

# Chapter 4

## Media Framing of “Medical Futility”: Flaming the Debate?

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### I. The role of the media

The cases of Charlie Gard and Alfie Evans can be approached from many different viewpoints. In this chapter, the role of the media, including social media, and in particular the language used therein, will be the primary foci. The aim is to highlight the need for a more ethical press reporting, to reveal the need for greater transparency and accessible language regarding doctors’ decisions, but also the opportunity for removal of discussion from the media gaze. Once in the media, the differing viewpoints became more intractable, with each side unable to persuade the other to a satisfactory, or at least mutually agreeable, solution. Mediation is therefore strongly suggested to avoid “framing and flaming” the debate. Mediation has been widely accepted in many spheres and offers at least the voicing of alternative interpretations in a neutral and confidential environment, and even of transforming the conflict – finding ways to redefine the issue.<sup>1</sup>

The methods used below to analyse the press include Framing theory as per Goffman<sup>2</sup> and linguistic analysis of mainly newspaper discourse, including quotes selected from relevant interested parties.<sup>3</sup> De-

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<sup>1</sup> S. Littlejohn, “The Transcendent Communication Project: Searching for a Praxis of Dialogue,” *Conflict Resolution Quarterly* 21 (2004): 337–359. doi: 10.1002/crq.66.

<sup>2</sup> E. Goffman, *Frame Analysis: An Essay on the Organisation of Experience* (Boston: Northeastern University Press, 1974).

<sup>3</sup> G. Tuchman, “Objectivity as Strategic Ritual: An Examination of Newsmen’s Notions of Objectivity,” *American Journal of Sociology* 77:4 (1972): 660-679. Gaye

spite the increase in various types of social media, newspapers continue to provide a major source of information for large sectors of the population, whether in hard copy or online versions. According to the National Readership Survey figures, *The Sun* and *The Daily Mail* are the most read UK wide newspapers.<sup>4</sup> It has been argued, and widely accepted, that reading a newspaper is a form of social ritual, and that social class and age influences the type of paper read.<sup>5</sup> Social class can be defined not by occupation, but from a person's way of being and living, their tastes, manners, arguably their propensity to emotion, their presentation of "self,"<sup>6</sup> including their vocabulary, and hence, even their perception and description of events. These are influenced by one's family, peers, and contacts, but also by one's reading. Hence, significant factors discussed below are the "reading" people undertake, including how the different newspapers and media posts appeal to readers, and how they "frame" and report issues.

However, it is also important to note that the use of social media, in the form of Twitter and Facebook, has increased exponentially in recent years. Research has shown how online communities can foster a shared sense of belonging and understanding, with shared cultural norms, arguably more powerfully than the press.<sup>7</sup> Twitter can similarly create a sense of shared community,<sup>8</sup> although it is more common to

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Tuchman, *Making News: A Study in the Construction of Reality* (New York: The Free Press, 1978).

<sup>4</sup> Ofcom, *News Consumption in the UK 2016*, p. 26.

[https://www.ofcom.org.uk/\\_\\_data/assets/pdf\\_file/0016/103570/news-consumption-uk-2016.pdf](https://www.ofcom.org.uk/__data/assets/pdf_file/0016/103570/news-consumption-uk-2016.pdf) (accessed June 20, 2018).

<sup>5</sup> A. S. R. Manstead, "The Psychology of Social Class: How Socioeconomic Status Impacts Thought, Feelings, and Behaviour," *British Journal of Social Psychology*, (2018), <https://doi.org/10.1111/bjso.12251> (accessed June 12, 2018).

<sup>6</sup> E. Goffman, *The Presentation of Self in Everyday Life* (Garden City, NY: Doubleday/Anchor Books, 1959), 1-2.

<sup>7</sup> N. K. Baym, *Tune in, Log On: Soaps, Fandom, and Online Community* (Thousand Oaks, CA: Sage, 2000). H. Rheingold, *The Virtual Community: Homesteading on the Electronic Frontier* (Cambridge, MA: The MIT Press, 1993).

<sup>8</sup> Benedict Anderson had identified the importance of "imagined communities" and the role of the media in his influential work on nationalism. B. Anderson, *Imagined Communities: Reflections on the Origin and Spread of Nationalism* (London: Verso, 2006).

follow accounts of those whom one does not know personally.<sup>9</sup> The lack of personal knowledge does not, however, necessarily preclude a sense of shared community. Indeed, the reach of social media was such that Donald Trump, the US president at the time, also expressed his support for the parents in both the Charlie Gard and the Alfie Evans cases.<sup>10</sup>

This chapter argues that the involvement of the media is an unprecedented development in medical cases such as Alfie Evans and Charlie Gard, creating further complications for the resolution of such disputes. The analysis below draws heavily from actual press reports and illustrates how, as Goffman notes: "People, otherwise quite similar in their beliefs may yet differ in regard to a few assumptions, such as the existence of second sight, divine intervention and the like."<sup>11</sup> Indeed, he further argued that: "[b]elief in God ... seems to constitute currently one of the largest bases of dissensus in our society concerning ultimate forces."<sup>12</sup>

For many parents of critically ill children, and noticeable in the cases of Charlie Gard and Alfie Evans and their supporters, their belief in divine intervention is often espoused, whether through pre-existing religious affiliation, hope, or desperation. This belief was evident in their posts and media discussion, fuelled by the involvement of the Pope in the debates surrounding both cases.<sup>13</sup> In the case of Charlie Gard, the Pope's intervention revealed "a change from the Holy See's position earlier in the week, when the Vatican's bioethics advisory panel had noted the need to do whatever helps a patient but also to some-

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<sup>9</sup> A. Marwick and D. Boyd, "I Tweet Honestly, I Tweet Passionately: Twitter Users, Context Collapse, and the Imagined Audience," *New Media and Society* 13 (2011): 96–113.

