“But I told you she was ill! The role of families in preventing avoidable harm in children”

Dr. Damian Roland
Consultant and Honorary Senior Lecturer in Paediatric Emergency Medicine
dr98@le.ac.uk
07727158213

1. SAPPHIRE Group, Health Sciences, Leicester University, Leicester, LE1 6TP
2. Paediatric Emergency Medicine Leicester Academic (PEMLA) Group, Leicester Royal Infirmary, Leicester, LE1 5WW

“But I told you they were ill!” These are chilling words for any health care professional to hear if harm has occurred to a child following failure to recognise a serious illness. Failing to detect and act on a child who is deteriorating is an important form of avoidable harm that remains a significant issue both in and out of hospitals [1,2].

Systems for tracking illness in children and triggering clinical response have been in use for some time, with a variety of Paediatric Early Warning Scores (PEWS) available[3]. Typically these systems utilise features common to clinical observations such as heart rate, respiratory rate and temperature. Anything which utilises the skills and knowledge of the person who knows the patient best – usually the parents – could be a very a welcome addition to improving recognition of the deteriorating child. Yet parental concern is only used in a minority of PEWS systems [4] in the United Kingdom with greater use of this component reported in the United States [5]. One possible reason for low rates of parental involvement in monitoring of their child’s condition in hospital is concern about how it might be optimally deployed, and such concern may be amplified when it is proposed to give parents a direct role in escalating clinical response.

In their work, Brady et al. examined the use of family-activation of a Medical Emergency Team (MET) in a large tertiary children’s hospital. They note that some concerns associated with families’ involvement in activating these teams might include: the system will be abused, it will divert interventions away from those needing them or it will require additional resources for training that aren’t available. That these concerns are paternalistic is almost ironic, so it is pleasing to see an organisation attempt to investigate them and involve parents and carers in every stage of the improvement initiative. Brady et al.’s study demonstrated that family activated MET calls were only a small proportion of the total MET calls made. This proportion was also far less than false positive clinician led calls (i.e. an unnecessary activation with no benefit for the patient) inferring families were not stressing the system unnecessarily.

What does this mean for hospitals currently using a PEWS or MET type system considering a family-activated component? For one they should not expect to be deluged with MET alerts. However, as the authors recognise, much effort may need to be invested in informing families about the process. The authors admit the hospital failed to collaborate with parents initially and required a revision of their information posters as a result. This highlights the importance of co-production, and is an important lesson for hospitals.

A second issue relates to the context in which the intervention was developed and delivered: one that already had an excellent safety culture, including, for example, patient advocates at all team
huddles. Deployment of a family-activated MET calls may depend on leadership that allows for honest and critical reflection of its own communication processes. The very fact the authors reflect on family-led MET calls which did not result in a PICU transfer as “..a positive communication threat” rather than a false-positive implies a cultural attitude that supports family engagement. Patient-centred leadership was demonstrated by the brave decision to allow families to call METs directly via their hospitals’ switchboard, since a less courageous organisation might have worried about a communication dynamic that seemed to suggest that a family no longer trusted their allocated nurse or doctor. Whether delivery and outcomes would be similar in a hospital still developing a robust patient safety programme is an open question.

For organisations willing to implement family-activated MET calls there is a great deal to be learned about quality improvement methodology in this paper. These include the up-front realisation that a number of improvement initiatives were ongoing during the study. Some, or many of these, may well have had an impact on the intervention. This should not detract from the results, as rarely does one intervention alone that transforms a safety culture. Second, learning from the improvement initiative itself was valuable in its own right:

“We also have observed at our centre that the “threat” of a family-calling an MET can empower a nurse to do so even when the physician team disagrees with the MET’s necessity.”

While the language of ‘threat’ may not be a culture an organisation wishes to endorse, the cascade of delivering impact from one mechanism (the family-activated MET call) to another (the empowerment of individual staff) is clear. One improvement approach may contribute to another. Recognising, and sharing, this is beneficial for understanding the effectiveness of the intervention.

With co-production and strong leadership it may be possible to consign those heart-breaking words “I told you they were ill” to the past.

2. An avoidable death from a three-year-old child with sepsis. June 2014 Health Service Ombudsman
4. Roland D, Oliver A, Edwards E et al. Use of paediatric early warning systems in Great Britain: has there been a change of practice in the last 7 years? Arch Dis Child 2014;99:26-29