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## Provider Emotions Surrounding Clinical Deterioration Events and the Associated Impact of Pediatric Early Warning Systems in Hospitalized Pediatric Oncology Patients

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By

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An abstract of

A thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of Master of Public Health in Global Health, 2020 Abstract

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## By Emily T. Giannars

INTRODUCTION: Pediatric oncology patients have a high rate of clinical deterioration and often require critical care. Patient deterioration events are distressing for providers, and little is known about how Pediatric Early Warning Systems (PEWS) impact provider emotional responses to deterioration events. The aim of this sub-analysis was to examine provider emotions around clinical deterioration events and assess PEWS impact on emotions.

METHODS: Semi-structured interviews were conducted with 83 nurses, pediatricians, oncologists, and intensive care providers who had recently participated in a patient clinical deterioration event at St. Jude Research Hospital (N=42 participants) in Memphis, Tennessee or at Unidad Nacional de Oncología Pediátrica (N=41 participants) in Guatemala City, Guatemala. Interviews were conducted in the participants' native language (English or Spanish), transcribed, and translated into English. Each transcript was coded by two researchers and analyzed for thematic content using MAXQDA software.

RESULTS: Emotions around patient deterioration, including concern, fear, and frustration, were reported across all disciplines at both hospitals. Three themes emerged from data analysis including topics regarding provider emotions around deterioration and care escalation, impact of PEWS on emotions, and confidence and clinical judgment. Elevated PEWS were concerning for intensive care providers, floor providers, and nurses. The concern resulted in increased provider alertness and attention. Persistently elevated PEWS scores resulted in various emotions, including a misleading sense of comfort. PEWS scores were linked to increased confidence in clinical judgment among nurses from both institutions. However, nursing judgment did not transcend objective evidence at UNOP. While most of the emotions expressed by providers were negative, some positive emotions, including comfort and understanding, manifested. Emotions expressed did not differ based on hospital resource-level.

CONCLUSIONS: Providers experience a range of emotions when faced with clinical deterioration. Elevated PEWS scores can exacerbate concern among providers by indicating that a patient is sick, but PEWS also instill an autonomy among nurses to escalate care. Studying provider emotions can enhance provider's course of treatment and patient care around clinical deterioration events.

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#### **CHAPTER 1: Introduction**

### **1.1 Introduction and Rationale**

Cancer is one of the leading causes of death among children globally and the cause of cancer among children remains widely unknown1. While children in general are considered a vulnerable population, pediatric oncology patients are particularly vulnerable due to their illness and toxicity of treatment2-3. These patients often decompensate and necessitate critical care interventions, such as mechanical ventilation and blood pressure support2-4. Among pediatric oncology patients, almost half will require admission to the Pediatric Intensive Care Unit (PICU) over the duration of their illness in order to receive life-sustaining interventions5. The timeliness of this transfer impacts patient chance of survival and positive outcomes. Identification of the need for PICU admission earlier in the course of illness has the potential to improve outcomes in pediatric oncology patients, while delays in recognition and intervention significantly increase the risk of mortality2.6.

The identification of clinical deterioration is often difficult in the pediatric oncology population because the warning signs and symptoms are variable, non-specific, and can go unrecognized<sup>7</sup>. Medical providers from all disciplines must use their clinical judgment to determine the severity of a child's status, but these skills are not always able to detect decompensation in a timely manner<sub>6</sub>. This is because it is based on subjective assessment that stems from each provider's level of expertise, knowledge, critical thinking skills, and decisionmaking abilities. Provider emotions can bolster, or impede, these skills and abilities. There has been research supporting the notion that provider emotions affect clinical judgment and decisionmaking, but the interplay between objective measures, such as Pediatric Early Warning Systems (PEWS), and provider emotions has not been considered as a factor in the treatment process<sup>8-12</sup>.

PEWS are clinical acuity tools that have been validated for use in the pediatric oncology population<sup>2</sup>. PEWS supplement clinical judgment and mitigate subjective issues by providing a standardized alert system that predicts adverse events before they occur. The systems utilize an escalation algorithm based on physiological and behavioral parameters to calculate a score disclosing a patient's risk of deterioration, thereby providing a standardized method aimed at helping providers recognize children with a higher chance of decompensating. While these objective measures minimize the influence of subjective factors (i.e., provider emotions), their presence is not entirely eliminated during patient clinical deterioration events. It is important to consider how provider emotions during deterioration events impact clinical judgment because it can subsequently affect patient care and safety.

The pediatric oncology population is inherently dependent on the decisions made by their medical providers, underlining why it is essential to study how providers' emotions can affect their clinical judgment. The provider plays a central role in the treatment provision that results in either a positive or a negative outcome. Emotions such as anger or high levels of stress can influence how attentive a provider is to their patient. Some emotions, such as worry, can increase attentiveness, while emotions such as anger can decrease attentiveness. PEWS, however, is based upon vital signs and other objective factors; the presence of a higher PEWS score can elicit emotions that increase provider attention. However, there can still be instances when providers decide not to prioritize a child based upon PEWS. There is a complex relationship between PEWS, provider emotions, and patient clinical deterioration that, to our knowledge, has not been explored yet. Research better targeted at understanding the interplay between these factors, as

well as the impact on patient safety, can serve to inform evolving safety measures to benefit this vulnerable population.

Furthermore, the context in which PEWS is used should be examined because there are differences that arise when the same tool is applied in high-income countries versus low- or middle-income countries (LMICs). Human resources, technological advances, and social contexts will affect how the tool is utilized and may impact the manifestation of emotions. Pediatric oncology wards in LMICs have less resources than wards in high-income countries, and the tools vary slightly between sites. Therefore, the emotions that arise among providers may vary depending upon resource-level. This should be considered in the framework of implementing PEWS, supporting providers, and improving patient care across various contexts. Research to better understand the influences on clinical decision-making can serve to inform developing PEWS implementation and clinical deterioration by determining the role of emotional affect has yet to be examined in great depth.

## **1.2 Problem Statement**

Most of the literature on cancer-related emotions is patient-focused, and supports the idea that providers should adapt to patient's emotional needs13. Frequently, clinicians concern themselves solely with the emotions of their patients while neglecting to explore their own feelings. However, it is imperative to recognize that clinicians experience a variety of emotions as they treat patients, particularly when patients have life-threatening illnesses or when treatment is not effective13. It is essential for clinicians to have an appropriate level of self-awareness pertaining to their emotions and the ability to acknowledge and manage these emotions effectively because unregulated or poorly managed emotions can lead to clinician stress and burnout, which have both been shown to have a negative impact on quality of care13.