<sup>10</sup> *The Guardian*, "Charlie Gard: Pope Shows Solidarity with Parents of Critically Ill 10-month-old" (July 2, 2017).

<https://www.theguardian.com/world/2017/jul/02/pope-shows-solidarity-with-charlie-gards-parents> (accessed Jul 12, 2018).

<sup>11</sup> Goffman, *Frame Analysis*, 27.

<sup>12</sup> *Ibidem*, 28.

<sup>13</sup> *The Guardian*. "Charlie Gard."

times accept the limits of medicine.”<sup>14</sup> The Pope similarly expressed support for Alfie Evans, against medical expertise.<sup>15</sup>

An Italian mother of a child with an allegedly similar condition to Charlie stated: “miracles happen, close to everyone, for God’s grace for us is immense, the problem is we don’t notice them. Our strength is in our Lord Jesus. ‘We can do all this through Him who gives us strength,’ the sentence is not ours, St. Paul said this, and he was right.”<sup>16</sup> Not all involvement was free from ulterior motives, or discriminatory affiliations. Alfie’s parents, for example, were supported by the Christian Legal Centre (CLC), a lobby group opposing abortion and gay rights.<sup>17</sup>

As noted above, with reference to Goffman’s work, there is no doubt that people’s beliefs often defy logic, appear impermeable to “reason” or to alternative narratives, and may potentially be harmful. Indeed, personal interests could lead to the dismissal of unpleasant facets relating to supporters, and to a rejection of a liberal democratic approach to alternative viewpoints for others. In the cases above, opposing viewpoints were often voiced vociferously and somewhat offensively, across the political or social spectrum. The British journalist, author, and public commentator Melanie Phillips, for example, strongly dismissed the supporters of Charlie Gard’s parents:

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<sup>14</sup> *Ibidem*.

<sup>15</sup> Research has indicated how cultural background, and context, affect one’s interpretation of divine intervention and the existence of “miracles.” Interpretation has tended to be unsympathetic to those expressing positive beliefs, seeing these as merely “delusional,” without attempting to understand the context. See: I. Stahl and B. L. Jackson, “Belief in Miracles: Divine Intervention or Psychological Delusion?” *LUMEN-TCA* 21-22 (November 2014), Targoviste, Romania.

<sup>16</sup> G. Baggi, “Don’t Give Up... Miracles Do Happen Mother of ‘Italian Charlie Gard’ says Son, 9, Given up for Dead as a Baby has a Happy Life of Painting and Chess” (5 July 2017). <https://www.dailymail.co.uk/news/article-4668068/Italian-Charlie-Gard-s-mum-says-Miracles-happen.html> (accessed July 13, 2018).

<sup>17</sup> *The Economist*, “The Pope’s Role in the Plight of Alfie Evans was Regrettable” (29 April 2018).

<https://www.economist.com/erasmus/2018/04/29/the-popes-role-in-the-plight-of-alfie-evans-was-regrettable> (accessed July 14, 2018).

I have never witnessed such concentrated ignorance, arrogance, stupidity, and unthinking cruelty as has been displayed by the American political right over the tragic case of Charlie Gard, ... Here's the really wicked thing about all this . . . This campaign led the parents to believe that such pressure could change the court's mind. And so the parents were reinforced in their refusal to face reality.<sup>18</sup>

Crucial to this chapter's argument for the acknowledgment of alternative viewpoints in a "safe space," it is argued that refusing to acknowledge the existence and the power of another's beliefs, however different from one's own, was significant in the media portrayal of the dispute, and in the entrenching of viewpoints. Many different interpretations can be made regarding the initial use of the media: to change viewpoints; to garner political pressure; to merely achieve recognition of one's views. However, the effect was that once in the public arena, support for the parents was successfully achieved since they proved more astute and more "media savvy" in this respect. It quickly became clear that no media discussion could alter the other's viewpoint, and that in fact the involvement of the media proliferated and exacerbated the conflict. Issues were portrayed in social media in terms of "good" v "evil", truth v lies, as hospitals such as Great Ormond Street (GOSH) and the medical profession in general were perceived as related to both the latter. Posters, for example, proclaimed "GOSH, Tell the truth, where is the proof, release Charlie."<sup>19</sup>

The medical profession experienced and perceived aggressive pressure to allow the parents' wishes in both cases, in conflict with medical evidence that a different practice or treatment would be futile.<sup>20</sup> Doubts were widely espoused via media regarding the truth of medical evi-

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<sup>18</sup> M. Phillips, *A Cruel and Ignorant Campaign* (July 26, 2017). <https://www.melaniephillips.com/cruel-ignorant-campaign> (accessed July 20, 2018).

<sup>19</sup> W. Gore, "Now Charlie Gard's Parents Have Ended Their Court Case, We Should Ask Why His Case Became The Media Circus It Did" (July 24, 2017). <https://www.independent.co.uk/voices/charlie-gard-court-case-ruling-became-media-circus-a7857841.html> (accessed March 1, 2019).

<sup>20</sup> Ibidem. See also N. Triggle, "Alfie Evans: Is 'Guerrilla Warfare' A Sign of Things to Come?" (April 30, 2018). <https://www.bbc.co.uk/news/health-43898972> (accessed August 2, 2018).

dence.<sup>21</sup> Indeed, the more “evidence” supplied by the medical profession (within the limits of professional ethics and confidentiality), the more the parents claimed they, and their children, were victims of an uncaring system, that their own wishes were being undermined, and the children were effectively imprisoned.<sup>22</sup> It has long been accepted that perceptions of “the truth” depend not upon evidence, but upon interpretation, and in particular, confirmation bias, influenced by context and one’s own background.<sup>23</sup> Each “side” inevitably felt their position was confirmed by the “evidence” they garnered. The effect was devastating, as the paediatrician Dr. Jayaram expressed:

It is sad to hear about cases that end up having to go to court; I wonder how the gulf of understanding between the families and the teams looking after their children has been allowed to open up. A judge’s decision on what should happen is an unsatisfactory outcome for everyone compared to a plan negotiated and designed together.<sup>24</sup>

## II. Framing of media stories

Those involved selectively chose evidence and saw this as justification for their views – examples of confirmation bias and can be related to the process of “framing.” Framing, as defined by Goffman, refers to the frameworks or schemata employed to interpret events. Since these can be subtle and rely on concepts of perceived “common sense,” their influence is often overlooked.<sup>25</sup> However, what is “accepted” as “common sense” is itself a normative process, that can differ between groups, but with a dominant perception framing any issue. Hence, the very notion of, and appeal to, “common sense” carries with it various

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<sup>21</sup> W. Gore, “Now Charlie Gard’s Parents.”

