WhenParentsTakeConflicts to Digital Media
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abstract

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. Parents are not always “successful” with such efforts; these cases have mixed outcomes and, sometimes, unintended consequences for parents. In this article, we address the current lack of understanding of parents’ goals, motivations, and rationalizations in initiating such campaigns. We analyze 12 cases in which parental digital media campaigns went viral that occurred between 2007 and 2018, with the aim of better understanding parents’ motivations for going public. We identify 7 themes raised by parent-initiated digital media campaigns: (1) changing doctors’ minds, (2) being heard, (3) feeling empowered, (4) buying more time, (5) raising public awareness, (6) feeling that they have done everything possible, and (7) financial gain. Greater attunement to these themes and what is driving parents in such conflicts may help to disrupt the highly adversarial narrative surrounding such cases. It may also inform how clinicians approach disagreements that cross a certain threshold of public interest at the bedside.

Digital media has the power to bring doctor-parent conflicts into the public domain. Parents can go online and describe, in great detail, their conflicts with doctors and garner immense public support. In many such situations, parents’ goals are crystal clear: they seek to influence treatment decisions for their child. But it is not always so simple. In some cases, it seems that parents have multiple complex goals, motivations, and rationalizations for turning to digital media. Many of the ethical and legal issues raised by such cases have been thoroughly addressed in the literature.1–4 However, parents’ goals, motivations, and rationalizations in initiating such campaigns have been largely unattended to in existing analyses. By analyzing public reports of such conflicts and parents’ self-reported experiences, in this article we attempt to better understand what drives parents to turn to digital media and go public with their conflicts. A better understanding of the goals, motivations, and rationalizations that underpin parents’ actions may help to cultivate a more respectful, tolerant, and reconciliatory atmosphere between doctors and parents and therein help to derail the adversarial narrative that often surrounds such cases.

METHODS

Outlined in Supplemental Table 1 are 12 cases of disagreement between parents and doctors that raised similar ethical and legal issues, dominated headlines, and attracted tens of thousands of hits on digital media.3,5–15 Supplemental Table 1 is intended to be a representative, not exhaustive, sample of such cases. There is no database of parent-initiated digital media campaigns. The authors already knew of many of the cases discussed because of the level of publicity they received.

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attracted. Some cases led us to other cases. We also consulted colleagues in bioethics to see whether they had heard of any additional cases in which parents “went public” on digital media. For the purposes of this article, the term “digital media” refers to both social media platforms, like Facebook and Twitter, where users self-report and share personal content, and mainstream conventional news media, such as articles, syndicates, and televised news reporting. Doctor-parent conflict refers to an entrenched disagreement between parents and health professionals over a child’s medical treatment. Ultimately, a dozen cases that seemed to exemplify a range of disagreements were selected for thematic analysis. Potential themes were identified and discussed by the authors until we reached agreement on the thematic material present in parents’ accounts. This is not a traditional qualitative study. The reported data and descriptions that our analysis is based on are heterogeneous and nonstandardized. Some are court records. Some are newspaper articles. Some are from social media. When possible, we have given preference to parents’ own words, posted directly online by parents or as they were quoted in the media. Because each case is so varied and because of the small sample size, it is difficult to extrapolate any generalizable claims from currently available reports. Despite this, it is possible from a close reading of available reports and comments on digital media to gain some insight into parents’ goals, motivations, and rationalizations for their actions, that is, to get a sense of why parents went public and what they hoped to accomplish by doing so. We have supported our hypotheses with published quotes from parents.

**TURNING TO DIGITAL MEDIA: 7 THEMES**

In this article, we discuss 7 themes illustrated by high-profile cases of doctor-parent conflict. Importantly, these themes may help to explain why parents embark on digital media campaigns, despite it not being guaranteed or even likely that they will be able to change doctors’ minds by doing so.