Furthermore, clinician opinion is affected by practice variation. Patients may not receive the exact same amount of care from an individual provider. For example, a patient who is seen on a provider's morning shift may be treated differently than a patient who is seen by the same provider at 2 a.m. Patient care may also vary across providers. Dr. X may use more simple language and verbal inflection to deliver treatment options, while Dr. Y is more tacit and straightforward about the patient's treatment. PEWS are intended to standardize the process of care and aid clinical decision-making by providing objective insight regarding patient status. Scores produced by these systems, however, should be used in concordance with clinical judgment to influence treatment provision, mainly because there are flaws in both methods that can fail to detect a deteriorating patient. PEWS may not always capture the state of the patient because there are patients whose vital signs may not accurately project their status. Their vital signs may be stable, but there could be other factors influencing the decline that aren't detected by the escalation algorithm. On the other hand, provider opinion is prone to human error. When used together, PEWS and provider judgment provide patient care that is standardized yet individualized and the methods support one another. However, the direct impact of these interventions on providers and patient safety is not widely known. It is pertinent to understand the impact of PEWS on provider emotions so the process can be improved for the sake of patients as well as providers.

## **1.3** Purpose Statement

This study will utilize qualitative research methods to enrich the body of knowledge concerning provider emotions, PEWS, clinical deterioration, and patient safety. Qualitative assessment utilizing in-depth interviews and thematic analysis can initiate a closure in the present knowledge gap by exploring the impact of interventions such as PEWS on provider emotions and subsequent decision-making. In addition to informing implementation and continuing refinements concerning the utilization of PEWS in the pediatric oncology population, this research will embody a novel contribution to a wider body of research on PEWS, pediatric oncology care, and influences on providers that impact patient care and safety.

#### 1.4 Research Objectives

To inform public health initiatives to improve patient safety among pediatric oncology patients, this qualitative study seeks to fulfill the following objectives:

- To explore the relationship between PEWS and provider emotions
- To determine the interplay between PEWS, provider emotions, and clinical deterioration
- To describe the impact of PEWS and provider emotions on patient care and safety

### **1.5** Significance Statement

Pediatric cancer is often fatal or linked to chronic disability. In 2017, pediatric cancer resulted in an estimated 11.5 million disability-adjusted life-years (DALYs). Of these, yearly lives lost (YLLs) accounted for 97.3% and 2.7% came from years living with a disability (YLDs)14. The

importance of improving risk-reduction strategies such as implementation of PEWS is pronounced because early intervention and outcome prediction can prevent disability and death. Since providers play such an integral role in the utilization of PEWS and the handling of patient clinical deterioration, it is important to examine emotional factors that may affect usage of the tool, adherence to PEWS score policies, clinical decision-making, and ultimately patient care and safety.

The context of where PEWS is utilized is also important to acknowledge because cancer is a large burden on a global scale, regardless of resource level. The burden of cancer is prominent in low- and middle-income countries, where the majority of cancer cases occur, but also in high-income countries where it is one of the top causes of mortality among young children behind trauma2,15. The variance in resources, as well as the differences in the usage of PEWS tools make for an interesting and applicable comparison of emotions expressed among providers in low-resource settings versus high-resource settings.

### **1.6 Definition of Terms**

Pediatric Early Warning Systems (PEWS): nursing-administered clinical acuity tools associated with escalation algorithms that improve early identification of clinical deterioration
Escalation Algorithms: rescue system triggering physician assessment or rapid response team
Decompensation/Deterioration: defined by Padilla and Mayo (2018) as the loss of the ability to maintain homeostatic function physiologically or psychologically

**Low-or Middle-Income Countries (LMICs):** defined by the World Bank as countries with Gross National Index (GNI) per capita of less than \$12,536 in 2019

**High-Income Countries:** defined by the World Bank as countries with GNI per capita of more than \$12,535 in 2019

**Clinical Judgment/Decision-making:** Tanner (2006) defined clinical judgement as "an interpretation or conclusion about a patient's needs, concerns, or health problems, and/or the decision to take action (or not), use or modify standard approaches, or improvise new ones as deemed appropriate by the patient's response"

**Patient Safety:** in 2017 the World Health Organization defined patient safety as "the absence of preventable harm to a patient during the process of health care and reduction of risk of unnecessary harm associated with health care to an acceptable minimum"

#### **CHAPTER 2: Literature Review**

## 2.1 Pediatric Oncology and PEWS

Pediatric oncology patients are a particularly complex and challenging population. They have a high rate of clinical deterioration and often require critical care due to the nature of their illness and toxicity of treatment<sub>2-3</sub>. Moreover, they have significantly worse outcomes when compared to other critically ill children. A systematic review of 31 observational studies over the past three decades showed that the death rate of pediatric oncology patients admitted to the PICU is high (28%), five-fold higher than mortality among the general PICU populations. However, studies have shown that early escalation of intensive care support, as opposed to intervention following multi-organ failure, significantly improved survival among pediatric oncology patients. When deterioration is recognized in the early stages and the patient is appropriately admitted to the ICU, their chances of survival increase. Conversely, deterioration occurring following patient admission to a non-critical care setting (i.e., the floor) is associated with an increased risk of death<sub>18</sub>.

However, the decision to admit a patient to higher care is not always a simple or clear-cut choice. It takes a variety of skills including experience, clinical judgment, and autonomy in order to accurately escalate a patient's care. Transferring a patient to the Intensive Care Unit (ICU) from the floor is often based on subjective assessment, fraught with opportunity for human error in the diagnosis and management of critically ill patients<sup>19</sup>. In the late 1990s, it was recognized that deteriorating adult patients were not being appropriately identified and treated, leading to deaths caused by conditions other than the primary illness<sup>7</sup>. This compelled hospitals to implement Early Warning Systems (EWS)<sup>7</sup>. EWS is a bedside scoring system combined with an

escalation algorithm designed to detect patient critical deterioration. EWS scores can be easily calculated on the floor by nurses and other caregivers<sup>19</sup>. Hospitals implemented EWS to detect deterioration at an earlier time interval and intervene appropriately, and these systems resulted in improved survival outcomes among patients<sup>7</sup>.

In 2006, pediatric health care providers developed PEWS, the pediatric adaptation of EWS, in order to improve pediatric patients' outcomes through early detection and intervention. The PEWS scoring process involves assessing a patient's neurologic, cardiac, and respiratory status utilizing a score for each category and adding them to a composite score with portrays the child's overall risk level?. This is usually done every four hours with vital signs. A higher score denotes a higher level of risk. Calculating this score increases provider awareness and encourages early conversations between care providers about the patient's status and potential need for intervention<sub>20</sub>.

## 2.2 The Role of PEWS in Early Identification

Research has shown that, when compared to controls, patients requiring PICU transfer often have variations in their PEWS scores as early as 24 hours prior to transfer, with a particularly significant increase occurring approximately 11 hours preceding PICU admission2. The purpose of PEWS is to prevent critical deterioration events and unplanned PICU transfer from occurring in the first place. PEWS have been shown to decrease the occurrence of clinical deterioration events among pediatric inpatients at hospitals utilizing PEWS (0.5 per 1000 patientdays) in comparison to standard of care hospitals (0.84 per 1000 patient-days)<sup>21</sup>. PEWS provide the opportunity for providers to recognize signs and symptoms of deterioration before more obvious signs occur (i.e., a drastic drop in blood pressure) and to initiate treatment before the patient becomes more ill.