<sup>22</sup> N. Triggles, *Alfie Evans: Is ‘Guerrilla Warfare’*.

<sup>23</sup> R. S. Nickerson, “Confirmation Bias: A Ubiquitous Phenomenon in Many Guises,” *Review of General Psychology* 2:2 (1998): 175-220.

<sup>24</sup> R. Jayaram, “As A Paediatrician, I Can Tell You That The Case Of Charlie Gard Isn’t As Black and White As It Seems,” *The Independent* (July 6, 2017). <https://www.independent.co.uk/Voices/charlie-gard-gosh-great-ormond-street-hospital-life-support-pope-donald-trump-a7827276.html> (accessed June 10, 2018).

<sup>25</sup> Goffman, *Frame Analysis*.

interpretations, not least one relating to potentially conflicting public or expert opinions. For the Romans, "common sense" was indeed that of the "common" people, and therefore seen as "vulgar." "Vulgar law" was understood as not official or classical Roman law, but the law practised by the peoples and their conception of what was required.<sup>26</sup> This is clearly not the Aristotelian view of common sense (*koine aisthesis* or *sensus communis*) as a higher-order perception that humans uniquely possess.<sup>27</sup> Nor is it the "common sense" defined by the Marxist Gramsci as reflecting and imposing the interests of dominant classes.<sup>28</sup> In the 21<sup>st</sup> century, we are theoretically attuned to the infinite variety of viewpoints that may exist, and yet opposing views tend to be framed within these three unequal concepts, even if subliminally. The legal and medical systems portray themselves as embodiments of rationality and reason,<sup>29</sup> and hence, a specific interpretation of "common sense." Encompassing differing opinions has proven problematic, but normally concerns refusal of treatment for example, for religious reasons, with some authors choosing to define these as "non-rational."<sup>30</sup>

Every day, these concepts of "rationality" and accompanying "legal and medical paternalism" are usually accepted. Parents' demands for treatment have been refused on the grounds of medical futility,<sup>31</sup> medi-

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<sup>26</sup> H. Brunner, *Zur Rechtsgeschichte der Römischen und Germanischen Urkunde* (Berlin, 1880), 113; see also 139; and idem, *Deutsche Rechtsgeschichte I* (Leipzig, 1887), 255, 2nd ed. 1906, 377, cited in Boudewijn Sirks (Hrsg.). *Aspects of Law in Late Antiquity: Dedicated to A.M. Honoré on the Occasion of the Sixtieth Year of his Teaching in Oxford*. (Oxford: Souls College, 2008): S. 35-53.

<sup>27</sup> *Aristotle's Psychology: A Treatise on the Principle of Life* (De Anima and Parva Naturalia), ed. W. Hammond, trans. William Hammond (Cambridge, MA, Swann Sonnenschein, 1907), 204. Digitised for Google Books on June 6, 2006.

<sup>28</sup> *Gramsci and Marxist Theory*, ed. C. Mouffe (London: Routledge, 1979).

<sup>29</sup> R. Anthony-Pillai, "Alfie Evans Case: Are the Notions of Best Interests and Futility Just Paternalism Rebranded?" *British Medical Journal* 361(2018) (Published June 1, 2018) doi: <https://doi.org/10.1136/bmj.k2436>.

<sup>30</sup> M. Stauch, "Rationality and the Refusal of Medical Treatment: A Critique of the Recent Approach of the English Courts," *Journal of Medical Ethics* 21 (1995): 162-5.

<sup>31</sup> L. J. Schneiderman, N. S. Jecker, A. R. Jonsen, "Medical Futility: Its Meaning and Ethical Implications," *Annals of Internal Medicine* 112 (1990): 949-54.

cal standards,<sup>32</sup> patient suffering, lack of net benefit to the patient,<sup>33</sup> or cost.<sup>34</sup> Numerous life and death cases are decided by various courts, including the European Court of Human Rights, without the accompanying public animosity revealed by the two cases of Charlie Gard and Alfie Evans. Indeed, public opinion is rarely invoked to assess legal or medical rationality. Doctors and charities stress that cases like Charlie Gard and Alfie Evans are exceptions.<sup>35</sup> However, doctors state that there are “at least 49,000 children and young people in the UK with illnesses that may cut their lives short.”<sup>36</sup> Therefore, the potential for future disputes exists, especially if the media become involved. The cases of Charlie Gard and Alfie Evans were highly publicised, across multiple media, and involved very young children, and young parents. It has been argued that medical futility cases result in mistrust between doctors and patients or their families<sup>37</sup> and that these two cases, in particular, may set a worrying precedent in that medical and legal decisions will be tried by the media, resulting not in solution, but disappointment and increased mistrust.<sup>38</sup>

The difficulty for the medical profession in such cases was highlighted by the paediatrician Dr. Jayaram:

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<sup>32</sup> J. J. Paris, M. D. Schreiber, M. Statter, et al, “Beyond Autonomy – Physicians’ Refusal to Use Life-Prolonging Extracorporeal Membrane Oxygenation,” *New England Journal of Medicine* 329 (199): 354-7.

