was not prompted to do so, and that data was considered missing.

Each patient was given an 8.5- × 11-in sheet of white paper with the choice of a 20-pack box of markers in a variety of colors or a pencil. The investigator told patients that they would have a period of 60 minutes of uninterrupted time to complete their drawings but that the investigator would return in ~15 minutes to see if they had any questions. The patient's bedside nurse assisted in ensuring that the drawing time would be uninterrupted. Additionally, the

investigator remained at the nurse's station to monitor the patient's room to ensure that there were no interruptions.

After completion, patients were asked to explain their drawings so that they were interpreted by study staff as the patients intended. The verbal explanation provided by the patient served as a narrative to accompany each patient's drawing for subsequent analysis. For standardization purposes, all patient requests for drawings were completed by the same study staff member.

To determine common categories, drawings were analyzed regarding the following: content, personification (individuals represented in the drawing), facial expression (expression of the patient and/or individuals represented in the drawing), physiologic representation; medical technology (monitors, alarms, and medical equipment), technological devices (television, cellular phone, and video game use), color content, and words or phrases included in the drawings. An additional analysis included coding of the accompanying narratives, and documentation of categories was completed on the basis of patients' explanations of their drawings and their verbal responses to study questions. Drawings were analyzed by the lead investigator and the art therapist separately and then reviewed by the principal investigator.

RESULTS

Forty patients age 6 to 17 years were enrolled in the study. Demographic data for the study sample are presented in Table 1. The most common categories in drawings were depictions of self (88%) followed by hospital monitors (53%), the intravenous (IV) line (50%), nurses (35%), television (33%), parent(s) (23%), physicians (5%), and food-service workers (5%).

Table 2 provides information regarding patient's verbal responses regarding their PICU experience. When patients were asked to choose "the best thing about your PICU experience," the PICU clinical staff was the most common response (25%) of patients. The response most frequently voiced by patients (25%) when asked about "the worst

TABLE 1 Demographic Data

Characteristic	Results
Age, y, median (range)	11 (6–17)
Length of stay, y, median (range)	2 (2–6)
Sex, <i>n</i> (%)	
Male	21 (52)
Female	19 (48)
Diagnosis, <i>n</i> (%)	
Respiratory	17 (43)
Cardiovascular	9 (23)
Neurologic	4 (10)
Metabolic	4 (10)
Hematologic	4 (10)
Postoperative	1 (2)
Other	1 (2)

thing about your PICU experience” was IV therapy.

Thirty-five (88%) patients included themselves in their drawings. Of the 35 patients who drew themselves, 11 included their facial expressions. Patients were asked by study staff to clarify facial expressions to ensure that the expression depicted was interpreted by study staff as the patient intended. Ten patients depicted themselves with a smile on their faces; however, only 1 (10%) of these patients verbally described themselves as happy. Nine (23%) patients described their facial expressions as scared, and 9 (23%) patients depicted

themselves as sad. Six (15%) patients described their facial expressions as angry.

Ten (25%) patients reported that IV therapy was the worst part of their PICU experience, and 20 (50%) patients included the IV line in their drawings. Three patients drew the IV needle as large and described it as the focus of their drawing. See Fig 1 A and B for examples (Fig 1A: 6-year-old boy with a respiratory diagnosis; Fig 1B: 11-year-old girl with a respiratory diagnosis). In Supplemental Fig 3 (6-year-old girl with a respiratory diagnosis), the patient drew a red mark, representing the IV tubing, and a large black mark, representing the puncture site.

Technology (defined as television, video games, cellular phone, and laptop) was a prominent category in patient drawings. Eighteen (45%) patients noted technology as having a significantly positive influence on their PICU stays. Two patients noted that the absence of technology (unavailability of video games) had a negative impact on them during their admissions. Patients noted television as something they relied on as a distraction. Three (8%) patients reported that their phones (texting and phone calls) were their connection to their friends and family and helped decrease the feeling of isolation while in the PICU.

Assigning meaning to food was exemplified in 4 patient drawings in which the patients chose food as the best thing about their

PICU experience. One patient, whose family was homeless and lived in a shelter, expressed how important having access to food was to him (Supplemental Fig 4A; 8-year-old boy with a respiratory diagnosis).

For 1 of the patients, the food-service provider in the PICU represented social interaction. The patient's parent could not be at the bedside, and she described herself as “feeling isolated.” The patient reported that talking with the food-service provider was something she looked forward to every day (Supplemental Fig 4B; 17-year-old girl with a respiratory diagnosis).

The role of colors used in the patients' drawings was a less obvious, but important, factor and was understood more clearly when patients explained their drawings. In Supplemental Fig 5A (10-year-old girl with a cardiac diagnosis), the patient chose a background of blue and purple in her drawing. She said the colors were pretty, but to her, they actually represented “sadness...they are sad colors.”