**To Change the Doctor’s Decision**

Sometimes, digital media campaigns are an effective way for parents to harness public support and get an outcome they desire. For example, in the case of Amelia Rivera (case 2, Supplemental Table 1), parents put pressure on a hospital’s decision not to provide a particular treatment to a child. In this case, the parents’ blog post, in which they accused the Children’s Hospital of Philadelphia (CHOP) of discriminating against their daughter on the basis of her cognitive impairment, went viral. The public support and pressure generated by the parents’ online presence and campaigning led to an apparent change in CHOP’s organ transplantation policy. The child ultimately received a kidney, donated by her mother. A similar effect is discernable in the cases of Sarah Murnaghan and Joshua Hardy (cases 5 and 6) and, to a lesser degree, the cases of Jahi McMath, Ashya King, and Jonah Puruleski (cases 4, 7, and 9).

In other cases, digital media pressure helps parents to disrupt or stall a course of treatment to which they object. For example, in the Oshin Kiszko case (case 8), the parents wanted to forego chemotherapy for their child. The doctors wanted to provide it. The final stage of court proceedings (during which there was a moratorium on further treatment of the child in question) continued long enough for the child’s condition to deteriorate to the point that further, court-ordered chemotherapy was deemed no longer appropriate. Thus, in a roundabout, procedural way, the parents in this case were successful in their refusal of further, undesired treatment.

However, digital media pressure appears to have no effect on the outcome of a disagreement in other cases, even those that generate significant public interest. For example, despite the immense public and financial support attracted by Charlie Gard’s parents (case 10), they were still unable to secure a timely transfer to the United States and access to the treatment they desired for their son. The parents of Alfie Evans and Isaiah Haastrup (cases 11 and 12) were similarly unsuccessful in their campaigns to have life support continued.

It is unclear why the pressure of mounting digital media attention is effective in some cases but not others. Cases 2, 4, 5, 6, 7, 9, and, arguably, 8 all resulted in a change of treatment plan on the basis of the parents’ digital media campaign. Six out of 7 of these cases occurred in the United States. One might tentatively surmise that clinicians, health care organizations, and courts in the United States are more responsive to media or collective pressure than clinicians, institutions, and courts in the United Kingdom or Australia because the only successful cases of media campaigns against doctors were in the United States. It is possible that other factors, such as parents’ socioeconomic status or race, may play a role in the “success” of a parental campaign, but there is currently a lack of data to confirm the role of such factors in these conflicts. Reflecting on a pre-social media case of parents turning to the media to raise money for their child’s treatment from the early 1990s, Thomasma et al.16 wrote, “One parent on a television program tearfully recounted her frustration in trying to get attention for her son’s liver disease. She said she simply did not know how to go about getting the media to help.” This example, like the cases outlined in Supplemental Table 1, illustrates the unpredictable nature of attempts to mobilize the media. Campaigns may also have unwelcome or unpredictable consequences. In
some cases, parents may change their mind about what is best for their child during the course of public interest and debate. Some parents may find it difficult to withdraw from the limelight or public disagreement process; they may feel that they are in too deep to change their minds or retreat from the public’s eye once there. They may also experience regret regarding the damage a campaign has done to their relationship with their child’s doctors or hospital or experience a significant loss of privacy as the result of a campaign. And, sometimes, digital media can lead to parents’ stories being co-opted by third parties and, ultimately, to patients’ and families’ voices being lost or misrepresented in the digital media maestrom. In a statement to the press, Alfi Evans’s father (case 11) publicly expressed regret over their fractured relationship with the child’s medical team, regret over not making the most of the limited time they had left with their child before his death, and a desire for the public to respect their privacy. Charlie Gard’s parents (case 10) expressed a similar desire for their privacy to be respected in a public statement made just before the death of their son. Although both sets of parents sought out media attention when doctors refused their initial request, voluntarily surrendering their own and their child’s privacy, it may be hard for parents to predict the degree of loss of privacy that will result from a campaign. It is a mistake to think that campaigns are only successful if parents get the treatment that they want for their child. There may be other ways in which parental campaigns might be considered “effective” or successful. Thus, we seek to address the current poor understanding of what drives parents, beyond the emphasis on “winning” (ie, changing doctors’ minds), with the aim of reframing the conversation in a way that disrupts the dominant, adversarial narrative associated with these cases. Doctors and parents are often pitted against one another as having diametrically opposed goals for a child. In this narrative, someone must win and someone must lose, and the parents’ main goal behind or reason for turning to digital media is to force clinicians to, through collective pressure, “give in” and do what they are not professionally inclined to do.