<sup>33</sup> S.H. Miles, “Informed Demand for ‘Non-Beneficial’ Medical Treatment,” *New England Journal of Medicine* 325 (1991): 512-5.

<sup>34</sup> F. D. Moore, “The Desperate Case: CARE (Costs, Applicability, Research, Ethics),” *Journal of the American Medical Association* 261 (1989): 1483-4.

<sup>35</sup> C. Burns, “Charlie Gard’s Parents Want ‘Charlie’s Law,’” Health Correspondent, BBC News (June 20, 2018).

<https://www.bbc.co.uk/news/health-44334306> (accessed August 2, 2018).

<sup>36</sup> *Ibidem*.

<sup>37</sup> Lawrence J. Schneiderman, Nancy S. Jecker, and Albert R. Jonsen, “Medical Futility: Response to Critiques,” *Annals of Internal Medicine* 125 (1996): 669-674.

<sup>38</sup> J. Sharman, “Stop Attacking Doctors and Read the Full Charlie Gard Court Judgments, Paediatrician Tells Social Media Users,” *The Independent* (July 8, 2017). <https://www.independent.co.uk/news/uk/home-news/charlie-gard-mother-connie-yates-donald-trump-pope-offer-help-not-in-pain-terminally-ill-baby-boy-a7828601.html> (accessed September 2, 2018); R. Heywood. “Parents and Medical Professionals: Conflict, Cooperation, and Best Interests,” *Medical Law Review* 21:1 (2012), 29.

As human beings, we like things to be black and white, good guys versus bad guys, the establishment versus the little man. Unfortunately, medicine inevitably operates in shades of grey and there is rarely a 100 percent “right” thing to do. Every decision is a balance of potential benefit against potential harm. As a result of the binary media coverage, many people have developed fixed opinions on the situation on one side or the other, which they express passionately and loudly.<sup>39</sup>

The media, and particularly the tabloid press or social media, are not traditionally known as fora for rationality, but often rely upon sensationalism, emotion, and simplification: the latter is seen as a lesser form of news journalism in much academic writing.<sup>40</sup> However, recent writing has questioned this value-driven interpretation, arguing that tabloid journalism represents the public interest.<sup>41</sup> As early as 1997, Franklin argued that all media was becoming more like tabloid media.<sup>42</sup> Thompson further argued that the mediated public sphere is one where struggles for visibility now occur.<sup>43</sup> The two legal cases have proven highly emotional, and widely publicised, with most criticism focussing upon the effect on the child and his parents. Many critics of the way the cases were handled supported and emphasised the “rights of parents,” in particular, to decide what medical treatment their children should receive. A common theme across social media, widely stated, and similarly believed by many, was that the parents were the ones fighting for what was best for their child.<sup>44</sup>

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<sup>39</sup> R. Jayaram, “As a Paediatrician.”

<sup>40</sup> *Tabloid Tales. Global Debates Over Media Standard*, ed. C. Sparks and J. Tulloch (Kindle Edition: Rowman & Littlefield, 2000).

<sup>41</sup> H. Örnebring and A. M. Jönsson, “Tabloid Journalism and the Public Sphere: A Historical Perspective on Tabloid Journalism” (published online: 17 Feb. 2007), 283-295.

<https://www.tandfonline.com/doi/full/10.1080/1461670042000246052?src=recsys> (accessed November 20, 2018).

<sup>42</sup> B. Franklin, *Newszak & News Media* (London: Arnold, 1997).

<sup>43</sup> J. B Thompson, *The Media and Modernity: A Social Theory of the Media* (Oxford: Polity Press, 1995), 247.

<sup>44</sup> *The Guardian*, “Connie Yates: We Will Always Know We Did The Very Best For Our Son Charlie Gard” (July 24, 2017).

Alternatively, doctors treating Charlie Gard and Alfie Evans relied upon their medical expertise, and argued that the children's conditions were irreparable, further intervention to be futile, and not in the children's best interests. However, beyond the issue of "rights" and "interests," the debates were framed in two very different types of language, crucially affecting the interpretation of the actual situations. Such interpretations have serious implications for the public perception of medical professionalism, beyond these two particular cases.

Both cases shared *emotive* information and language through social media, coming from the parents, not from the medical viewpoints. For instance, Charlie Gard's parents characterised the hospital and its lawyers as "evil," before rushing out of the courtroom when medical evidence was given.<sup>45</sup> Medical experts cited the facts of Charlie's condition, that he had a rare form of mitochondrial disease, and may have been suffering.<sup>46</sup>

Undoubtedly this media information did inform and capture people's attention and mobilised many people in support of the parents, resulting in a form of activism. Research upon Twitter references to Great Ormond Street Hospital revealed an overwhelming use of the words "murder" and "killed."<sup>47</sup> As Das argues, the analysis of words used to suggest devastation and loss revealed the top ten to be: devastated, heart-breaking, cruel, death panel, loss, tragic, and threaten.<sup>48</sup>

This chapter argues that the use of social media for such purposes requires some ethical dimension, considering the consequences of selective "information sharing" and, moreover, what should be shared, and how. Medical staff suffered abuse at both Great Ormond Street Hospital and Alder Hey Hospital, with Merseyside police investigating

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<https://www.theguardian.com/uk-news/2017/jul/24/connie-yates-we-will-always-know-we-did-the-very-best-for-charlie-gard> (accessed July 28, 2017).

<sup>45</sup> ITV Report, "Dad Yells 'Evil' as Lawyer Reveals Charlie Gard's Latest Scan Makes 'Sad Reading'." <https://www.itv.com/news/2017-07-21/dad-yells-evil-as-lawyer-reveals-charlie-gards-latest-scan-makes-sad-reading/> (July 21, 2017) (accessed August 3, 2018).

<sup>46</sup> *Ibidem*.