The early identification component of patient care is especially important among the pediatric oncology population because delayed intervention has dire consequences. If patients are not identified to be at risk, there is no consideration of care escalation or admission to the ICU and care is delayed. A study on pediatric patients evaluating the use of electronic Cardiac Arrest Risk Triage (eCART), a modification of EWS, found that delayed ICU transfer was associated with increased in-hospital mortality (33.2% vs. 24.5%, p<0.001) and longer hospital stay. The relationship between mortality and delayed transfer was linear, with each one-hour increase in transfer delay associated with a 3% increase in the odds of in-hospital death19. However, it is important to understand that there are many factors that affect the timeliness of transfer. ICU bed availability, clinician identification of the deterioration, and clinical judgment regarding the appropriate transfer thresholds are factors encompassed by variability and changes19.

## 2.3 PEWS and Clinical Judgment

PEWS scores are intended to supplement, rather than replace, provider judgment and expertise7,22-23. In practical settings, providers utilize their intuition and judgment to make decisions regarding patient treatment. A provider's "gut feeling," described as the incorporation of knowledge, experience, and information pertaining to the patient, can influence these decisions24. An objective measure, such as a PEWS score, can encourage providers to further question clinical decisions or, alternatively, reinforce their choices in care. PEWS scores oftentimes support clinician judgment, so providers feel more confident in their decision. Conversely, PEWS may signify an outcome that deviates from what the provider feels will happen. These occurrences can urge providers to re-assess the patient and investigate why PEWS is scoring the patient this way, which increases the provider's awareness regarding the patient.

Qualitative studies examining the experiences of providers using PEWS demonstrate factors that may augment or hinder the use of PEWS in clinical settings. Jensen et al. (2018) conducted five focus group discussions divided by specialty (i.e., pediatric oncology and hematology, orthopedic surgery, abdominal surgery, cardiology, nephrology, etc.) among 23 nurses with direct experience using PEWS. In this study, participants identified PEWS as one way to assess patients and clinical judgment as another method, with the two weighing against one another. Some of the nurses felt that using a standardized method of measurement deflected their natural intuition or made them feel that their opinion was not valuable25. Furthermore, there are qualitative studies that examine the provider perspective on how useful PEWS are. Findings from Bonafide et al. (2013) revealed that, even among those who experienced EWS score failures, providers defined extensive benefits in using the tools to identify deteriorating patients as well as surpass care escalation barriers by serving as an objective communication tool.

## 2.4 Emotional Influences on Provider Judgment

Pediatric oncology is inherently an emotionally challenging clinical field. Providers are often faced with high-stress situations, medical uncertainty, life-altering diagnoses, and the death of patients<sub>26-27</sub>. All of these factors can stimulate an array of emotional responses. Providing quality care encompasses integrating these emotions (i.e., fear, surprise, anxiety, and shame) constructively as opposed to detaching from them<sub>28</sub>. It is important to find the right balance of emotional expression for providers and facilitate a tailored approach to patient care because each individual might have varying preferences on how they receive that care29. Furthermore, there is a vast amount of research supporting the concept that provider emotions affect clinical judgment and decision-making8-12. This effect can be positive or negative, depending upon the type of emotion and intensity of the emotion. For example, gut-feelings can detect clinical deterioration prior to it occurring, even if the PEWS score itself is not elevated. However, unregulated or poorly managed emotions can lead to clinician stress and burnout, which have been shown to have a deleterious impact on quality of care13.

Relatively few studies have focused on the emotions of the clinician, but insufficient emotional intelligence skills may lead to unexamined biases, errors in practice, and confusion between the emotional needs of the patient and those of the clinician<sub>13</sub>. Moreover, emotional suppression and mismanagement can affect the provider's response to the patient's condition as well as the effectiveness of their clinical decision-making skills. Emotional suppression has the capacity to affect a provider's ability to make sound, logical decisions regarding patient course of treatment, thus compromising patient safety. Emotions are an important cognitive resource for clinicians to utilize because emotions can enhance provider understanding of the patient and open up empathetic reserves to deliver quality health care<sub>28</sub>.

In general, there is limited research on provider emotions and there is even less research regarding the impact of clinical acuity tools like PEWS on these emotions, particularly in the context of pediatric oncology and LMICs. Emotions have emerged as an important factor influencing patient care and safety in lieu of clinical judgment. Further qualitative research and mixed-methods analyses involving provider emotions in various contexts are needed in order to

#### **CHAPTER 3: Manuscript** (Prepared for JCO GO)

**TITLE:** Provider Emotions Surrounding Clinical Deterioration Events and the Associated Impact of Pediatric Early Warning Systems in Hospitalized Pediatric Oncology Patients

#### ABSTRACT

INTRODUCTION: Pediatric oncology patients have a high rate of clinical deterioration and often require critical care. Patient deterioration events are distressing for providers, and little is known about how Pediatric Early Warning Systems (PEWS) impact provider emotional responses to deterioration events. The aim of this sub-analysis was to examine provider emotions around clinical deterioration events and assess PEWS impact on emotions.

METHODS: Semi-structured interviews were conducted with 83 nurses, pediatricians, oncologists, and intensive care providers who had recently participated in a patient clinical deterioration event at St. Jude Research Hospital (N=42 participants) in Memphis, Tennessee or at Unidad Nacional de Oncología Pediátrica (N=41 participants) in Guatemala City, Guatemala. Interviews were conducted in the participants' native language (English or Spanish), transcribed, and translated into English. Each transcript was coded by two researchers and analyzed for thematic content using MAXQDA software.

RESULTS: Emotions around patient deterioration, including concern, fear, and frustration, were reported across all disciplines at both hospitals. Three themes emerged from data analysis including topics regarding provider emotions around deterioration and care escalation, impact of PEWS on emotions, and confidence and clinical judgment. Elevated PEWS were concerning for intensive care providers, floor providers, and nurses. The concern resulted in increased provider alertness and attention. Persistently elevated PEWS scores resulted in various emotions, including a misleading sense of comfort. PEWS scores were linked to increased confidence in clinical judgment among nurses from both institutions. However, nursing judgment did not transcend objective evidence at UNOP. While most of the emotions expressed by providers were negative, some positive emotions, including comfort and understanding, manifested. Emotions expressed did not differ based on hospital resource-level.

CONCLUSIONS: Providers experience a range of emotions when faced with clinical deterioration. Elevated PEWS scores can exacerbate concern among providers by indicating that a patient is sick, but PEWS also instill an autonomy among nurses to escalate care. Studying provider emotions can enhance provider's course of treatment and patient care around clinical deterioration events.

