

Disclosing medical errors: prioritising the needs of patients and families

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A slow but significant change has occurred in how healthcare professionals and organisations are expected to respond when something has gone wrong in a patient's care.¹ In 2001, the US accreditation organisation The Joint Commission began to require that healthcare facilities disclose all outcomes of care, including 'unanticipated outcomes', to patients.² Over time and across the world, the need to be transparent with patients and families when care has not gone well is now recognised as a key element of high-quality, safe and patient-centred healthcare. In 2020, the US National Steering Committee for Patient Safety released 'Safer Together: A National Action Plan to Advance Patient Safety'.³ One recommendation was that organisations 'implement and maintain programmes for providing appropriate ongoing support in the aftermath of harm'. The following year, the WHO's 'Global Patient Safety Action Plan 2021–2030' emphasised the need to 'Establish the principle and practice of openness and transparency throughout health care, including through patient safety incident disclosure to patients and families'.⁴ New toolkits and other resources have been developed to support transparency, and in the USA, hundreds of healthcare organisations are embracing this new paradigm.⁵

However, a significant gap still persists.⁶ Some organisations have yet to welcome a transparent and accountable approach, and others fail to turn these principles into reliable actions. Closing these implementation gaps requires revisiting the fundamental assumptions underlying this work.

The performance implementation gap may be linked to the paucity of data regarding how the response to harmful medical errors occurs in actual practice. In the current issue of the journal, Passini *et al* present a thoughtful study where

physicians and nurses were asked to submit voluntary, anonymous reports of errors that occurred in 10 neonatal intensive care units (NICUs) in France.⁷ These reports included information on the type and severity of the error, whether the error had been disclosed to the parents, the self-reported motives for disclosure or non-disclosure, and the perceived parental reaction to the disclosure.

Over 20 months, 1822 errors were reported, of which 41% were disclosed to the parents. Error disclosure rates varied by almost twofold across the participating centres (low of 38% vs high of 75%). Errors were less likely to be disclosed to the parents if the harm was minor, the error was discovered at night, less time had elapsed since admission and when the patient's gestational age at birth was lower. The most common reasons that clinicians gave for non-disclosure were parental absence when the error occurred, the belief that the error had only minor consequences and fear of causing distress for the parents. Participating clinicians perceived parents most frequently responded with understanding, and reported anger from parents as being uncommon.

The authors are to be applauded for rigorously and prospectively collecting information on the rate of medical errors in this setting and on the perceptions of clinicians about communication with parents. They also appropriately acknowledge several limitations. First, all the data were self-reported by the involved clinicians. Even more importantly, the data do not reflect the perspective of the involved parents on the nature of the error, whether the error was disclosed to them and their reaction to this discussion. In addition, the data do not shed light on what information was shared with the parents or what attempts were made to support the parents.



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Nonetheless, several important implications emerge from these data:

1. The interaction between patients/families and clinicians after medical errors is highly susceptible to our human frailties and biases.

Harmful errors in healthcare typically occur when fallible humans interact with complex systems of care. Similarly, the response to these errors fundamentally relies on the behaviour of the humans involved in the event. In some respects, maximising the engagement of clinicians, patients and families after harmful errors is essential to re-establishing authentic interpersonal interactions, the rebuilding of trust and the demonstration of caring that are so critical to the healing of all involved.¹⁸

However, this study highlights how our human frailties and biases likely contribute to the sizeable gap between best practices and our behaviour. Humans have a natural tendency to avoid difficult conversations. Fearing repercussions, being vulnerable and experiencing shame, many clinicians do not feel ready to disclose an error to patients and their families.^{9 10} In addition, some clinicians believe that not disclosing information about errors might be better for patients and families (a perspective not shared by the patients and families themselves).¹¹ This study also confirms prior research that found clinicians are less likely to share information about errors that patients and families might otherwise be unaware of.¹⁰ Overcoming these natural human reflexes and biases will require that organisations invest in robust processes for detecting and responding to errors, including just-in-time support for those talking with patients and families about what happened.

2. Patients and families are in a vulnerable position after error disclosure.

A common barrier to conversations with patients and families after error is clinicians' deep-seated fear that sharing this news will trigger an angry response.¹² Some clinicians may breathe a sigh of relief when reading the finding of Passini *et al* that participating clinicians thought parents did not respond with anger to the disclosure but instead parents often reacted to the news with empathy and understanding.