<sup>47</sup> R. Das, "The Charlie Gard Twitterstorm: A Violent and Negative Impact (New Research)," <https://blogs.lse.ac.uk/polis/2017/08/04/the-charlie-gard-twitterstorm-a-violent-and-negative-impact-new-research/>.

<sup>48</sup> *Ibidem*.

allegations that patients and staff at the latter had been intimidated.<sup>49</sup> Arguably, such behaviour was not solely or even largely due to the information shared, but more *the manner in which the situation was manipulated by parents and the media, particularly the tabloid press.*

Studies on the language of the press have previously shown significant differences in use in the tabloid and broadsheet press. The former contains more emotive and often inflammatory language, for example “killing a child,” and reducing the case to a “soap opera.”<sup>50</sup> Social media, for example upon the internet, and Twitter, similarly rely upon soundbites and appeals to the emotional. Indeed, the 2002 Nobel Prize winner, psychologist Daniel Kahneman, in his book *Thinking, Fast and Slow*, demonstrated how people use two very different systems in their minds: Intuitive and Automatic, and Lazy and Calculative.<sup>51</sup> The former utilises gut instinct, emotions, and unconscious decision-making: the latter slow, conscious, and rational thinking. Anger is one of the strongest emotions, and hence, it can be activated quite easily in media campaigns, such as the two cases herein. Whilst the rational can override the emotional, in reality, people tend to rely more upon the first system. Social media draws upon this psychological reality to its own advantage, whereas the medical profession, arguably, tends to be centred in the second system, and thus more limited in its social appeal potential.

The academic studies above on “framing” and “thinking” processes have not traditionally considered medical cases, although some recent works have done so.<sup>52</sup> They have, however, focussed upon the social

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<sup>49</sup> BBC News, “Alfie Evans: Legal Battle Toddler Dies” (April 28, 2018). <https://www.bbc.co.uk/news/uk-43933056> (accessed August 4, 2018).

<sup>50</sup> C. Mortimer, “Charlie Gard Medic Hits Out at ‘Soap Opera’ Surrounding the Court Case and Meddling of Politicians,” *The Independent* (August 5, 2017). <https://www.independent.co.uk/news/uk/home-news/charlie-gard-court-case-great-ormond-street-hospital-high-court-battle-connie-yates-chris-gard-a7878026.html> (accessed August 9, 2018).

<sup>51</sup> D. Kahneman, *Thinking, Fast And Slow* (London: Penguin Books Ltd., 2012).

<sup>52</sup> T. V. Perneger and T. Agoritsas, “Doctors and Patients’ Susceptibility to Framing Bias: A Randomized Trial,” *Journal of General Internal Medicine* 26:12 (2011): 1411–17.

doi:10.1007/s11606-011-1810-x. PMC 3235613. PMID 21792695.

construction of social phenomena, and social interaction.<sup>53</sup> Thus, this chapter argues that not only what information is given, but the language used, and the context, have a significant effect upon perceptions of “reality” and have a significant impact, proving crucial in these medical cases. Regarding what information was available via the press, it was stated that:

... journalists and the SMC (Science Media Centre) found it very difficult to find medics, paediatricians and palliative nurses who could speak. Once again, the voice of the medical community was represented by very few individuals. And so once again the level of information available to the public was woefully imbalanced... Managers and executives in hospitals, NHS Trusts, and medical institutions were preventing their staff from speaking to the media about the Alfie Evans story. Time and again I was told “I’ve been told I can’t give you a quote,” “I am being muzzled,” “I agree experts need to be heard but my manager has put us all on lockdown.” These comments did not come from hospital juniors, but from professors, senior medics and leading paediatric nurses.<sup>54</sup>

No doubt, medical professionals and managers feared reprisals and were risk averse regarding engaging with the press. However, the effect was that the subsequent press coverage was severely imbalanced, and in the parents’ favour.

Moreover, even when messages were given by the medical profession, these appeared tied to mainly managerial and medical rhetoric, defining the condition in medical terms, “mitochondrial disease” and “best interests.” In contrast, the legal profession, still constrained by protocol, was able to state, as per Mr Justice Francis, that the decision to allow the cessation of life support was made: “with the ‘heaviest of hearts’ but with ‘complete conviction’ (that) it is in Charlie’s best inter-

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<sup>53</sup> Goffman, “Frame Analysis”; *Media Effects: Advances in Theory and Research*, ed. J. Bryant & M. B. Oliver (New York: Routledge, 2008); T.V. Perneger, T. Agoritsas, “Doctors and Patients.”

<sup>54</sup> T. Sheldon, “There will be Another Alife Evans: Experts Need to Engage” (May 10, 2018). <http://www.sciencemediacentre.org/there-will-be-another-alfie-evans-experts-need-to-engage/> (accessed August 4, 2018).

ests.”<sup>55</sup> In contrast, the parents and the mainly tabloid media were able to utilise often highly emotive and inflammatory images. As Wittgenstein argued, “the meaning of a word is its use in the language.”<sup>56</sup> Thus, meaning is not a concrete reference, “language (is) a game: the game of language.”<sup>57</sup>

Social media proved more adept at playing the game and manipulating public opinion via language and images. Both sets of parents used selective information and photographs of their children not necessarily related to the child’s current situation. Charlie Gard’s parents, for example, used photographs of a two-week old Charlie, thus taken before his condition was diagnosed at eight weeks, when he was admitted to hospital with encephalomyopathic mitochondrial DNA depletion syndrome. The medical name would mean little to the layperson, particularly since this was a rare disease caused by mutations in gene RRM2B inherited from both parents. Indeed, it was widely reported, particularly in the tabloid press, that only 16 people in the world have been diagnosed with this condition.<sup>58</sup>

The images supplied via the media gave little or no indication of the actual serious condition of Charlie. Instead, these images often showed earlier images or those suggesting merely sleep, accompanied by children’s comforters, such as teddy bears. The language of the media thus includes visual imagery. Indeed, a teddy bear became an image associated with Charlie Gard, worn by his parents, and attached to the gates of the Royal Courts of Justice.<sup>59</sup>

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<sup>55</sup> Mirror News, “His Legacy Will Never Die’: Charlie Gard Passes Away after Capturing Nation’s Hearts in 11 Previous Months” (July 28, 2017). <https://www.mirror.co.uk/news/uk-news/charlie-gard-baby-boy-dies-10891696> (accessed August 4, 2018).