**KEY WORDS:** pediatric, oncology, early warning systems, PEWS, emotions, qualitative research

#### INTRODUCTION

Children who unexpectedly decline in hospitals often show signs and symptoms of declining status in the 24 hours preceding actual decompensation2,25,30. Early detection strategies, such as Pediatric Early Warning Systems (PEWS), are instrumental in preparing for, and preventing, rapid decline among hospitalized pediatric patients. PEWS are nursing-administered clinical acuity tools that utilize escalation algorithms to facilitate early detection of children at-risk of decompensation. PEWS are important for pediatric oncology patients because they have a high rate of clinical deterioration and often need critical care2-3. During the course of their illness, approximately 40% of pediatric oncology patients will require admission to the Pediatric Intensive Care Unit (PICU). PEWS are frequently used to aid in early recognition of clinical deterioration, and have been identified as a top research priority to improve clinical care of these patients2, 5, 7, 32.

Pediatric cancer is a global health issue, with most of the burden falling on LMICs. Annually, more than 160,000 children are diagnosed with cancer, with approximately 80% of those diagnoses occurring in countries with limited resources15. While there is limited data on the use of PEWS in resource-limited hospitals, studies have shown that PEWS help providers accurately recognize warning signs of clinical deterioration regardless of resource-level33-34. PEWS implementation in resource-limited pediatric oncology hospitals has been shown to reduce clinical deterioration events, hospital costs, and improve interdisciplinary communication20, 35-36.

Clinical deterioration events impact patient outcomes and are stressful to bedside teams. Beyond objective measures of deterioration, such as vital signs, subjective components, such as clinical judgment, are essential components of patient assessment. For these reasons, it is particularly important to explore provider emotions, as emotions have been shown to impact decision-based outcomess-12. Caring for vulnerable or deteriorating patients influences providers' emotions in a myriad of ways and can affect judgment and care. PEWS may alter a provider's approach when evaluating and managing a patient, but it remains unclear how this impacts provider emotions and affects patient care and safety. It is also not known if these emotions vary based upon hospital resource-level. The aim of this study is to investigate the relationship between PEWS and pediatric oncology provider emotions surrounding deterioration events in two hospitals of different resource levels. Our goal is to inform PEWS implementation and global patient safety improvement efforts and explore the impact of these systems on provider emotions to improve provider experiences.

#### METHODOLOGY

Pediatric oncology providers from various disciplines were interviewed at Unidad Nacional de Oncología Pediátrica (UNOP) and St. Jude Research Hospital (SJCRH), two freestanding hematology-oncology hospitals, during fall of 2018. The methods of this study have been previously described<sub>20</sub>. Eligibility criteria was based on providers' involvement in recent patient deterioration events, defined as unplanned patient transfer from the inpatient ward to ICU, in the 8 weeks prior to interviews being conducted.

#### Setting

UNOP is located in Guatemala City, Guatemala. It is considered a low-resource setting, characterized by insufficient supplies and staffing. SJCRH is located in Memphis, TN, USA and is considered a high-resource setting. These hospitals were selected for the study based on their

similar missions, patient populations, and patient volume<sub>20</sub>. Furthermore, the two sites underwent a parallel process of PEWS implementation involving multidisciplinary teams with "EVAT" being implemented at UNOP in 2014 and "SJAWS" being implemented at SJCRH in 2016.

The PEWS scoring tool and algorithms are similar at each site. Bedside nursing assessments are conducted at defined time intervals and result in a composite score for each patient. If that score is above a certain threshold, a ward and/or ICU provider must be notified so they can assess the patient and intervene if deemed necessary<sub>20</sub>.

#### **Population**

Participants from UNOP and SJCRH included all staff typically involved in PEWS and escalation of care<sub>20</sub>. This includes bedside nurses and unit nursing coordinators, frontline physicians (pediatricians and pediatric hematology-oncology fellows), and critical care providers, such as attending physicians and fellows, advanced practice practitioners (APPs; SJCRH only), and critical care nursing coordinators (SJCRH only). The study included 41 providers from UNOP and 42 providers from SJCRH<sub>20</sub>.

### Study Design and Analysis

All 83 transcribed interviews underwent content analysis utilizing inductively derived broad themes20. Three research team members iteratively read the transcripts and used exploratory memos to identify themes and potential codes. A larger group discussed and defined codes as they developed before conceptually defining them. Small groups of transcripts (3-5) were initially coded to test and refine codes. A codebook was finalized with definitions once all transcripts underwent the refinement process. Each transcript was double-coded by two researchers. All transcripts were reviewed by a larger group and inter-reliability was evaluating, achieving a kappa value of 0.7820. COREQ guidelines were followed to ensure quality in qualitative data analysis and reporting. MAXQDA software was used for data management.

Further thematic analysis was conducted to identify emotional patterns across the three disciplines and two hospital sites. Pre-coded themes were explored during the data familiarization stage. These pre-coded themes explored included "emotions," focusing specifically on overlap between "emotions" and "negative perceptions" and "positive perceptions," and are defined in the supplemental code book (Appendix 2). Emotion-based themes were inductively identified, developed, and refined. Themes were finalized upon agreement among the authors.

#### Ethical Considerations

Study personnel who approached potential participants were not involved in PEWS implementation or the discussed deterioration events, and they were outside of the participants' line of employment.

Verbal consent was obtained from participants in English or Spanish and the study was explained in participants' native language by native speaker. Written documentation was waived. No identifying information was collected from participants and participants were asked to avoid using private health information during the interview. This study was exempt from SJCRH IRB approval. The study was approved by UNOP IRB.

## RESULTS

A total of 83 interviews were conducted. Of these, 42 were conducted at SJCRH and 41 were conducted at UNOP<sub>20</sub>. Table 1 describes the provider distribution interviewed at both institutions. Content analysis revealed three main themes, including "provider emotions around patient deterioration and care escalation," "impact of PEWS on emotions," and "confidence and clinical judgment."

Health Care Provider Category	UNOP	SJCRH
Nurses	20 (49)	13 (31)
Coordinator	8 (20)	2 (5)
Bedside Nurse	12 (29)	11 (26)
Floor physicians	14 (34)	16 (38)
Oncology fellow	6 (14)	6 (14)
Resident/pediatrician	8 (20)	3 (7)
APP (NP, PA)	N/A	7 (17)
PICU provider	7 (17)	13 (31)
PICU nurse	N/A	2 (5)
APP (NP, PA)	N/A	5 (12)
PICU fellow	6 (15)	N/A
PICU attending physician	1 (2)	6 (14)
Total	41 (100)	42 (100)

#### **Table 1: Demographics of Interviewed Participants**

NOTE. Data presented as No. (%).