In Supplemental Fig 5B (16-year-old girl with septic shock), another patient depicted a gradation of colors in her drawing to reflect her feelings. The beeping of the alarms was a constant distraction and was “annoying,” so she drew the monitors and wires in red. The color blue represented the positive; thus, PICU nurses checking in on her were drawn in blue. Green was neutral; she wrote in green that she was extremely hungry;

TABLE 2 Children's Verbal Responses Regarding PICU Experience

	Themes	<i>n</i> (%)
Most common theme in verbal response to the question, “What was the best thing about your PICU experience?”	PICU staff (physician, nurse, food-service provider)	10 (25)
	Technology (television, video games, cellular phone, laptop)	6 (15)
	Food	5 (13)
	Nothing	4 (10)
	Getting to eat or drink after NPO status	3 (8)
Most common theme in verbal response to the question, “What was the worst thing about your PICU experience?”	IV therapy	10 (25)
	Alarms	4 (10)
	Physical pain and/or discomfort	4 (10)
	Nasal cannula	3 (8)
	Missing family (parents, siblings)	3 (8)

NPO, nothing by mouth.

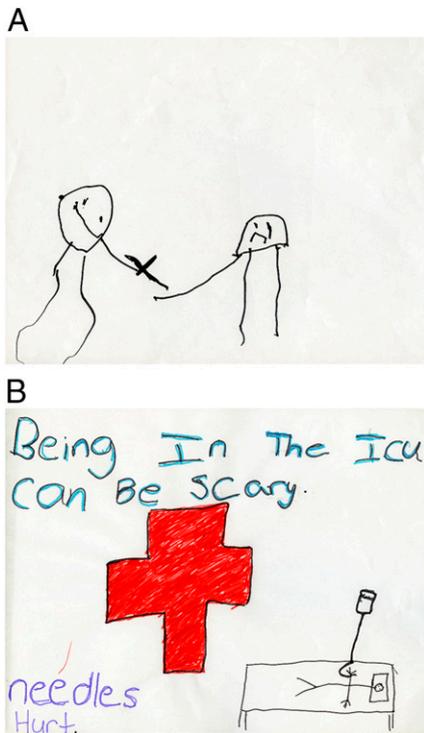


FIGURE 1 A, Fear of IV needle. B, Fear of IV needle.

however, when asked why that was drawn in a neutral color, she said that she understood the reason she could not eat (nothing by mouth before surgery), so it made her discomfort more tolerable. In Supplemental Fig 5C (11-year-old boy with a gastrointestinal diagnosis), the patient drew his entire drawing in red because red was the color of blood, reflecting his preoccupation with his IV line.

Another patient's drawing exemplified the importance of communication and of understanding the patient's perspective. In her drawing, the patient depicted a doctor coming into her room with a "large plate of green and red pills" (she explained that this is how it felt to her). She said that the pills looked like candy but that it did not "feel" like eating candy. The patient explained that the doctor was enthusiastic and hopeful, so the patient depicted herself as having a smile on her face to please the physician, but she was actually thinking "no" and was resistant to the potential of more medication. When asked to explain further, the patient said that she had to keep a smile

on her face so that no one would be upset with her, but she was angry that she had to "take all of these different medications and no one could figure out what was wrong with me" (Fig 2; 14-year-old girl with a cardiovascular diagnosis).

The patients interviewed were acutely aware of what was happening in their immediate environment (hospital room) and were observant of individuals who were present. Even the patients who might be perceived as preoccupied (ie, patients who were experiencing pain or fatigue) were able to express their interpretations of others' feelings in their drawings. Examples of this include the expressions depicted on the faces of patients' parents as well as on the faces of staff. One patient drew herself asleep in bed, 1 parent lying down, and the other parent sitting in a chair (Supplemental Fig 6A; 6-year-old girl with a respiratory diagnosis). In the drawing, she depicted both parents with wide eyes. When asked, the patient explained, "My parents are very worried about me. I know they watch me when I'm asleep...all night, I don't think they shut their eyes." In Supplemental Fig 6B (16-year-old girl with a neurologic diagnosis), the patient drew her parents at

the bedside, and their worry and concern was depicted as a straight line to represent their mouths. Despite being in a significant amount of pain, the patient explained that she felt bad about causing distress to her parents.

DISCUSSION

In our study, we describe a unique combination of PICU patients' drawings and the accompanying narratives. It was clear from the explanations provided by the patient narratives that their drawings could easily be misinterpreted without their explanation. Engaging the patients to draw their experiences in the PICU and then communicating with the patients about their drawings enabled patients to express emotions and frustrations, enabled patients to be heard and validated, and enabled patients to potentially improve their PICU experiences.

The patients in our pilot study were interviewed 12 hours before being discharged to the floor or from the hospital; thus, at the time of the interview, the patients were not critically ill, which could indicate that our findings may be generalizable to some patients on the



FIGURE 2 "If the meds don't work, we'll add more."

pediatric ward. The median length of stay was 2 days, and no patients interviewed were mechanically ventilated or on pressor support during their PICU admission; thus, the population was not critically ill at the time they were interviewed for the study.