<sup>56</sup> L. Wittgenstein, *Philosophical Investigations* translated by G.E.M. Anscombe (Oxford: Basil Blackwell, 1963): Sect. 43.

<sup>57</sup> *Ibidem*.

<sup>58</sup> Reported in Alison Smith-Squire and Sophie Roberts, “If We Were British Our Son Would Be Dead” (*The Sun*, April 13, 2017). <https://www.thesun.co.uk/living/3318065/arthur-olga-estopinan-arturito-charlie-gard-court-case/> (accessed November 20, 2018).

<sup>59</sup> The image can be seen within this online article: C. Domonoske, “Terminal-ly II Baby Charlie Gard Will Move to Hospice Care to Die,” <https://www.kut.org/post/terminally-ill-baby-charlie-gard-will-move-hospice-care-die> (accessed November 20, 2018).

Furthermore, both sets of parents denied the medical definitions of their children's conditions, and both vociferously argued that potential treatment abroad could be "life-saving."<sup>60</sup> Medical professionals stated that both Charlie and Alfie had severe brain damage, that Charlie could not move his limbs or breathe unaided, and that no cure existed.<sup>61</sup>

The parents used many types of descriptions for the evoking viewpoints to which they disagreed, partly depending upon the narrator. When brain scans were used in court to reveal the extent of Charlie's situation, his parents responded by calling the lawyer "evil" for revealing this.<sup>62</sup> Alfie Evans<sup>63</sup> was diagnosed by scans at Alder Hey Hospital as having "catastrophic degradation of his brain tissue."<sup>64</sup> The hospital argued that further treatment for Alfie was not only futile but also "unkind and inhumane,"<sup>65</sup> Alfie's parents responded by "heavily (criticising) medical staff, with Mr Evans suggesting his son was a 'prisoner' at the hospital and had been misdiagnosed."<sup>66</sup> Michael Mylonas QC, representing the hospital, said: "One of the problems of this case is they [Alfie's parents] look at him and, barring the paraphernalia of breathing and feeding, he's a sweet, lovely, normal-looking boy who opens his eyes, [and] will smile..."<sup>67</sup> Whereas the hospital asserted that any movements by the child were "spontaneous seizures as a result of touching."<sup>68</sup>

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<sup>60</sup> N. Debnath, "Charlie Gard: Mother Connie Yates Makes Heartbreaking Plea to Try New Treatment" (July 7, 2017). <https://www.express.co.uk/showbiz/tv-radio/825809/Charlie-Gard-mum-Connie-Yates-Chris-Gard-Good-Morning-Britain-ITV> (accessed August 15, 2018).

<sup>61</sup> BBC News, "Who was Alfie Evans and What Was the Row over His Treatment?" (April 28, 2018). <https://www.bbc.co.uk/news/uk-england-merseyside-43754949> (accessed July 11, 2018).

<sup>62</sup> G. Heffer, "Timeline: Parents' Battle to Save Charlie Gard," (August 4, 2016). <https://news.sky.com/story/timeline-parents-battle-to-save-charlie-gard-10914755> (accessed July 6, 2018).

<sup>63</sup> BBC News, "Alfie Evans: Legal Battle Toddler Dies" (April 28, 2018) <https://www.bbc.co.uk/news/uk-43933056> (accessed July 10, 2018).

<sup>64</sup> *Ibidem*.

<sup>65</sup> *Ibidem*.

<sup>66</sup> *Ibidem*.

<sup>67</sup> BBC News, "Who Was Alfie Evans."

<sup>68</sup> *Ibidem*.

Examples of the *constraints of managerialism* within the NHS can be seen in the comments of medical ethicist Dr. Daniel Sokol. Indeed, Dr. Sokol's comment neatly summarises the language outside of the medical profession, but also the limitations placed upon an NHS response. He stated that the approach of the parents:

smacks of "guerrilla warfare" where threats, insults, intimidation, and distortion of facts were used to put "unbearable pressure" on the health service... In both cases, parents and their supporters were able to use social media to make their points. And when faced with emotional pleas from parents - ... it is almost impossible for the NHS to provide the counter-argument while ensuring it maintains patient confidentiality, remains respectful to families and protects its staff. It creates an environment where the NHS can be painted as uncaring and the weight of expert opinion can be ignored by the public.<sup>69</sup>

Clearly, however, Dr. Sokol was not averse to evoking the language of warfare when discussing the parents and the media coverage. Undeniably the literal, metaphorical, and visual imagery of warfare was overt in social media. The metaphorical imagery is common in discourse regarding, particularly, cancer (with both negative and positive implications).<sup>70</sup> However, in the cases above, the metaphors involved more than one connotation, suggesting both a fight against disease in general, but also against the medical profession, and the hospitals involved. The public were visibly and vociferously engaged in the parents' legal fights with the hospitals. Charlie Gard's parents used "Charliesfight" and "charliesarmy" in their banners.<sup>71</sup> Alfie Evans' father referred to: "My gladiator laid down his shield" on social media.<sup>72</sup> Web pages and Twitter feeds used the titles: [Charliesfight.org](http://Charliesfight.org) and [#charliesarmy](https://twitter.com/charliesarmy). Charlie was proclaimed to be "still fighting," despite there being little indication

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<sup>69</sup> N. Triggle, "Alfie Evans: Is 'Guerrilla Warfare'?"