Abbreviations: APP, advanced practice provider; N/A, not available; NP, nurse practitioner; PA, physician assistant; PICU, pediatric intensive care unit; SJCRH, St. Jude Children's Research Hospital; UNOP, Unidad Nacional de Oncología Pediátrica.

#### **Provider Emotions Around Patient Deterioration and Care Escalation**

Patient deterioration events stimulated feelings of concern, fear, frustration, discomfort, fatigue, and comfort across participants. Concern was mentioned most often in this context, with the remaining emotions being mentioned to a lesser degree. Increased concern among providers in response to patient deterioration was mentioned across all disciplines at both hospital sites. There were instances in which patient status changed from baseline, worrying providers:

"...the progression of his symptoms that's what worried me, not the specific number." (ICU physician, SJCRH)

However, alterations in vital signs led to elevated PEWS scores, which were a cause for concern: *"So, if they tell us the patient has* [a PEWS] *of 3, 4 5, I already know that he is a patient that is going to get sick."* (floor provider, UNOP)

"...the [PEWS] is in 3 because the child is tachycardic or tachypneic or is becoming saturated, one tells you the cause of why the [PEWS] is altered." (floor nurse, UNOP)

If this concern was met with a lack of action (i.e., ICU consult, care escalation), it fostered negative feelings. This was reflected across all disciplines at SJCRH, though not explicitly mentioned by any UNOP participants. For SJCRH nurses, it increased their level of concern, as well as frustration, when they felt like their worries weren't being received appropriately by others:

"I guess once I actually know that it's a problem and they're not really doing anything about it, that's when I have more concerns. If I know it's a febrile teenager and it will be gone in like the next hour or two after they've had their Tylenol, I'm not as worried about it. But, when I send my patients to the ICU, I was like we need to do something other than keep telling you every two hours, hey we're still at this number." (floor nurse, SJCRH)

SJCRH ICU providers also expressed frustration when appropriate action wasn't being taken: *"But when they continue to call you and not take your recommendations, that's frustrating"* (ICU provider, SJCRH).

Similar to SJCRH nurses, UNOP nurses also experienced increased levels of concern, but for a different underlying reason. Their concern was induced by not having access to essential resources needed to take care of deteriorating patients on the floor:

"We are worried about having a complicated patient here because we do not have the equipment, we do not have for example a defibrillator, our position is not 100% as for example to attend a heart attack." (nurse, UNOP)

Conversely, when care was appropriately escalated it eased the burden of taking care of deteriorating patients on the floor for both UNOP nurses and SJCRH floor providers:

"You feel more at ease when you know that a patient is already at intensive care. The personnel down there know how to manage these types of patients and they know what needs to be done..." (floor nurse, UNOP)

"There's definitely a lot more patients that have been going to the ICU for observation for 24 to 48 hours, which I think is an improvement over previously, when previously we were managing these patients on the floor. There was a lot of distress over taking care of and worrying about. I think from a communication piece, that has really helped sort of move patients along the spectrum and have the ICU know about those patients earlier." (Floor physician, SJCRH)

In terms of patient care, an UNOP nurse spoke directly as to how PEWS plays a role in its improvement:

"It had improved the patient quality a lot because you notice more or by the EVAT numbers you worry a little more. We can't have an EVAT 3 or 2 and waste time, don't report it, besides it is written in the paper, the patient gets worse." (nurse, UNOP)

#### Impact of PEWS on Emotions

The implementation of PEWS seemed to both heighten and relieve providers' emotions around deterioration events similarly across disciplines at both sites. PEWS and its scoring components increased concern among all providers because they acted as a warning signal that a patient's status was declining. This concern was linked to providers feeling more alert and attentive to their patients because they had to be ready to initiate treatment in a timely manner:

"When they already have a [PEWS] number 3... we monitor the patient, we are already concerned and checking on him every hour to think about a transfer to another service." (floor nurse, UNOP)

The increased concern heightened awareness of the patient among nurses, floor providers, and ICU providers because they had to be ready to make the critical decision to escalate care if the team deemed it necessary. UNOP nurses frequently expressed how PEWS scores increased worry, which in turn increased awareness:

"So, if I tell [the doctor], 'But my [PEWS] is in 3,' then they worry, and they pay more attention." (floor nurse, UNOP)

"Many times, we just say, look at [PEWS] in 4. When we say that [the nurse coordinator] automatically worries, 'why? What's wrong with him? What happened?' Then we become alert." (floor nurse, UNOP)

By communicating a PEWS score that was elevated, it induced worry among providers and increased their attentiveness towards the patient through more frequent monitoring.

Furthermore, PEWS scores increased the level of concern and sense of urgency expressed by providers across disciplines. If a patient had a higher score, the provider was more worried about them than a patient with a lower score. One SJCRH ICU nurse practitioner spoke to how specific scores change their emotion" "*A 7 or 8, I'm going to have a very different feeling than a 5. I'm going to feel a little more urgency to get to the room.*" (ICU, SJCRH). An ICU provider from UNOP felt a similar way:

"I think one is more alarmed when the EVAT is higher, and I think part of being alarmed a little more is paying more attention. For example, he has an EVAT of 5, let's better review him." (ICU, UNOP) Alternatively, the absence of an elevated PEWs score brought a sense of comfort that the patient was at a low risk of deterioration. UNOP floor providers discussed this relationship:

"If we see a [PEWS] of 0, I presume everything is fine." (floor provider, UNOP)

"...if I see a value of 0, I don't have worries, no problem... I hope to see all the values in 0 and I have no complications, actually I trust what I am doing." (floor provider, UNOP)

When a patient had a consistently elevated PEWS score, it resulted in a mixture of emotions. For some providers, it induced a foreboding feeling: "...*I feel like if they're repeatedly* [a PEWS] *of a five there's something wrong*" (nurse, SJCRH). Additionally, it was frequently mentioned that persistently elevated scores manifested an alarm fatigue which produced a false sense of security among providers. At SJCRH, participants from all disciplines mentioned this phenomenon. However, alarm fatigue did not appear in any transcripts from UNOP. Continually elevated PEWS scores in a patient led to providers developing a misleading comfort that the patient was stable which decreased the amount of concern that the patient was at-risk of deteriorating. A SJCRH nurse spoke directly about this false sense of security:

"...other kids that look unwell but are maintaining a high [PEWS] score, it's like, I kind of would like you to keep reassessing, because I think it also makes us nursing slack a little bit too, you're like, oh they're just a four, and you're like, we get like, comfortable with a four or a five when we, those vitals are not normal." (nurse, SJCRH)

SJCRH nurses and ICU providers expressed that these repeated alarms lessened the value of the scores and even caused some providers to ignore the calls:

"I think a barrier is just how many calls [providers] get and just getting that complacent mindset of... okay it's another [PEWS] call, three, four, the same thing that it's been for 12 hours... I think that may just be like the burnout of how many calls they do receive..." (nurse, SJCRH)

