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When Parents Take Conflicts to Digital Media

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When Parents Take Conflict to Digital Media

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IRB Number (if applicable): N/A

Describe role of Submitting/Presenting Trainee in this project (limit 150 words):

Lead author/primary contributor

Problem Statement/Question:

How ought clinicians and hospitals 1) think about and 2) respond to cases where the parents of a child use digital media (online news and social media platforms) to attract public support for controversial treatment requests or refusals?

Background/Project Intent (Aim Statement):

Over the past decade, there have been numerous cases around the world in which parents have used digital media to orchestrate public opposition to doctors' recommendations—usually recommendations to withhold or withdraw life-sustaining treatment. These cases bring together two domains within bioethics: debates about inappropriate or futile treatment and debates about the role and use of digital media in medicine.

Our aim was to review cases in which digital media campaigns went viral in order to understand 1) parents' motivations for going public; 2) how digital media changes the stakes in doctor-parent disagreements; and 3) the ethically appropriate institutional response in such cases.

Methods (include PDSA cycles):

Review of literature on medical futility and on digital media in medicine; Textual analysis of high-profile cases in which parents used digital media to organize opposition to doctors' recommendations.

Results:

We analyzed 12 cases that occurred between 2007-2018. We identified six parental motivations for turning to digital media: 1) to be heard; 2) to feel empowered; 3) to buy more time; 4) to raise public awareness; 5) to feel

that they have done everything possible; 6) for secondary gain. Certain institutional responses—such as “siding” with their staff and taking parents to court—frustrate some parental goals. We suggest that other institutional responses could help to fulfill other parental goals, by shifting the focus of the debate towards identifying and scrutinizing the interests and motivations of the political collectives that inevitably coopt these high-profile cases. For this goal, institutions and parents may be allies.

Conclusions:

Digital media changes the nature of disagreements about a child’s treatment. Healthcare institutions have been reluctant to comment on these cases. We argue that there thoughtful and ethically responsible ways for healthcare organizations to directly engage with these cases, without violating confidentiality or being coopted by the dominant, adversarial narrative that surrounds such cases. Hospitals should seek an alliance with the parents around the goal of public discussion and utilize web-based platforms to provide the public with information about medical conditions, experimental treatments, and how clinical ethics deliberation in hospitals works. Institutions should view these events as opportunities for public education. Approached with care, such cases could become “teachable moments” for society.