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The Harm of Media in Pediatric Intensive Care Conflicts: Lessons from the Charlie Gard Case

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Abstract

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By Katherine Riedel

As pediatric critical care medicine has grown in technological capability, fewer children die suddenly. Instead, most children who die in the pediatric intensive care unit (PICU) do so following a controlled withdrawal of life sustaining technology. Given that children lack the developmental capacity to express their wishes, serious PICU decisions are made jointly between parents and pediatric healthcare professionals. Although the pediatric family centered model of care requires an attitude of shared decision-making, there are many factors such as parent emotional strain and physician bias that can make this process challenging. PICU conflict is common, most often arising from communication failures, and value differences.

Parents who encounter PICU conflict may be tempted to utilize the media for support. While media use can offer many benefits for these families, it can also come at the risk of serious ethical harm. The Charlie Gard case is one such example of how well-intentioned media use can quickly escalate to harming the interests of critically ill children. The following details many of the ways in which media use can negatively impact the sick child's human rights. Of particular concern are the rights to future welfare, dignity, and privacy. To mitigate these harms, a case is then made, not only for more bioethical attention regarding child media harm, but also for strategies to mitigate PICU conflict without the need for media attention.

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Contents

In the past century, Western society has undergone multiple technological changes. Although many of these technologies, such as advances in medical science and the invention of global media, have social benefits, the consequences of the technologies often intersect in new ethically complex ways. One such intersection, namely the impact of media involvement in pediatric critical care decision making conflict is the focus of this paper. I suggest that the field of pediatric bioethics has been slow to address the unique ethical implications of media involvement in disagreements regarding critically ill and dying children. While I concede that media coverage holds many potential benefits, primarily for families, I argue that there is risk of substantial ethical harm to the fundamental rights of children. Throughout the paper, I use the media coverage of British infant Charlie Gard as a case example of the many potentials for complex and lasting harm. It is through this discussion that I conclude with a discussion of conflict mitigation strategies, aiming to address the unique bioethical considerations of critically ill children and their families.

Prior to the 18th century, half of all children died before their fifth birthday. Largely attributed to improvements in public health and the expansion of pediatric focused medicine, child mortality rates have dropped dramatically from 100 per 1,000 births in 1900 to 5.9 per 1,000 births in 2015 (Miller-Smith, 2019). One of the factors' influencing mortality was the 1960s creation of a pediatric critical care medicine subspecialty (Miller-Smith, 2019). The modern pediatric intensive care unit is a technologically sophisticated place in which specialized medical teams care for a wide range of childhood trauma, congenital disease, and life-threatening illness.

While most modern pediatric death occurs in the intensive care environment, even here, death is rare, with mortality in only 3% of all intensive care admissions (Miller-Smith, 2019). Of

these deaths, few result from unsuccessful attempts at cardiopulmonary resuscitation. Instead, approximately 70% of all deaths occur in a controlled manner, following the elective withdrawal of life-sustaining technology (Miller-Smith, 2019). Unfortunately, improvements in mortality rates do not necessarily reflect changes in morbidity. Of the children who survive their intensive care admission, approximately 80% do so with a new lasting illness or disability (Rissman, 2023). This expansion in medical ability brings up important questions about the ways in which children die, as well as the costs we are willing to accept to maintain their lives. With scores of life-sustaining options available, the decision to apply and/or remove technology is made on judgements of benefit vs. burden (Miller-Smith, 2019).

Over the past 30 years, pediatric medicine has seen an expansion of parental authority through a developmental care model known as family-centered care. In family-centered-care, pediatricians acknowledge the multiple ways in which a child's growth and wellbeing are grounded within the family dynamic (AAP, 2012). Parents are traditionally the primary surrogate medical decision-makers for their children, as children lack developmental capacity to make autonomous decisions (Lantos, 2017; Bridgeman, 2020). While specially trained physicians are responsible for diagnosis and prognostication, treatment decisions are jointly made with the child's family (Lantos, 2016).