The patient experience has become a crucial component of care quality and reimbursement. Pediatric patients may not effectively express their experiences, either because of lack of language or lack of reflection regarding how they feel. In addition, pediatric patients may feel that there is neither an understanding nor an acceptance that children are, in fact, experts on their own lives and are capable of meaningful participation in matters that affect them, particularly in a hospital setting. Assisting with the revelation of their experiences may bolster the confidence they have in their own capabilities to manage difficult situations,^{9,10} such as a PICU admission.

Patient surveys are often the standard approach to assess patients regarding their experiences; however, some disciplines have revealed expression through art as a mode of communication that works well in a pediatric population. The literature reflects that pediatric oncology and pediatric palliative care practices have long understood the value of art-based methods and the value of art therapy as an effective method of communication for the patient. Given the sense of vulnerability often felt by the pediatric patient, particularly in an intensive care setting, we felt that this mode of communication might be advantageous. In addition, art created by the patient is often believed to provide insight that would not have been possible given pediatric patients' potential inability to accurately express themselves verbally because of their sense of vulnerability or their command of language.

Our study revealed information about the patients' experiences that helped the PICU staff learn more about how practices in the PICU affect patients. The experiences detailed in drawings and narratives provide PICU staff with an opportunity to improve the care provided, including by (1) enhancing positive experiences noted by

patients, (2) addressing negative experiences and making changes or adjustments to clinical practices (when possible), and (3) engaging in communication with patients to both educate as well as learn from them.

Pediatric patients are aware of their environment and are able to clearly voice what is important to them¹¹ when given a mode of communication with which they are comfortable. Because patients were able to explain the details of their drawings and the meaning behind what they chose to draw, it was an opportunity for patients to disclose information that they otherwise might not have shared. The knowledge gained was a result of learning the meaning behind what the patients drew. The patients were more than willing to share these details; they just needed to be asked. Small adjustments to PICU practice could result in a positive effect on individual patients.

Our study revealed that there are many ways in which educating patients about typical practices in the PICU might address some of their concerns. Some practices may be changed, but for many patients, knowledge of why certain practices are followed would, at the least, reduce frustration. One patient noted that "the beeping and alarms were going off all night while I was trying to sleep. It seems like it's the opposite of what they're trying to do, which is to let kids sleep and get better." Another patient reported that her understanding of what the ICU stood for was "I see you....every 30 minutes. How am I supposed to sleep?" Explaining to patients why the alarms and the monitors make a beeping noise and how they help alert staff, explaining what the ICU stands for, and explaining that a necessary part of intensive care is overnight monitoring would help pediatric patients understand their care. It may help alleviate some frustration or anger patients feel when they are enduring something that, from their perspective, is not necessary.

Educating children regarding how the PICU staff cares for patients is a simple, effective tool that can be easily implemented by all staff. Educating and also learning from PICU patients validate the sense that they are seen as patients, not just children, implying that although they are children, they should

still be able to participate in their medical care and provide feedback to their clinical team, as would any adult patient.

Understanding the patients' thought processes when explaining their drawings proved to be insightful. The seemingly simple choice of what colors to use in a drawing, the effect of a relatively benign interaction with a physician who did not smile, and the importance of the hospital menu and meal delivery are examples of how much pediatric patients interpret actions and assign meaning to what they experience. These patients' emotional responses are based on these experiences, and the most critical factor is that their thought processes are not self-evident.

There were no incidences of psychological distress reported by any of the patients to either the interviewer or the clinical team caring for the patient. The attending physician on service in the PICU and the patient's bedside nurse were aware of the patient's participation in the study and were asked to report any concerns or adverse events to the study staff. Anecdotally, the interviewer found that the patients who participated found the exercise of drawing their experiences to be therapeutic and valued the opportunity to express themselves to an individual who was not part of their clinical care team.

Our study limitations included the following: (1) a small sample size, with only 40 patients enrolled; (2) 1 location, a PICU, but no enrollment in the pediatric wards or other floors; (3) patients who were no longer critically ill at the time of the study interview (although the patients were admitted to an ICU); and (4) lack of a standardized approach to analyze qualitative data.

CONCLUSIONS

Drawing as a means of communication enables patients admitted to a PICU to disclose information about their experiences that they may not have been comfortable expressing otherwise. Facilitating drawing and obtaining narratives may be a cost-effective and time-efficient method to improve patient care in a PICU setting by increasing providers'

awareness regarding both positive and negative aspects of a PICU admission through the patient's perspective. Standardizing this form of communication may have a future role in how we evaluate provision of pediatric care. We have shared the results of the study with PICU staff and are considering developing an educational in-service training on the basis the results of the study. Plans for future studies involve research with pediatric patients on the wards.

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