Martha’s rule presents a unique opportunity for improving patient care

Helen Haskell outlines some principles for creating an effective family activated system

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Much has been written recently about Martha’s rule—the proposal to allow patients in hospitals in England and their families the right to demand an urgent second opinion if their condition is deteriorating. The call has been led by the parents of Martha Mills, who died of sepsis at King’s College Hospital just before her fourteenth birthday.1 The coroner, Mary Hassell, said, “The serious incident investigation identified that Martha’s care fell down between the paediatric hepatologists and the paediatric intensivists.” This was a major contributor to Martha’s death.2 4

The policy think tank Demos has recently published a proposal for Martha’s rule which combines elements of two existing programmes: Ryan’s rule—a programme in Queensland, Australia, named after a 3 year old boy, Ryan Saunders, who died from undiagnosed streptococcal infection—and Call 4 Concern, a family activated rapid response system established at the Royal Berkshire NHS Foundation Trust by critical care nurse consultant Mandy Odell. Ryan’s rule is a hotline—patients and families can call a single statewide number for a review of medical care that they feel has gone astray. Call 4 Concern is a more traditional hospital based rapid response scheme run by the critical care outreach team, who pre-emptively check on patients deemed high risk.5 6

Formal systems for incorporating the voices of patients and families into rapid responses have existed since the introduction of Condition Help at the University of Pittsburgh in 2005.7 The International Society for Rapid Response Systems includes the presence or absence of a family trigger as one of its measures of rapid response system effectiveness.8 Ironically, given the fears of physicians and nurses, the problem with family activated systems is not that families use them for frivolous reasons, but that they do not use them enough. Without active promotion and encouragement, patients and families are often unaware of help systems, or lack the confidence to activate them.9

Ryan’s rule and Call 4 Concern are probably the most successful of the family activation systems precisely because they receive more calls. With Ryan’s rule, uptake may be partly because of broad support in the Queensland press, which considers it “a Queensland success story.”10 The widely publicised national number gives patients more latitude about when they can call and the system has been enthusiastically supported by the Queensland health authority.11 Call 4 Concern, in contrast, is built on the NHS system of critical care outreach, with nurses visiting and encouraging patients and families to call. It is now present in many hospitals in the NHS. Nurses are accustomed to the programme and appear to welcome the support.12

Martha’s rule presents an opportunity to take the best from these and other existing family activated programmes. As the mother of a child who deteriorated and died in an American hospital, I have followed these programmes for years. Here are some principles that I see for creating an effective system.

- **Breadth** The advantage of Call 4 Concern is that it is rapid and focused. The advantage of Ryan’s rule is that it covers many healthcare systems, including hospitals, emergency departments, and home health.5 Both approaches can be lifesaving. Some combination of the two should be created.

- **Urgency** The system should not be treated just as a “second opinion,” as it is often described. Until otherwise proven, these calls should be treated as emergencies, similar to 999 calls. One criticism of Ryan’s rule has been that referrals are often delayed—this can be dangerous as families may downplay the situation.13 In this situation a rapid response, such as Call 4 Concern, is in line with the programme’s goals.

- **Continuity** The system should be available 24 hours a day, every day, including weekends and holidays. Martha died following a bank holiday. In my years of talking to patients and families, I have found that disasters of this type occur with unsettling frequency on low staffed weekends and holidays. Medical crises do not keep business hours.

- **Independence** Opinions should come from experienced clinicians who are not part of the treating team. Communication failures and concerns about care provided by bedside providers, including trainees, are common reasons for family calls. Calling in another trainee or a member of the treating team is not a way to inspire trust.

- **Feedback** It is critical to learn the story behind a call. Most family activated systems include an evaluation process that asks whether the family was satisfied with the response but, crucially, does not ask about patients’ experiences leading up to the call or why the call was placed. Given that most calls are said to be about breakdowns in communication, it is important to learn what that miscommunication looks like to patients.14

One hesitation that many providers have about patient activated calls is a phenomenon that has been
documented in almost every system: most calls, while concerning serious health matters, do not involve active deterioration. Analyses of Ryan’s rule cases suggest that responders downplay the significance of family calls because few of the patients meet the objective criteria for deterioration.\textsuperscript{13, 14} Families may call much earlier in the trajectory of an illness, using subjective criteria based on their knowledge of the patient, and they may call for other reasons, such as uncontrolled pain. This is not a bad thing. Fear and suffering are valid reasons to call for help.

Finally, some providers are concerned that Martha’s rule may divert resources.\textsuperscript{15} This is not a new argument.\textsuperscript{16} But, as Martha’s case shows, the recurring problems of hierarchy, arrogance, and poor culture have not been tackled despite what now amounts to decades of effort. It is not the job of patients and families to wait around for healthcare providers to sort out their culture. Patients, the reason for the system’s existence, should have the agency to try to save their own lives. It may be that this spark of accountability is what is needed to bring openness to a system that has so far resisted it.

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2 Mills M. “We had such trust, we feel such fools”: how shocking hospital mistakes led to our daughter’s death. Guardian. 3 Sept 2022. www.theguardian.com/lifeandstyle/2022/sep/03/13-year-old-daughter-dead-in-five-weeks-hospital-mistakes


7 University of Pittsburgh Medical Center. Condition Help, a patient and family hotline. www.upmc.com/about/why-upmc/quality/care-decisions/condition-help