With that consideration, decisions made in the intensive care unit are high-pressure experiences to which many parents lack prior context. Not only is there an experiential split between parents and medical teams but there is also the significant potential for competing interests, such as physician bias and parental emotion. (Kopelman, 1997; Birchley, 2015; Lantos, 2017). Ideally, families and medical teams can come to a consensus on the best course of action.

Unfortunately, disagreements are not rare, with almost half (46%) of families reporting some form of conflict during their loved one's intensive care stay (Abbott, 2001).

Conflicts usually arise from breakdowns in communication and are more likely to occur when there is poor prognosis or elevated levels of medical uncertainty (Abbott 2001; Bridgeman, 2020). Most disagreements can be resolved between participants, however, on rare occasions, they become intractable, where both sides are no longer willing to seek a mutually agreeable compromise (Miller-Smith 2019). These conflicts are often philosophical in nature, involving fundamental disagreement regarding the child's interests (Lantos, 2017).

As the capabilities of pediatric medicine have increased, so have many other social technologies. Media is an integral component of modern life. Not only does the media offer entertainment, but it provides an easy means for the rapid dissemination of information (Mackey, 2016). Media technology has explosively expanded, from the twenty-four-hour television and radio news cycles to the invention of the internet, smart phones, and social media. Media use has many appeals, ranging from the facilitation of self-education to providing an avenue for interpersonal connection (Mackey, 2016; Barrett, 2019).

When critical care disagreements occur, some parents elect to publicize their conflict in the media. This is particularly likely when parents feel as though they are incapable of reaching satisfactory resolution within the shared decision-making process (Barrett, 2019; Kubheka, 2020). Media allows parents to attract the attention of society at large (Moore, 2019). Although the parental motivation may be simply to garner additional support for parental desires, once media attention has been drawn, the outcomes are often variable (Barrett, 2019; Moore, 2019). Children, parents, and healthcare workers may all experience ethically significant harm in the

sequalae of media coverage. The case of British infant Charlie Gard is one such example. (Hurley, 2017).

Charlie Gard

In the United Kingdom on August 4th, 2016, a little boy named Charlie Matthew William Gard was born. Charlie was delivered uneventfully after a full-term uncomplicated pregnancy and initially appeared to be a healthy infant. After several weeks at home however, Gard's parents noted that Charlie's psychomotor skills began to deteriorate. He was no longer interactive with his parents and struggled with developmental milestones typical of his age (Wilkenson, 2017; Montgomery, 2010).

With concern for his health, on October 2, 2016, Charlie's parents took him to a local hospital where he noted to be underweight with significant muscle weakness. Supplemental feedings of high-calorie formula via nasogastric tube were initiated then. On October 11, 2016, after a continued decline in weight and muscle tone, Charlie was transferred to Great Ormond Street Hospital (GOSH), a large pediatric tertiary care center in London. GOSH diagnosed Charlie with failure to thrive, poor feeding, and respiratory failure. While experts searched for an underlying cause, Charlie was moved to the intensive care unit and placed on a mechanical ventilator to support his now minimal respiratory effort. (Wilkinson, 2017; Waldman, 2018; Montgomery, 2019).

Over the next month, Charlie underwent numerous tests to include neurological imaging and genetic studies (Wilkinson, 2017). In early November, genetic tests came back positive for a particularly rare form of infantile onset encephalomyopathic mitochondrial DNA depletion

syndrome (MMDS). MMDS is a series of autosomal recessive disorders that affect the functioning of DNA in mitochondria. Mitochondria are the parts of the cell responsible for cellular energy and functioning. Without functioning mitochondria, individuals experience significant impairment in cellular processes to include the metabolism of energy sources (El-Hattab, 2013).

Charlie's form of MMDS, mutation RRM2B primarily impacts the functioning of the nervous system and the muscles. The gene RRM2B encodes for promotes DNA nucleoside production within the mitochondria (El-Hattab, 2013; Waldman, 2018). With misfunctioning mitochondria, Charlie's muscles were unable to gain enough energy to support movement. Equally, Charlie's nervous system, including his brain would be deprived of necessary nutrients for functioning and starving, ultimately disintegrate. Before Charlie, only fifteen infants in the world were diagnosed with the RRM2B MMDS mutation, all dying in early infancy (Wilkinson, 2017).