<sup>70</sup> D. J. Hauser and Norbert Schwarz, "The War on Prevention Bellicose Cancer Metaphors Hurt (Some) Prevention Intentions," *Journal of Experimental Social Psychology* 48 (2014): 948-952.

<sup>71</sup> Image available here: BBC News, "Alfie Evans Legal Battle."

<sup>72</sup> *Ibidem*.

or possibility of him voluntarily exerting such action.<sup>73</sup> The metaphors of army and fighting thus reaffirmed not only the image of conflict and war, against a disease, or medical condition but also of incompatibility and intractability regarding the medical advice. Arguably, such negative connotations severely hindered the public understanding and ultimate discussion and resolution of these difficult cases.

Ms. Yates, Charlie's mother, stated on national television and other media that she had spoken to doctors all over the world, with five offering treatment<sup>74</sup> and had endlessly researched a possible cure for Charlie's condition. Indeed, Charlie Gard's case achieved not only worldwide notoriety but the support of "celebrities" such as Sam Faiers, Billi Mucklow (reality television stars), television presenter Gaby Roslin, and actress Linda Robson. Interest extended beyond television with the UK Prime Minister Theresa May, and, as noted above, the Pope and Donald Trump also supporting Charlie Gard's parents. None of these supporters were medically or legally qualified. Moreover, the media itself subjectively manipulated opinion. Hurley argues, for example, that the *Daily Mail* juxtaposed images from the Charlie Gard case next to a headline relating to a different recent event – "Manslaughter" and the Grenfell tragedy.<sup>75</sup>

Whilst Great Ormond Street Hospital did supply statements regarding the ongoing court decisions, the language was subdued and respectful, albeit given by "a spokesperson," and hence not someone with whom the public could identify. On the final decision by the High Court to not pursue further treatment, the hospital gave a public statement. The message paid tribute to the family involved, yet also reiterated the hospital's role for countless others. Arguably this understandable

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<sup>73</sup> Ibidem.

<sup>74</sup> N. Debnath, "Charlie Gard."

<sup>75</sup> R. Hurley, "How a Fight for Charlie Gard Became a Fight against the State," *British Medical Journal* (2017): 358, j3675BMJ (1 August 2017). The "Grenfell Tragedy" occurred on 14 June 2017. This refers to a fire at the 24-storey Grenfell Towerblock of flats in North Kensington, West London. It caused 72 deaths, including those of two victims who later died in hospital. More than 70 others were injured, and 223 people escaped. It was the worst UK residential fire since the Second World War. Its causes are under investigation, with some in the press believing that gross negligence manslaughter could be an appropriate consideration.

emphasis may have suggested to some that the reputation of the hospital was a primary concern. In the light of the negative publicity surrounding these cases this is perhaps only to be expected:

A spokesperson for Great Ormond Street Hospital said: We have always paid tribute to the extraordinary courage and strength of Connie Yates and Chris Gard and their devotion to their son. Today our hearts go out to them as they face the most difficult decision that any parent should ever have to make.

Our staff share the parents' sadness over Charlie, whom they have cared for with dedication during the months he has spent at Great Ormond Street Hospital. We were heartened to hear their appreciation of our staff's care in their recent public statement.

We seek to care for and support every parent who brings their child to Great Ormond Street Hospital and it is a source of great regret in the very rare cases when an agreement cannot be reached about what is in the child's best interests.

This has been an incredibly complex case, going to the heart of medical ethics and when, and if, experimental treatment is acceptable for children suffering from rare diseases. We would like to acknowledge all those who have contributed their expertise and advice.<sup>76</sup>

### **III. Conclusion: the need for mediation**

Above has discussed the role of the media in medical futility cases. It has highlighted the apparent "intractability" that can occur once such cases enter the media gaze. Below concludes by discussing the potential for mediation to avoid "framing" and "flaming" the debates in such difficult cases, and for ideally enabling a mutually acceptable conclusion. At the very least, mediation gives the opportunity for all sides to state their views, in a confidential environment. To avoid, or ameliorate, similar situations to the Charlie Gard and Alfie Evans cases in the

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<sup>76</sup> "Latest Statement on GOSH Patient Charlie Gard" (July 24, 2017). <https://www.gosh.nhs.uk/news/latest-press-releases/gosh-position-statement-issued-high-court-24-july-2017> (accessed July 25, 2017).

future, this chapter argues for the need to recognise that there may be strongly held, but potentially incompatible, beliefs by the parents and the medical profession regarding the treatment of young children. Mediation is suggested as a method to promote if not a completely satisfactory result for all parties, one that is capable of achieving a remotely acceptable result, without the risk of mass media involvement and public antagonism.

Ideally, the format would be a neutral environment, utilising an impartial mediator. The current dependency upon the law to resolve disputes that have become intractable is far from ideal. Since clinicians are more constrained in the information they can reveal to the press, and the methods of doing so, the confidential and impartial forum that mediation offers would be preferable. Much of the antagonism directed towards the hospitals in the cases above appears to emanate from a sense of not being listened to, and an inability to express alternative viewpoints.<sup>77</sup> The benefits of mediation are often espoused as providing a forum and an atmosphere conducive to mutual understanding and cooperation. The ultimate aim is a mutually-agreed resolution, determined by the parties. Mediation is stated to be a cost-efficient method, not merely in financial terms.<sup>78</sup>

As Heywood states, the costs associated with a breakdown in the relationship between clinicians and parents can be financial, emotional, and physical. Clinicians are, in a very real sense, mediators. Treatment is an enterprise that is dependent upon cooperation and this necessitates a relational approach. Whilst the duty to communicate with and consult parents is clear in both law<sup>79</sup> and ethics,<sup>80</sup> the waters are muddied by inconsistent ethical guidance on unproven, innovative treatment and latterly by inconsistencies in the legal approach.<sup>81</sup> The involvement of the ECtHR in *Glass v UK*, for example, focussed upon legal avenues,

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<sup>77</sup> C. Burns, “Charlie Gard’s Parents Want ‘Charlie’s Law’.”