"I think that's where we've seen failures in the system where a kid always has [a PEWS] of five or six or whatever and then we just ignore them." (ICU, SJCRH)

One SJCRH floor provider talked about how this alarm fatigue fails to incite concern among providers, which leads to ignoring calls or getting frustrated:

"How do you make it so that we don't develop a long fatigue where it's a—while they're [PEWS] 3, they're always [PEWS] 3. They always have this. I'm not concerned and then start to ignore these things or kind of get frustrated with the fact that every couple of hours I'm getting paged or called." (floor MD, SJCRH)

A St. Jude floor nurse practitioner noted that the presence of a PEWS score at all should initiate concern among providers, but that not all providers share that same feeling:

"...I think it's alarm fatigue because, you know, they'll say, one or two, but if someone has an S-Jaws at all, I feel like we should be concerned about it, but we just hear they have this number so often that it almost like means nothing to us at this point." (floor provider, SJCRH)

#### **Confidence and Clinical Judgment**

Nurses from both St. Jude and UNOP expressed that PEWS increased their confidence and level of comfort when it came to exercising clinical judgment. UNOP nurses and SJCRH nurses, as well as SJCRH floor providers, noted that PEWS gave nurses evidence to back their claims that a patient was deteriorating. A SJCRH nurse stated:

"...it does give us a little more concrete evidence to base our hormonal feelings on and our perceptions of how patients do... it makes us more comfortable reaching out to a physician or nurse practitioner saying that we're concerned if we have evidence to back it up." (nurse, SJCRH)

SJCRH floor providers also stated that the measures gave nurses more autonomy and increased confidence to make decisions. A SJCRH floor provider explained:

"I think that it has certainly given the nurses more latitude to call for medical intervention earlier on. Especially I think for newer nurses or younger nurses. It's easier than just saying, 'Well, I don't know why but I'm just worried about this patient.' They can actually have a more sort of concrete, 'I had to call you because the S jaws is blank.'" (Floor MD, SJCRH)

UNOP nurses also felt empowered and confident in their clinical judgment. However, their viewpoint played less of a role in eliciting a response form ICU and floor providers. Objective evidence induced concern more among those providers than worry from a nurse:

"I think I would give more points to the objective part in the subjective way as well. That is, if they are concerned and I see that objectively there is something in the evaluation of [PEWS] that really needs intervention, I am more alarmed." (ICU, UNOP) An UNOP floor provider explained how objective evidence plays a role in their clinical judgment and decision-making process:

"...what I really look is the EVAT, if it's a 3 at least the child has tachycardia or something wrong is present besides the nurse or the family... at that moment I check the vital signs to look closer, when the EVAT shows 1 but the patient has tachycardia, I am worried... I won't wait until a 4; on the other hand, if the signs are good, my worries finish and I don't do anything" (Floor provider, UNOP)

#### DISCUSSION

Pediatric oncology providers work in an emotionally-charged environment. Emotions have been shown to affect clinical judgment and provider response to clinical situations, yet the relationship between emotions and patient safety is not widely acknowledgeds-12. Conversely, the relationship between PEWS ad patient safety has been well described—PEWS facilitate improvements in patient safety by warning providers of concerning patient changes, prompting them to consider the possibility of deterioration and potential care escalation23. Our study reinforces these findings and presents evidence that describes emotions around patient deterioration. Furthermore, our findings support the notion that PEWS, which detect and draw attention to deteriorating patients, positively and negatively impact provider emotions. These findings can be incorporated into improving global patient safety initiatives and provider experience with PEWS, which can serve to increase provider retention and decrease physician burnout.

Clinical deterioration and PEWS affected emotions in both high-resource and resourcelimited hospital settings in our study. Participants across all disciplines mentioned patients showing signs of deterioration and/or an elevated PEWS score elicited concern. Oftentimes, providers responded to increased levels of concern by implementing stringent monitoring and remaining alert to the patient's status. Conversely, persistently elevated PEWS scores resulted in "alarm fatigue" and potentially created a false sense of security, masking the high risk of decompensation among patients with elevated scores. This can also be consequential in the sense that alarm fatigue and unregulated emotions can increase provider burnout and decrease resilience<sub>13</sub>. Increased concern and attention may contribute to improvements in patient safety by supporting earlier engagement between interdisciplinary team members and consideration of care escalation, while the false sense of security could impede safety efforts by keeping these conversations from occurring until decompensation is imminent. These themes were more prevalent among SJCRH providers potentially due to their increased ability to handle deterioration events on the floor, whereas at UNOP they did not always have the resources to do so. This inability to handle severe deterioration may increase anxiety among these nurses, leading them to be more vigilant and advocate for higher care.

Additionally, when care was not perceived as being appropriately escalated, concern increased among nurses from both institutions. The underlying reason stimulating the concern varied by resource-level. SJCRH nurses described worry and frustration resulting from others no sharing their concerns and subsequently taking action, while nurses at UNOP were apprehensive because they lacked the resources to care for a critically declining patient on the floor. However, when care was perceived as being aptly escalated to the PICU, participants expressed relief from the burden of caring for critically ill patients on the floor. In a qualitative study by Jensen et al. (2018), nursing participants felt that using a standardized method lessened the validity of their clinical opinions. The results of this study deviate from these findings. Nursing participants from both UNOP and SJCRH often expressed that PEWS scores enhanced their ability to convey their clinical opinions to providers from other disciplines and having evidence to support their judgment enabled them to communicate their concerns with ICU and floor providers. These findings are similar to results from from Bonafide et al. (2013) which stated that PEWS scores empowered nurses to overcome escalation barriers and communicate worries, helping them initiate action to rescue deteriorating patients. Additional research confirms the significance of effective communication, as it decreases mortality rates, increases quality of care, and improves patient-centered outcomes<sub>20</sub>. This research contributes to the literature by describing and exploring emotions felt by providers and the concordant situations that they may occur in, which provides a framework for developing interventions aimed at improving provider experience decreasing the occurrence of physician burnout.

