SEUP
SOCIEDAD ESPAÑOLA DE URGENCIAS DE PEDIATRÍA

EMERGENCIASPediátricas
Vol. 5. No. 3

Emergencias Pediátricas. 2026; 5(3): –

EDITORIAL

Working with families to keep children safe: "Are you worried that your child is getting worse?"

Trabajar con las familias para mantener a los niños seguros: "¿le preocupa que su hijo esté empeorando?"

Simon Craig[1,2*], Erin Mills[1,2]

[1] *Department of Paediatrics, School of Clinical Sciences at Monash Health, Monash University, Clayton, Victoria, Australia* [2] *Emergency Department, Monash Children's Hospital, Clayton, Victoria, Australia*

"Patients do not deteriorate suddenly. Healthcare professionals suddenly notice."

— Anonymous

The early stages of life-threatening pediatric conditions can resemble benign (and much more common) childhood illnesses. Sepsis may initially look similar to routine viral infections; surgical pathology (such as appendicitis or intussusception) may mimic gastroenteritis; and respiratory distress due to severe asthma may resemble a panic attack. *Failure to recognize, or delay in treating, any life-threatening illness can lead to serious adverse consequences*.

A key component of safe, high-quality healthcare is providing timely and appropriate care to patients whose condition is acutely deteriorating.[1] However, failure to respond appropriately to caregivers' concerns has been a recurring theme in high-profile pediatric deaths in Australia[2], the United Kingdom[3], and Brazil[4,5].

Received April 22, 2026
Accepted April 23, 2026
Published November 20, 2026

*Correspondence:
Simon Craig.
Email:
simon.craig@monash.edu

Cardiac arrest in hospitalized children is often preceded by periods of physiological instability that can be detected through regular monitoring of vital signs and other bedside clinical findings (e.g., skin color, pain, behavior). In recent decades, the activation of recognition-and-response teams has focused on repeated physiological measurements, often referred to as "Early Warning Scores (EWS)." These clinical findings are measured repeatedly (tracked) until they cross a threshold (either through a scoring system that assigns points to a combination of factors or because a single measurement is abnormal) to "activate" a rapid response from staff trained in intensive care.[6]

However, relying solely on a system that uses physiological measures may be unreliable and insufficient. Multiple Pediatric Early Warning Score (PEWS) systems have been developed, but there is little empirical evidence about which system is most effective,[7] leading to inconsistent implementation and use.

The unique knowledge families have of their children may enable them to recognize subtle changes in behavior or temperament before even the most expert physician, and before there are clear signs of clinical deterioration.[8] Despite this, a 2020 systematic review evaluating user-initiated escalation in the hospital setting found that (a) the ability of user-initiated escalation processes to achieve their fundamental goals has yet to be adequately evaluated, and (b) further research is needed to guide the best ways to implement, support, and optimize user-initiated escalation systems.[9]

Emergencias Pediátricas. 2026; 5(3): –
https://doi.org/10.65350/emped.v5n3.en.001
http://www.revistaemergenciaspediatricas.com/

© 2026 The authors. This article is distributed under the terms of the **Creative Commons Attribution 4.0 International License (CC BY 4.0)**. Published by index on behalf of the Sociedad Española de Urgencias de Pediatría (SEUP) and the Sociedad Latinoamericana de Emergencia Pediátrica (SLEPE).

Barriers to escalation of care by users in response to clinical deterioration include (a) *lack of knowledge* about the process for escalating care, (b) *cultural and linguistic diversity* (a challenge in Latin America, home to more than 420 languages[10]), (c) *reluctance to question medical authority* ("*the doctor knows best*"),[11] (d) *differences in perspectives between clinicians and families regarding the legitimacy of a concern* (most activations by patients and/or caregivers relate to concerns about care rather than acute concerns about clinical deterioration)[2], and (e) the fact that *existing communication structures are poorly equipped* to incorporate families' expertise.[8]

"Listen to parents" is the mantra of pediatric training, and it is commonly taught that, because of the challenges involved in assessing young children, a parent's or caregiver's concern that their child "just isn't right" should always be taken seriously.[12] Parents often notice subtle signs of behavioral change that could indicate deterioration, beyond typical vital signs, and may therefore identify deterioration before clinicians do.[11] Despite this, failure to respond to caregiver concerns is often identified retrospectively following an in-hospital pediatric death.