We agree that an overtly angry response from patients and families to being told of an error is far less common than clinicians assume. However, we believe this finding points to a different and more fundamental truth, namely the intensely vulnerable position in which patients and families find themselves after these events.^{13 14} When a medical error is disclosed, more often than not, patients are heavily dependent on the clinical team who was involved with the event to provide ongoing care. This was certainly the case in this study, as the parents being told about the error were relying on the NICU clinicians for continued care of their child. In our prior work, an important obstacle patients experienced to sharing concerns about care is

a fear that 'complaining' might disrupt the relationship with their clinical team and adversely affect their future care.¹⁵

Clinicians also frequently assume that most patients' and families' needs after harmful errors centre around information and apology. In reality, especially after errors that lead to significant harm, patients and families have a much broader array of needs related to their physical, mental, emotional and financial health, needs that often extend (and change) over time. While programmes to support clinicians after error disclosure are welcome, much more attention should be devoted to understanding what support patients and families need. The most important first step is simply asking the patient and family early and often what can be done to help them cope with the disclosure and any associated harm, and then striving to meet these needs. In addition, the fact that patients and families are in such a vulnerable position relative to the clinical team is one reason many organisations are developing a liaison role distinct from the clinical team that can support patients and families after error disclosure.

3. Data on processes around error disclosure are key to improvement.

One of this study's most noteworthy contributions is demonstrating the value of data about processes around error disclosure. Most organisations have no way to track the proportion of errors that should have gone through their formal response process, which elements of the process were used and what outcomes occurred. Lacking these data, most organisations are in the dark regarding the performance of their disclosure process. Even though the data in this study consisted solely of self-reported provider perceptions, it still sheds valuable light on situations in which clinicians hesitated to communicate with patients and families about errors, thereby providing targets for intervention. Every organisation should use standard metrics to track and improve their disclosure response.¹

LOOKING FORWARD: CREATING HARM RESPONSE PROGRAMMES THAT PLACE PATIENT AND FAMILY AT THE CENTRE

While improving the disclosure of errors to patients is an admirable goal, a much more fundamental transformation is underway, namely the development of comprehensive and highly reliable programmes for identifying and responding to harmful medical errors. In some respects, the development of harm response programmes reflects what patients and families have been telling us all along that they want after harmful errors, namely not only disclosure but to also receive honest and open communication and apology, not to be abandoned, to know that there are robust processes in place to learn from the event to prevent recurrences, and to receive support for their practical, emotional, and financial needs.

The fact that the field has been slow to develop the comprehensive harm response programmes that patients seek reflects a lack of focus on the needs of patients and families after harm. While studies are beginning to describe the experiences of patients and families after harmful medical errors,^{6 16 17} the literature overall has been weighted towards exploring the perspectives of clinicians and healthcare organisations. The response to disclosure of a harm should be the most patient-centred element of healthcare but is frequently the least. Clinicians and organisations do not consciously disregard the impacted patient and family. Rather, they are so preoccupied with the event’s impact on themselves and the organisation, that the needs of the patient and family inadvertently recede into the background.

When one listens to patients and patient advocates regarding how the response to harmful errors can be improved, the issue of terminology immediately surfaces. The words we use to describe the process of responding to medical errors matter deeply, highlighting our goals, revealing our biases and illuminating our blind spots.

To start with, the term ‘disclosure’ has multiple shortcomings. Disclosure connotes a unilateral decision by the clinician whether to reveal information that was hidden from the patient about an error. Disclosure further suggests a unidirectional flow of information via a one-time discussion, allowing little room for patient’s viewpoint. Disclosure focuses on the perspective of the clinician (what will they choose to tell the patient)

rather than on how the information is received by the patient and what is most important for them to hear. This is why the field has moved away from a focus on ‘disclosure’ and towards ‘communication’ which implies an ongoing, bidirectional interaction between clinicians and the patient/family.

There is also the need to decide on what types of events to focus on. The patient safety field distinguishes between errors (the failure to carry out a planned action as intended or application of an incorrect plan) and adverse events (incidents that resulted in harm to the patient).⁴ Some adverse events are due to error (and are preventable), but many are not. Similarly, some, but not all errors cause harm. The article by Passini *et al* covers all medical errors. Yet, most current patient safety standards advocate a focus on supporting patients and families after harm (US National Patient Safety Steering Committee). Anytime patients and families are harmed, they deserve an explanation for what happened (whether the harm was preventable) and support. This does not mean that we should not continue to be interested in the broader realm of medical error, or that patients should not be informed when they experience medical errors that did not result in harm, but rather that prioritising harm events keeps the experience of the patient and family front and centre when care does not go well.