This study has several limitations. Though the implementation process was similar at UNOP and St. Jude, the PEWS escalation algorithms vary slightly between the sites. The culture and context of each oncology ward, along with provider education and training, also contribute to differences between the hospitals<sup>20</sup>. These factors introduce variability that affect the functionality of PEWS and participant perception of the tool. However, our findings reveal vast similarities between the two institutions and the emotions expressed by providers of different disciplines. It is possible that social desirability bias played a role in the participants' given responses, but this was mitigated by using interviewers and other study personnel from outside of the institution or medical care<sup>20</sup>. Consequentially, this may have limited the ability of the

interviewers to probe about issues mentioned by the participants, reducing the capacity to gather more rich data for the purposes of the study. Nonetheless, the vast majority of emotions that emerged were negative emotions. This shows that participants did not avoid elucidating on negative experiences or focus heavily on only discussing positives of the tool and experienced emotions. Selection bias is a possibility because nurses at UNOP were enthusiastic about participating, resulting in more UNOP nursing interviews20. However, the number of UNOP ICU providers was limited. Input from each discipline was not represented evenly, but extra nursing opinions are suitable for reviewing emotional themes since they are the providers that are mostly at the patient's bedside and use the tool most often. Furthermore, the study utilized both English and Spanish for communication purposes, with all transcripts being analyzed in English. While this increased consistency in the analysis phase, it may have minimally changed the intent of the original statements. All transcripts were retained and reviewed as necessary, with a bilingual team member reviewing 20% of the Spanish transcripts to minimize errors and inaccuracies20. Despite these limitations, our findings reveal the similarities between emotional expression across providers from various disciplines at two hospitals with divergent resource levels. These results can be used to further improve global patient safety initiatives to decrease the global burden of pediatric cancer and increase provider retention thereby improving patient access to experienced providers.

#### CONCLUSIONS

This study demonstrates that there is a complex relationship between clinical deterioration and provider emotions, which can be modified by PEWS. Elevated PEWS scores

signifying that a patient is at a high risk of clinical deterioration raise provider concern and encourage action. This high level of alertness could be beneficial for patient safety by prompting patient evaluation and consideration to escalate care. However, alarm fatigue can result in increased clinician stress and burnout and the resulting misleading comfort that accompanies alarm fatigue could be detrimental to patient safety outcomes. This study emphasizes the importance of understanding provider emotions in settings with varied resources and a high severity of illness, and the potential impact on patient safety and provider burnout.

#### **CHAPTER 4: Recommendations**

The research outlined sought to understand the role of emotional affect and PEWS on pediatric oncology providers, and how these emotions manifested during clinical deterioration events in two hematology-oncology hospitals of varying resource levels. Observations of findings generated through this study support the subsequent research suggestions and policy recommendations.

- 1. **Investigate factors contributing to delays in care:** Alarm fatigue and the resulting false sense of security that emerged in the transcripts has the potential to delay detection and subsequent care escalation among critical patients, compromising their safety. Participants' reports provided some insight on this phenomenon and how it can affect physician response, but a more thorough and comprehensive understanding of this topic is warranted. Additionally, further research on elements leading to delays in detection of clinical deterioration and escalation of care as well as their impacts on patient outcomes is merited in order to decrease the global burden of pediatric cancer. More detailed information on factors that may interact with PEWS or clinical deterioration events should be identified so appropriate interventions can be piloted and implemented. Efforts to expand the literature on PEWS and delays in detection and care escalation would contribute to enhanced prevention efforts as well as improved health and experiences at the individual, interpersonal, institutional, and community levels. Over time, this research could be extrapolated to other hospitalized patients to maximize care efficiency across many subspecialties.
- 2. **Develop theoretical models to describe provider emotions:** Provider emotions were found to be evoked by a myriad of stimuli, but there are still gaps in the research that

should be filled in order to develop a more nuanced theoretical model explaining the relationship between provider emotions, clinical decision-making, and patient safety. By formulating a detailed, comprehensive model to elucidate the interplay between these factors, a clearer image of how emotional aspects impact patient safety can be achieved 10. Understanding the fundamentals of this complex relationship is imperative to cultivate effective interventions targeting patient safety initiatives. Not only will these efforts contribute to knowledge on how to bolster patient care and safety, but addressing emotional issues can improve provider experience and strengthen retention.

- 3. Understand and address emotions elicited by PEWS: The findings of this study revealed that PEWS scores can elicit concern from providers through their core function of identifying deteriorating patients. Less is known about the role of PEWS and how they directly impact provider emotions. Providers should be probed more about their emotional experiences in concordance with using PEWS and how it may differ from emotional experiences pre-PEWS implementation. Further investigation could reveal an array of emotions that manifest as a result of seeing a high PEWS score (i.e., surprise, panic) versus a PEWS score of 0. Through learning more about how PEWS impact provider emotions, the training process could include an emotional intelligence enhancement component to prepare providers for what to expect and how to cope with feelings that arise.
- 4. Interventions for burnout and emotional intelligence: Unregulated or poorly managed emotions can lead to clinician stress and burnout, which adversely affects patient safety13. However, conducting research on the benefits of emotional intelligence is fundamental to improving outcomes in work wellness, retention, interdisciplinary collaboration, and

overall clinical performance<sup>10</sup>. Furthermore, interventions such as emotional debriefing have been shown to reduce burnout and increase resilience among medical providers<sup>26</sup>. By focusing on building emotional capacities in providers, patient safety can be improved and clinicians' self-efficacy can be increased<sup>10</sup>. The effectiveness of interventions such emotional debriefing and emotional intelligence development should be studied in this unique population of pediatric oncology providers because they face a diverse set of challenges (i.e., patient death) when it comes to patient care. Not only can emotional capacity building interventions be valuable to promoting physician well-being and longevity, but ultimately, they can optimize patient safety.

5. Research on LMICs: The impact of PEWS on patient outcomes may be greater in LMICs due to high baseline mortality rates and lower monitoring capacity<sub>20</sub>. This study found that, while providers from both sites may have experienced similar emotions, there are various underlying reasons for these emotions that differ based on resource-level. Thus, in order to optimize the implementation and utilization of PEWS in LMICs, it is important to understand these differences and how to improve providers' experiences in multiple settings.

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## **APPENDIX 1: PEWS Material**

## Supplemental Figure 1: Escala de Valoración de Alerta Temprana (EVAT) PEWS Reference Tool

PEWS reference tool from Unidad Nacional de Oncología Pediátrica (UNOP), translated from Spanish. Reproduced with permission from Agulnik A, Mora Robles LN, Forbes PW, et al. Improved outcomes after successful implementation of a pediatric early warning system (PEWS) in a resource-limited pediatric oncology hospital. *Cancer*. Apr 25 2017.