<sup>78</sup> H. Morreim, “Conflict Resolution in the Clinical Setting: A Story Beyond Bioethics Mediation,” *Journal of Law, Medicine and Ethics* (Research Article First Published December 1, 2015). <https://doi.org/10.1111/jlme.12324>.

<sup>79</sup> *Glass v United Kingdom* (App no 61827/00) [2004] 1 FCR 553.

<sup>80</sup> R. Heywood, “Parents and Medical Professionals: Conflict, Cooperation, and Best Interests,” *Medical Law Review* 20:1 (2012): 29-44.

<sup>81</sup> E. Cave, E. Nottingham, “Who Knows Best (Interests)? The Case of Charlie Gard,” *Medical Law Review* 26:3 (2018): 500-513.

and the need for doctors to seek authorisation from the courts to overrule parents' objections, when both sides felt they were acting in the "best interests of the child." The mother in *Glass* sought an unsuccessful judicial review of the doctor's treatment and similarly unsuccessful criminal action. However, the ECtHR found a breach of Article 8 for failure to seek legal backing prior to action being taken. It has been argued that in the Charlie Gard case:

Professional guidance from the GMC and Royal College of Paediatrics and Child Health raised doubts as to the ethics of sanctioning the unproven therapy and in law, it was questionable on existing legal precedent that it would satisfy either the best interests test or the *Bolam* standard of reasonable care. In light of this, mediation could not have focussed on finding a compromise, for there was no such middle path.<sup>82</sup>

Undoubtedly, sanctioning mediation as a method to consider the wishes of the parents, including the use of unproven therapy, provided the risks were understood, could be a departure from the emphasis upon ethical and legal guidelines, and requires a rethinking of what, and who decides, is in the child's best interests. However, this chapter argues that such an approach could be considered in the future. The final mediation decisions would be binding, but confidential, unless a public interest case existed, and must respect any human rights issues.

Without the possibility of a "public interest" clause, such confidentiality would mean that these cases would not set a precedent for the future which could be considered a negative outcome for developments in this area. Indeed, a number of critics (e.g. Fiss; Nader; and Edwards) have made such comments, accusing mediation of "sweeping injustices under the carpet by dealing with each individual dispute privately, so that bad practice attracts no negative publicity and no precedents are set for the future."<sup>83</sup>

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<sup>82</sup> *Ibidem*.

<sup>83</sup> C. Irvine, "Mediation Confidentiality: Limitations and a Proposal" (2012). <http://mediationblog.kluwerarbitration.com/2012/09/12/mediation-confidentiality-limitations-and-a-proposal/> (accessed August 5, 2018). O. M. Fiss, "Against Settlement," 93 *Yale Law Journal* 1073 (1984): 1085–87; L. Nader, "Disputing Without the Force of Law," 88 *Yale Law Journal* 998(1979):

Conversely, as this chapter argues, once in the public sphere, the wishes and perceptions of the parents appear paramount and are most often espoused, in highly emotional terms. In this arena, the medical profession appears cold and distant, constrained by confidentiality and medical jargon. In the forum of mediation, both parties would have the opportunity to voice their views, without the opportunity for the media to “frame and flame” the debate. As Mr Justice Francis in the Charlie Gard case stated: “It is my clear view that mediation should be attempted in all cases such as this one even if all that it does is achieve a greater understanding by the parties of each other’s positions.”<sup>84</sup>

Since the death of Charlie Gard, his parents have used the media to campaign for *Charlie’s Law*: “One key part of the law would be having independent medical mediators involved in disagreements as early as possible.”<sup>85</sup> In their media campaign, they quoted Great Ormond Street Hospital as agreeing that: “mediation is one of the important ways in which we work with families to reach agreements, in the best interests of the child.”<sup>86</sup> However, Charlie’s parents stated that they had asked for mediation in the months prior to Charlie’s death, but that this had been refused.<sup>87</sup> As this chapter argues, one key issue in such cases is the need for both parties, and in particular, the parents, to feel that their voices are being heard. If this is not undertaken via mediation, it is highly likely that a media campaign will provide that space. As Charlie’s father stated: “If mediation had taken place with an independent mediator, we would have felt our voices were being listened to.”<sup>88</sup>

Whilst Great Ormond Street Hospital argued that it offered mediation in the final few days of Charlie’s life,<sup>89</sup> clearly, this was too little,

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1007–08). See also H. Edwards, “Alternative Dispute Resolution: Panacea or Anathema?” *Harvard Law Review* 99 (1986): 668–684, 671–72, 675–82.

<sup>84</sup> Mr Justice Francis, quoted in *The Guardian*, “Charlie Gard’s Short Life Pitched Parents into Turmoil and Grief,” (July 28, 2017).

<https://www.theguardian.com/uk-news/2017/jul/28/charlie-gards-short-life-pitched-parents-into-turmoil-and-grief>. See, also, for example, <https://www.medicalmediation.org.uk> (accessed August 10, 2018)

<sup>85</sup> C. Burns, “Charlie Gard’s Parents Want ‘Charlie’s Law’.”

<sup>86</sup> *Ibidem*.

<sup>87</sup> *Ibidem*.

<sup>88</sup> *Ibidem*.

<sup>89</sup> *Ibidem*.

too late, to prevent the involvement of the media, with the subsequent effects discussed above. Lessons for the future should include the timing of the offer of mediation. The final word is given to Sarah Barclay, Director of the Medical Mediation Foundation, who mediates between five and ten parents-doctors conflicts a year: "Sometimes it feels like there's a bit of a battle developing." She explains: "Mediation is always surprising in the way it can break through really intractable conflicts."<sup>90</sup>

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<sup>90</sup> Ibidem.