To Be Heard

Parents may feel that clinicians are not listening to them, that their beliefs, values, and opinions have not really been heard and taken seriously. Digital media networks and public support may make parents feel heard and that their beliefs, values, and opinions have been recognized and are legitimate. Comments from parents that illustrate this theme include the following:

“No one was listening to us, and I can’t prove it, but I really feel in my heart: if Jahi was a little white girl, I feel we would have gotten a little more help and attention.”

“If mediation had taken place with an independent mediator, we would have felt our voices were being listened to.”

“We [cannot] wait . . .to help those in need and who aren’t being noticed, listened [to], or respected!”

“The court must learn to take parents opinions with same reverence as doctors. We were [viewed] from the prism of sympathy and ‘grieving parents’ instead of the court [according] significant consideration to our accounts and [Isaiah’s] observations.”

To Feel Empowered and Gain or Regain Control

Many parents still experience a power imbalance in the doctor-patient-parent relationship. Parents often perceive themselves as up against powerful institutions with expert medical knowledge and considerable resources at their disposal. Turning to digital media may be a way of “leveling the playing field” and giving parents a sense of empowerment and control in a situation in which their child’s future may feel largely out of their control. Parental comments illustrative of this theme include the following:

“I’m totally not usually a person that runs to the news, but I’ve got my child’s life in my hands. . .I have to fight. If this is the way I’ll do it.”

“We (and by we, I mean the thousands of you who spoke up with letters, comments, petitions, and phone calls—all I did was write our story) came together, voiced our concerns and people listened. Changes have been made.”

“This is not about revenge. This is about making people accountable and making the medical community think twice before they take actions that can do damage to a child and a family that can be irreversible.”

“I am truly grateful for the amount of love and support my daughter Jahi McMath and I have received from people all over the world. . .Because of your unselfish generosity I was able to do what I was afraid I would never be able to do, move my daughter from Children’s Hospital Oakland before they removed her from her ventilator and stopped her heart.”

“You efforts are working. The company cannot continue to ignore us. They cannot continue to ignore the fact that they and they alone have to power to save Josh. We will succeed. It is a war of attrition and we are stronger.”

“There are a lot of emotions involved here, Oshein’s sisters, ours as well, and a lot of pressure, they fire a lot of stuff at you while you are feeling the fear.”

To Buy Time

Campaigning may be a way to buy more time with a child or together as a family. Parents may feel that every day they have with their child counts and any day that the hospital is prevented from withdrawing life-sustaining interventions is a success. Parents may also hope for a miracle or cure if a child is kept alive long enough, that is, if they can hang in there just a little longer. One parent wrote, “We always took the
opportunity to celebrate monthly birthdays because with Trisomy kids you just never know how long you are given. Each day is such a gift and each month you are blessed with should be celebrated! A victory over Trisomy’s evil grip each month!"  
(case 9). Campaigning may also be a kind of coping mechanism for parents or form of denial or anticipatory grief.

Sometimes, campaigns are also effective at “stalling,” insofar as they place clinicians and institutions in the public eye, where they are sometimes more reluctant to take any immediate action that goes against parents’ wishes, and this buys parents some time. Other illustrative quotes from parents include the following: “I just want to spend time with my son. . .I want to let him die naturally without someone coming up and saying we’re going to cutoff on a certain day”  
(case 1) and “I am so thankful I got to spend so much time with him though it was extremely hard to watch him want to do more with his life”  
(case 6).