# Escala de Valoración de Alerta Temprana (EVAT)



#### UNOP WIEMA MACINAL DE ONCOLOGÍA

# Reference Tool (Translated from Spanish)

Escala de Valoración de Alerta Temprana (EVAT)						
	0	1	2	3	Result	
Behavior / Neurologic	<ul> <li>Alert/Sleeping appropriately</li> <li>Patient is at baseline state of alertness</li> </ul>	<ul> <li>Sleepy, drowsy when not stimulated</li> <li>Responds only to verbal stimuli</li> </ul>	<ul> <li>Irritable, difficult to console</li> <li>Responds only to painful stimuli</li> </ul>	<ul> <li>Lethargic, confused, without strength</li> <li>Unresponsive</li> <li>Seizures</li> <li>Unreactive pupils or with anisocoria</li> </ul>		
Cardiovascular	<ul> <li>Appropriate skin color for patient</li> <li>Capillary refill ≤ 2 seconds</li> <li>Normal peripheral pulses</li> </ul>	<ul> <li>Pale</li> <li>Vasodilated</li> <li>Capillary refill 3-4 seconds</li> <li>Mild tachycardia*</li> </ul>	<ul> <li>Capillary refill 4-5 seconds</li> <li>Moderate Tachycardia*</li> <li>Diminished peripheral pulses</li> </ul>	<ul> <li>Mottled</li> <li>Fill capillary&gt; 5 seconds</li> <li>Severe tachycardia*</li> <li>Symptomatic bradycardia</li> <li>Irregular rhythm (not sinus)</li> </ul>		
Respiratory	<ul> <li>Within normal parameters</li> <li>No retractions</li> <li>Normal breathing pattern</li> <li>Saturation &gt;95%</li> </ul>	<ul> <li>Mild tachypnea*</li> <li>Mild work of breathing (nasal flaring, intercostal retraction)</li> <li>Up to 1 L of oxygen via nasal cannula (NC)</li> <li>Saturation 90% -94% without oxygen</li> </ul>	<ul> <li>Moderate tachypnea*</li> <li>Moderate work of breathing (nasal flaring, intercostal retraction, grunting, use of accessory muscles)</li> <li>1-3 L of oxygen via NC</li> <li>Nebulization every 4 hrs</li> <li>Saturation 88-89% without oxygen</li> </ul>	<ul> <li>Severe tachypnea*</li> <li>Respiratory rate below normal for age*</li> <li>Severe work of breathing (head-bobbing, thoraco-abdominal dissociation)</li> <li>Oxygen via facemask with reservoir (not post-sop)</li> <li>&gt; 3 L oxygen via NC</li> <li>Nebulization &gt; every 4 hours</li> <li>Saturation &lt;90% with oxygen</li> <li>Apnea</li> </ul>		
Nurse concern	Not concerned	Concerned				
Family concern	Not concerned and present	Concerned or absent				
				TOTAL		

#### \* Please refer to Heart Rate and Respiratory Reference Tool

Based on Bonafide C, et al. Development of Heart and Respiratory Rate Percentile Curves for Hospitalized Children. Pediatrics 2013;131;e1150.

	Mild	Moderate	Severe
Respiratory rate and heart rate	90-95th percentile for age	95-99th percentile for age	> 99th percentile for age

Supplemental Figure 2: Escala de Valoración de Alerta Temprana (EVAT) PEWS Escalation Algorithm

PEWS escalation algorithm from Unidad Nacional de Oncología Pediátrica (UNOP), translated from Spanish. Reproduced with permission from Agulnik A, Mora Robles LN, Forbes PW, et al. Improved outcomes after successful implementation of a pediatric early warning system (PEWS) in a resource-limited pediatric oncology hospital. *Cancer*. Apr 25 2017.



Supplemental Figure 3: St. Jude Advanced Warning Score (SJAW) PEWS Reference Tool PEWS reference tool from St. Jude Children's Research Hospital (St. Jude).

	0	1	2	3	Score
Behavior /Neuro	<ul> <li>Playing /Sleeping</li> <li>Alert at patient's baseline</li> </ul>	<ul> <li>Sleepy when not disturbed (oriented when awake but if left alone falls back to sleep</li> </ul>	<ul> <li>Irritable, difficult to console or arouse</li> <li>Increase in patient's baseline seizure activity</li> </ul>	<ul> <li>Lethargic, confused, floppy</li> <li>Reduced response to pain</li> <li>Prolonged or frequent seizures</li> <li>Pupils asymmetric or sluggish</li> </ul>	
Cardiovascular	<ul> <li>Normal heart rate for age</li> <li>Skin tone appropriate for patient</li> <li>Capillary refill ≤ 2 seconds</li> </ul>	<ul> <li>Mild tachycardia*</li> <li>Pale</li> <li>Capillary refill 3 seconds</li> </ul>	<ul> <li>Moderate tachycardia*</li> <li>Grey</li> <li>Capillary refill 4-5 seconds</li> </ul>	<ul> <li>Severe tachycardia</li> <li>Symptomatic bradycardia</li> <li>Mottled</li> <li>New onset/increase in ectopy, irregular heart rhythm or heart block</li> <li>Capillary refill &gt; 5 seconds</li> </ul>	
Respiratory	<ul> <li>Normal respiratory rate for age</li> <li>No retractions</li> </ul>	<ul> <li>Mild tachypnea*</li> <li>Mild increased work of breathing (flaring, retracting)</li> <li>&lt;5L via OxyMask™</li> <li>Up to 1L NC &gt;patient's baseline need</li> <li>Increase in FiO2 via trach collar &lt;35%- 40%</li> <li>Mild desaturation* (&lt;5 below patient's baseline)</li> <li>Intermittent apnea self-resolving</li> </ul>	<ul> <li>Moderate tachypnea*</li> <li>Moderate increased WOB (flaring retractions, grunting, use of accessory muscles)</li> <li>&gt;5L or ≤10L via OxyMask™</li> <li>2L NC &gt;patient's baseline need</li> <li>FiO2 via trach collar 40-55%</li> <li>Moderate desaturation* (&lt;10 below patient's baseline)</li> <li>Apnea requiring repositioning or stimulation</li> <li>Nebs q 1-2 hour</li> </ul>	<ul> <li>Severe tachypnea*</li> <li>New onset RR below normal for age</li> <li>Severe increased WOB (head bobbing, paradoxical breathing)</li> <li>&gt;10L via OxyMask<sup>™</sup> or requires non- breather</li> <li>&gt;2L NC &gt;patient's baseline need</li> <li>FiO2 via trach collar &gt;60%</li> <li>Severe desaturation* (&lt;15 below patient's baseline)</li> <li>Apnea requiring interventions other than repositioning or stimulation</li> <li>Nebs every 30 min - 1 hour</li> </ul>	
Staff Concern: add one point	(1)	(1)	(1)	(1)	
Family Concern: add one point	(1)	(1)	(1)	(1)	

## St. Jude Advanced Warning Score

Follow guidelines for heart rate, respiratory rate, and oxygen saturations based on age and severity: normal, mild and moderate and severe.

Agulnik, A., Forbes, P., Kleinman, M., Rodriguez-Galindo, C., & Stenquist, N. (2016). Validation of a pediatric early warning score in hospitalized pediatric oncology and hematopoietic stem cell transplant patients. *Pediatric Critical Care Medicine*, 17(4), e146-153.

Supplemental Figure 4: St. Jude Advanced Warning Score (SJAW) PEWS Escalation Algorithm

PEWS escalation algorithm from St. Jude Children's Research Hospital (St. Jude).



Patients with POST (DNAR) should not have care escalated based on their goals of care