By the time of diagnosis, Charlie was entirely paralyzed and dependent on the mechanical ventilator for all his respiratory functions. He also began to show significant deterioration in other senses like his hearing. Finally, in addition to his muscles and nervous system, Charlie's heart, liver, and kidneys also began to display signs of failure. Although the team would continue providing intensive care support for Charlie's body, GOSH physicians advised that they would not escalate therapy and gave his parents a terminal prognosis (Waldman, 2018; Montgomery, 2019). The GOSH physicians were supported by the hospital's ethics committee who advised both against further escalation of therapy as well as against initiation of long-term mechanical ventilation via tracheostomy placement (Wilkinson, 2017; Waldman, 2018; Montgomery, 2019).

Gard's parents acknowledge that his "present condition was not one they would fight to sustain" however rejected the premise that his deterioration was irreversible (*GOSH v. Yates and Ors,* 2017*).* They began to search for experimental therapies, identifying a physician in the United States who was researching the use of orally supplemented deoxypyrimidine nucleosides in another less severe variation of MMDS. The supplement appeared to halt the rate of mitochondrial disintegration with marked improvement in functional status noted. Unfortunately, success had been noted only in early administration prior to symptom onset and in models with a quite different and less severe variation of disease (Hurley, 2017; Wilkinson, 2017). Nucleoside therapy had never been tested in Charlie's RRM2B mutation, nor in patients displaying signs of advanced disease (Hurley, 2017; Waldman, 2018).

In collaboration with the US team, GOSH conceded that there may be a "theoretical possibly of improvement" if no permanent brain damage had occurred (*GOSH v. Yates and Ors,* 2017*).* An MRI showed no structural brain damage and GOSH agreed to proceed with tracheostomy placement and a trial of nucleoside therapy in the pediatric intensive care unit. Unfortunately, prior to trial initiation, Charlie began experiencing prolonged seizures with a repeat MRI showing structural changes. At this point, GOSH physicians judged that any trial would be incapable of reversing the damage that existed, and that subsequently that the potential harms of enrolling Charlie in an experimental trial was not in his best interests (Hurley, 2017; Wilkenson, 2017).

Charlie's parents felt differently and still wished for him to receive experimental nucleoside therapy. The United States team offered to provide the therapy in America, provided that the Gards could pay for transport and treatment associated costs (Waldman, 2018). GOSH physicians were deeply opposed to this plan, arguing that the harms of experimental therapy and

the risky trans-Atlantic transport of a critically ill infant were not in Charlie's best interests (*GOSH v. Yates and Ors,* 2017; Wilkenson, 2017; Waldman, 2018). When Gard's parents remained persistent in their wish, GOSH sought temporary guardianship and appealed via the United Kingdom's Family Division of the High Court for permission to withdraw mechanical ventilation and to provide hospice care. This first case, filed in February 2017 was upheld in favor of GOSH, stating that Charlie should be allowed to "die with dignity" (GOSH *v. Yates and Ors,* 2017; Wilkinson, 2017).

Not only did Charlie's parents legally resist this court ruling, but they also embarked on an extensive media campaign to gain public funding for Charlie's care (Richards 2018). Charlie's parents released pictures, video clips, and details of his medical history with the public via both traditional and social media outlets. The public was wildly responsive (Das 2018; Richards, 2018). Not only did the Gard family raise 1.3 million pounds to be used for Charlie's transport and nucleoside therapy, but they also garnered international support from prominent public figures such as Donald Trump and Pope Francis (Waldman, 2018; Kubheka, 2020). As the Gard case proceeded through a series of appeals to the Family Court, High Court, Court of Appeals, Supreme Court, and European Court of Human Rights, the public rose as an additional stakeholder (Wilkenson, 2017; Das, 2018; Choong, 2019).