The patient and family perspective has been critical in moving towards a much more robust response to harm in healthcare, now referred to as Communication

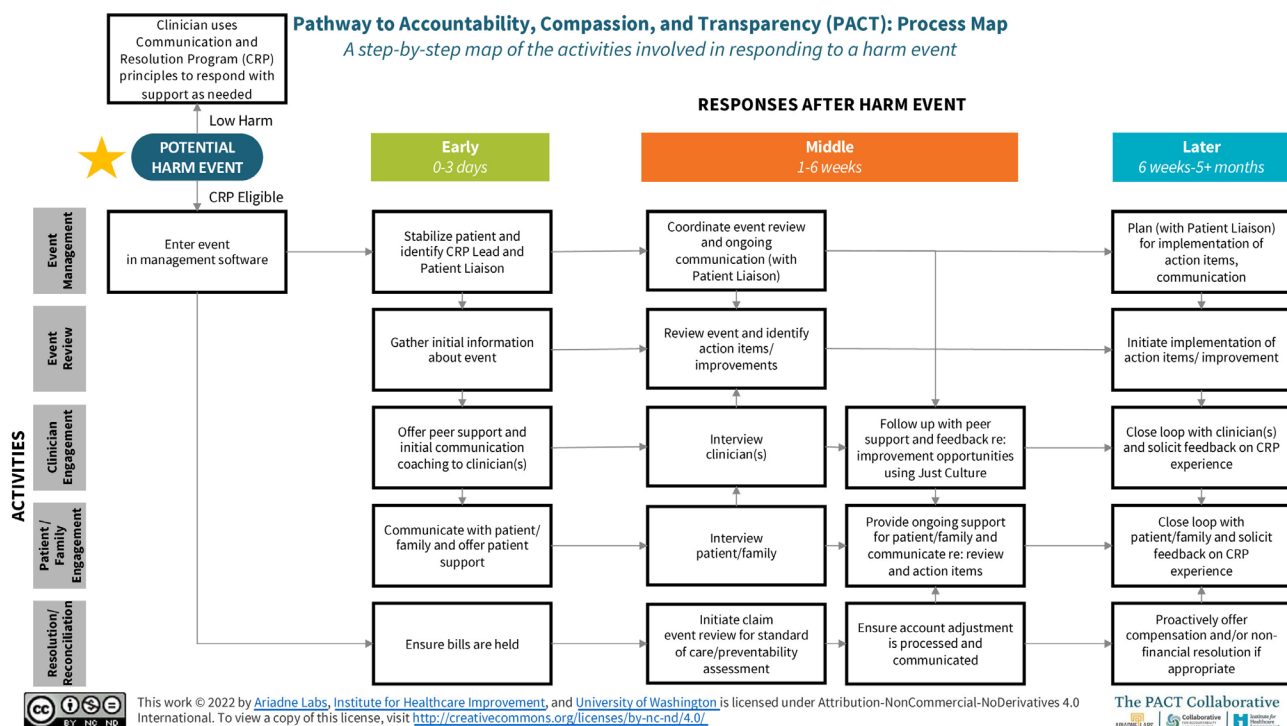


Figure 1 PACT Process Map.

and Resolution Programs (CRPs).¹⁸ The essential elements of a CRP exist in many different forms, including programmes such as CANDOR, CARE, HEART, HEAL, to name a few. Patient advocates themselves developed the name for a national CRP learning community, called the Pathway to Accountability, Compassion, and Transparency (PACT). PACT seeks to support healthcare organisations in developing and implementing highly reliable, mission-critical CRPs through newly designed tools and metrics (<https://www.ariadnelabs.org/pact/>). Figure 1, the PACT Process Map, outlines in detail each of the related steps that should occur over time in a highly reliable response to harm.

Patients and patient advocates continue to encourage the field to move forward. The term ‘communication and resolution programme’ itself has shortcomings. Most glaring is the term ‘resolution’, which implies a process that is completed when the organisation is done sharing information, or perhaps when it provides compensation to the patient and family. Yet, for most patients and families, the experience of harm is never resolved. Alternative terms such as ‘reconciliation’, ‘restoration’, ‘reparation’ or ‘restitution’ have been proposed. CRPs provide a welcome focus on ensuring the clinicians involved in harm events also receive support. Initially, the field referred to the impacted clinicians as ‘second victims’ (with the patient/family being the first victim). Patient advocates, while encouraging robust programmes to support clinicians affected by harm events, have challenged the healthcare field to abandon the ‘second victim’ term in order to ensure that the needs of patients and families affected by harmful errors are prioritised.^{19 20}

The field is also wrestling with how to make real the learning that is so critical to patients and families after preventable harm. Meeting patients’ and families’ needs more consistently after disclosure will also require organisations to invest in applying change management skills, implementation science and learning from high reliability organisations. Tools and learning collaboratives such as PACT can support organisations in using new resources and metrics to prevent harm events when possible and respond to those that do occur with transparency and accountability.

Much work is needed before we can be confident that any time patients are harmed by their healthcare, they will receive an effective response. The growing community of stakeholders that share this goal offers exciting opportunities to accelerate progress. As the debate over terminology and focus continues to unfold, healthcare organisations and providers should redouble their engagement with patients and families who have been harmed by their healthcare, and use the principles of accountability, compassion, and transparency to drive the response.

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