To Feel That They Have Done Everything Possible for Their Child

Some parents may campaign to reaffirm their parental identity; part of this is feeling like they have fulfilled or performed their social role of parent. Some parents may not only need to challenge doctors but be seen as challenging them and fighting for their child. Sometimes, we equate doing good with doing.  
Parents may feel that doing something, anything, is preferable to doing what feels like nothing (eg, withdrawing or withholding treatment or quietly accepting that their child is going to die and standing by while this happens). Some parents may fear experiencing decisional regret. They may deal with that fear by becoming advocates for all available treatment, even when further treatment might be doing more harm than good. Illustrative parental comments include the following: “They [Charlie’s parents] wish to exhaust all possible options. . .They don’t want to look back and think ‘what if?’ This court should not stand in the way of their only remaining hope.”  
(case 10)

To Generate Discussion or Raise Awareness About a Particular Condition or Issue

Many of the parents in these cases above have used their public platform to become advocates for children suffering from their child’s condition.  
For many parents, an important part of this motivation may be their sense of their child’s legacy. A child’s legacy may take the form of changing laws or policies to prevent future children and families from experiencing similar barriers to treatment or care, or it may concern how people remember the child. Parents may wish to publicize their child’s story so that more people remember their child. It is possible that high-profile cases of patients and families challenging barriers to treatment, in addition to mounting political support for the belief that certain barriers to treatment are unjust, has contributed to the implementation of right-to-try laws in some jurisdictions. Parental comments illustrating this theme include the following: “We know a lot of kids who are waiting and little people who are waiting. Just knowing that they’ll have greater access is a really amazing feeling.”  
(case 5)

“Because of Josh, more current day Joshes are getting this drug and I can’t thank God for Josh’s legacy like that legacy enough. My prayer is that we can improve upon our current system so more people can have just 5 more minutes.”  
(case 6)

“We feel that the foundation will be a lovely legacy for Charlie, and we hope that you will all continue to support us in honouring the life of our little warrior as he helps other poorly children and their families.”  
(case 10)

For Financial Gain

By turning to digital media, parents may be seeking gain in the form of additional financial support for their family during the course of their child’s illness. Through campaigning efforts, Charlie Gard’s parents raised £1.3 million to cover the cost of experimental treatment in the United States (money that ultimately went toward the creation of a foundation to support research for other children with mitochondrial disorder).  
For some families, the child’s situation may be viewed as an opportunity to acquire financial support for a range of purposes and with a range of motives; campaigns can be a quick and efficient way of accomplishing this goal.

This list of possible reasons for why parents turn to digital media is not intended to be exhaustive or necessarily true of all parents in these circumstances. But, revisiting the 12 cases outlined in Supplemental Table 1, the 7 themes we identify are plausible explanations for why many parents turn to digital media. A theme may relate to parental goals, motivations, or rationalizations. It can be difficult to distinguish between these factors and determine, with certainty, what underpins parents’ actions in these cases. As more such cases occur, it may be possible to discern, with greater certainty, patterns and insights about what drives parents to go public with their conflicts.

IMPLICATIONS

Parents’ goals, motivations, and rationalizations are complex. A family
might start a digital media campaign both because they hope it will buy them more time with their child and because they want to gain as much additional financial support as possible for their family. Parents may simply feel desperate and act without careful thought. Smith\textsuperscript{40} writes, "[Even] the most loving parents will sometimes make bad decisions in moments of extreme stress." We think the themes we identify are important to consider. They can help doctors and hospitals refocus and reframe these cases. This, in turn, may help doctors and hospitals develop strategies that might limit the damage that is sometimes caused by high-profile conflicts with families.