Since 2020, in our health service in Melbourne, Australia, a co-designed project has sought to develop a process for clinical staff to proactively identify caregivers' concerns about clinical deterioration. Whenever vital signs are recorded, nursing staff are asked to ask family members: *"Are you worried that your child is getting worse?"* The question is asked verbally and is also presented on a laminated card translated into the 10 most commonly spoken languages in the health service. If a caregiver answers "Yes" to the question about their concern, they are asked for more information, a physical assessment is conducted, and care is escalated as clinically indicated.[13]

In 2025, we published an analysis of 24,239 pediatric emergency department visits in which the caregiver concern question was asked. There were 189,708 responses in total; 8,937 (4.7%) indicated concern about clinical deterioration.[13] Compared with patients whose caregivers did not document concerns, those whose caregivers reported concern about clinical deterioration were more likely to be admitted to the ICU (6.9% [326/4,721] versus 1.8% [352/19,518]), receive mechanical ventilation (1.1% [53/4,721] versus 0.2% [48/19,518]), or die during admission (0.1% [5/4,721] versus 0.02% [4/19,518]).[13] Multivariable analysis showed that caregiver concern about clinical deterioration was independently associated with ICU admission (adjusted odds ratio [aOR] 1.72 [1.40–2.11]) and mechanical ventilation (aOR 1.85 [1.36–3.15]), but not with death (probably due to the low overall mortality rates in our population).[13]

After adjusting for other variables, caregiver concern (aOR 1.72 [95% CI 1.40–2.11]) was more strongly associated with ICU admission than *any* abnormal vital sign (which ranged from aOR 1.12 [95% CI 1.08–1.17] for abnormal heart rate to aOR 1.26 [1.21–1.32] for abnormal respiratory rate).[13] In 19.3% of cases, caregiver concern was documented *before* vital sign abnormalities were detected, with a median interval of seven hours between caregivers identifying a concern and vital signs indicating a problem.[13]

Asking "Are you worried that your child is getting worse?" is now part of routine practice and has been incorporated into early warning systems in multiple Australian states and territories.[14,15] The *proactive* approach (actively seeking an answer to the question) addresses some of the many barriers parents and other caregivers face when communicating their concerns. The *specific* nature of a question focused on deterioration (rather than general "concern") seems to work well in the Australian context and reduces the risk that an affirmative response is due to hunger, prolonged waits, or communication difficulties.[2]

As our emergency departments or hospitals become increasingly busy, a question to identify caregivers' concerns about clinical deterioration could help identify a higher-risk cohort of patients earlier and prioritize them for review. Including parents and/or caregivers as a resource to help stratify risk could be even more useful in lower-resource settings or in health services with staff who have less experience in managing pediatric patients.

Potential challenges in implementation include cultural and linguistic differences, overcoming concerns that it could lead to the escalation of frivolous issues, workload pressures, and ensuring an appropriate response when concerns are raised.

Engaging patients and families from the earliest stages of designing these systems is vital to ensure that the right questions are asked in the right way, and research to evaluate the implementation and impact of such a program is essential. Harmonizing data from electronic health record systems is important. More research is needed to help us understand the relative importance of vital signs and caregiver concern in predicting deterioration overall, across different healthcare systems and populations, and in detecting specific conditions such as sepsis.

No one cares more about a child than their loved ones. As healthcare professionals, it is our responsibility to determine the best way to harness this care to improve the treatment we provide to children every day. One simple but fundamental first step on this journey is to ask: *"Are you worried that your child is getting worse?"*

Funding

No funding was received for the research, authorship, and/or publication of this article. Our original publication related to caregiver concern was supported by a grant from the Australian Government Medical Research Future Fund (GNT2031265): *The role of caregivers in recognizing and responding to serious childhood illness: a mixed-methods study.*

Author Contributions

Simon Craig: Writing – original draft, Conceptualization

Erin Mills: Writing – review and editing, Conceptualization of the research program on caregiver concern

Conflicts of interest

The authors declare that there are no commercial or financial conflicts of interest related to this research.