Striving to understand why parents are doing something might help clinicians avoid adversarial thinking, regardless of whether they agree or disagree with what parents are doing. We recognize that parents may act in ways that seem more or less admirable to the staff caring for their child. Clinicians may be less inclined to view parents’ decisions in a judgmental or adversarial light if they can recognize that they turned to the media out of love or grief. If committed to humanizing parental behavior and maintaining a collaborative relationship with parents, clinicians should not lose sight of the fact that the goals, motives, and rationalizations of parents dealing with their child’s serious illness are often complex.

Clinicians may find some of these reasons, as well as the experience of being unable to informally resolve a disagreement with parents, frustrating, but understanding what is motivating parents may help to cultivate a respectful, tolerant, and reconciliatory atmosphere throughout whatever dispute resolution processes are in effect. Most of the time, parents in these challenging situations have goals, motivations, and rationalizations that are compelling and understandable and have not been definitely established as ethically illegitimate reasons for a parent to take certain actions or make certain decisions regarding their child. We think that greater attunement to these themes may help to remind clinicians that they share goals, such as the best interests of the child and avoiding decisional regret, with parents. This reminder may help to break down the sense of clinicians and parents being diametrically opposed in their goals and values that often surrounds these cases. A deeper understanding of parents’ goals, motivations, and rationalizations could be helpful in redirecting mediation efforts toward shared goals for the child.

Efforts in medical education and professional development should be directed at improving communication skills and cultivating empathy, professional humility, and tolerance.\textsuperscript{4,41,42} Health care professionals should be cognizant of their positive and negative judgments of parents and avoid or minimize being overly judgmental and labeling families or parents as “difficult” and try to identify and address what we might label ‘adversarial creep’ before it snowballs. Situations of entrenched disagreement between doctors and parents are often situations in which there is reasonable disagreement about the application of relevant values and ethical principles.\textsuperscript{43} Reframing these conflicts in terms of the parental drivers we identify may help clinicians recognize that, sometimes, in cases of reasonable disagreement, parents’ values and goals may need to take priority.

Most of the time, themes we identify can be addressed through effective, ongoing communication with parents and multidisciplinary approaches to patient- and family-centered care, for example, by involving an ethics consultant or committee, mediator, or patient or family advocate, when appropriate. Clinicians should aim to avoid creating an environment in which the best or only way for the parents of critically ill children to satisfy their goals or gain support is by turning to outside sources of support, such as digital media. Given the sometimes unpredictable and unwelcome effects of digital media attention, parents may want a professional ally.

LIMITATIONS

In analyzing the texts our account is based on, we did not use formal qualitative research methods. There are a large number of secondary sources on the cases discussed, not all of which were included in our analysis, given our informal methodology and the fact that we did not use any analytic software. It is possible that the themes identified and findings discussed reflect our biases and previous views. Because of the limited information that is currently publicly available, important details about the experiences of parents, and their direct reflections on these cases after the fact, are missing. There are few publicly available comments from parents in some cases. There may also be other factors that drive parents to turn to digital media. Possible directions for future research include empirical inquiry into the experiences and attitudes of the parents involved in high-profile cases of disagreements. Interviews with willing parents could be used to contribute to a better understanding of this phenomenon. Such interviews would need to be approached with great care and sensitivity and appropriate ethical oversight because the parents in many of these cases ultimately experienced the death of their child.

CONCLUSIONS

The power of digital media is unpredictable and sometimes difficult to harness. Parents who campaign against doctors and hospitals are not
always obviously successful in their efforts. The themes we draw attention to may help to explain why some parents turn to digital media, despite the risks and unintended consequences. In these situations, a greater attunement to what is driving parents (the goals, motivations, and rationalizations behind their request for or refusal of treatment) may help to disrupt the highly adversarial narrative surrounding such cases. Understanding can breed empathy. Greater understanding of parental motivations may change how clinicians approach disagreements that cross a certain threshold of public interest by helping them to recognize that they share some goals with parents.

### Abbreviation

CHOP: Children’s Hospital of Philadelphia

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