Use of artificial intelligence tools

ChatGPT was used to identify Spanish- and Portuguese-language media coverage of children in Latin America who experienced adverse outcomes after caregivers raised concerns about their deterioration. All identified cases were then checked against the original sources. Google Translate was used to assist in translating these sources into English. Apart from the aforementioned searches of media archives and language translation, we declare that no artificial intelligence tools were used in this article.

REFERENCES

1. Australian Commission on Safety and Quality in Healthcare. NSQHS Standards: Responding to Acute Deterioration [Internet]. . Available at: https://www.safetyandquality.gov.au/.
2. Dwyer TA, Flenady T, Kahl J, Quinney L. Evaluation of a patient and family activated escalation system: Ryan's Rule. Aust Crit Care. 2020;33(1):39–46.
3. Dudley J, Turner SW, McKean M, Bamber J, Cheung CR. Rollout of Martha's Rule: implications for care. Arch Dis Child. 2025;110:241–242.
4. Bernardino J, Oliveira Y. "Nunca vou entender", diz mãe após morte de filho de 4 anos em hospital do RJ [Internet]. CNN Brasil; 2024. Available at: https://www.cnnbrasil.com.br/nacional/sudeste/rj/nunca-vou-entender-diz-mae-apos-morte-de-filho-de-4-anos-em-hospital-do-rj/.
5. MaisPB. MP instaura procedimento para investigar morte de bebê em hospital de CG [Public Prosecutor opens investigation into death of baby in hospital in Campina Grande] [Internet]. 2026 [cited 2026 Apr 6]. Available at: https://www.maispb.com.br/825144/mp-instaura-procedimento-para-investigar-morte-de-bebe-em-hospital-de-cg.html.
6. Chapman SM, Maconochie IK. Early warning scores in paediatrics: an overview. Arch Dis Child. 2019;104(4):395–399.
7. Lambert V, Matthews A, MacDonell R, Fitzsimons J. Paediatric early warning systems for detecting and responding to clinical deterioration in children: a systematic review. BMJ Open. 2017;7(3):e014497. Available at: https://doi.org/10.1136/bmjopen-2016-014497.
8. Brady PW, Giambra BK, Sherman SN, others. The Parent Role in Advocating for a Deteriorating Child: A Qualitative Study. Hospital Pediatrics. 2020;10(9):728–742.
9. Albutt AK, O'Hara JK, Conner MT, Fletcher SJ, Lawton RJ. Is there a role for patients and their relatives in escalating clinical deterioration in hospital? A systematic review. Health Expectations. 2017;20(5):818–825.
10. UNESCO. International Decade of Indigenous Languages: Progress and Challenges in the Americas [Internet]. Paris: UNESCO; 2025. Available at: https://www.unesco.org/en/articles/international-decade-indigenous-languages-progress-and-challenges-americas.
11. Gill FJ, Leslie GD, Marshall AP. Family initiated escalation of care for the deteriorating patient in hospital: Family centred care or just "box ticking". Australian Critical Care. 2016;29(4):195–200. Available at: https://doi.org/10.1016/j.aucc.2016.07.004.
12. Roland D, Snelson E. So why didn't you think this baby was ill? Decision-making in acute paediatrics. Arch Dis Child Educ Pract Ed. 2019;104:43–48.
13. Mills E, Lin P, Asghari-Jafarabadi M, West A, Craig S. Association between caregiver concern for clinical deterioration and critical illness in children presenting to hospital: a prospective cohort study. The Lancet Child & Adolescent Health. 2025;9(7):450–458. Available at: https://doi.org/10.1016/s2352-4642(25)00098-7.
14. Clinical Excellence Commission. Worried they are getting worse? [Internet]. Sydney: NSW Health; 2026 [cited 2026 Apr 6]. Available at: https://www.cec.health.nsw.gov.au/keep-patients-safe/worried-they-are-getting-worse.
15. Safer Care Victoria. Safer Care for Kids: ViCTOR [Victorian Children's Tool for Observation and Response project] [Internet]. Melbourne: Victorian Department of Health; 2025 [cited 2026 Apr 6]. Available at: https://www.safercare.vic.gov.au/improvement/projects/safer-care-for-kids-victor.