Naming themselves "Charlie's Army," supporters of Charlie's parents conducted their own campaigns (Wilkenson, 2017; Das, 2018; Choong, 2019). This "army" waged a multitude of tactics from petitions and fundraisers to harassment and death threats (Das, 2018). As public interest continued to grow, Charlie's case reached the twenty-four-hour media circuit. At all hours of the day and night, Charlie's image and details of his medical care were subject to broadcast and social media discussion (Das, 2018; Richards, 2018). Public accusations were

made that treatment was being withheld based on discrimination against the significantly disabled as well as that Charlie was not receiving treatment because the single payer socialized healthcare system in the United Kingdom did not wish to pay for it. These accusations were often accompanied by inflammatory language and violent imagery, such as "waging war," child murder," "hostage" and "prisoner" (Das, 2018).

Throughout this process, social interest causes such as the "right to life" movement adopted Charlie's case as poster child (Hurley, 2017; Das, 2018; Waldman, 2018). Politicians in both the United States and Italy proposed granting Charlie citizenship (Wilkenson, 2017). Hospitals in both countries also made public statements that they would facilitate nucleotide therapy if the parents so desired (Kubheka, 2020). While GOSH and the British court system remained opposed to Charlie's transfer, they allowed multiple rounds of appeals as well as the admission of new expert witnesses provided to the parents via media publicity (Wilkinson, 2017; Waldman, 2018).

Admis the court proceedings, Charlie remained in the intensive care unit dependent on mechanical ventilation and artificial nutrition and hydration. While he no longer spontaneously moved or showed any signs of awareness, GOSH physicians upheld that life sustaining treatment was causing Charlie to experience pain and suffering (Caplan, 2017). Upon review of Charlie's latest neurological testing, the United States physician offering experimental treatment stated that he no longer thought it probable that Charlie could benefit from nucleoside therapy (Waldman, 2018). After a final court appeal, on July 27th, 2017, with his parents' consent, Charlie's mechanical ventilation was removed, and he died (Wilkinson, 2017).

While there are undoubtedly numerous debates to be had about the medical, legal, and research components of the Gard case, I do not plan to linger on them here. Instead, I wish to use

Charlie's case to discuss a specific aspect of modern pediatric intensive care decision-making disagreement, namely, that by invitation of parents, a powerful third player's opinion can be introduced into the circumstances surrounding the end of a child's life. While in the past, intractable disputes may have been kept private, Charlie's case has proved that the media can act, quite literally, like an army, forcing influence via its volume and size (Das, 2017; Barrett, 2019).

Wide society engagement enters questions of collective social responsibility. When neither parents nor healthcare providers can agree, is there a role for the court of public opinion? Who defines this responsibility, and more importantly who regulates it? As the media became more engaged in Charlie's case, many individuals felt compelled to action without necessarily having direct roles or complete facts (Das, 2017). Equally, questions arise about the consequences of engaging public attention in matters that impact the lives of vulnerable individuals. Could media coverage have caused harm? To whom?

In this paper, I will use Charlie Gard's case as an example of the complex ways in which media involvement can be harmful. While I concede that there may be some potential benefits to media, I take the position that in intensive care conflict, any benefits gained will be far outweighed by harm. Of primary focus will be harm to the welfare of the critically ill child. This harm will be understood as a violation of the child's fundamental rights to privacy and dignity. I will also take time to discuss how the harms of public involvement may extend beyond the child. Harm to the family, the medical team, and society at large will be discussed. These harms are related back to the child through the family centered model of pediatric healthcare. I will argue that the growing expanse in media has prompted the need for revised ethical policies limiting the sharing of personal information of critically ill and dying minors, even with their parents'

consent. I then conclude with a discussion of preemptive and mitigating measures that may help intensive care conflict find resolution without media harm.

The paper will proceed as follows. The first chapter is focused on the rights of children. I take a historical approach, first discussing how philosophy regarding child rights has shifted from the idea of parental property to the possession of independent human rights. I focus on the concepts of present and future oriented welfare rights, particularly regarding privacy and dignity. I argue that even critically ill children are entitled to considerations for their present and future welfare. In the second chapter I discuss those with the responsibility for protecting a child's rights. Parental authority, which is to be understood as a conditional fiduciary right, is counterbalanced by medical expertise via a shared decision-making process. Pediatric bioethical theories of best interest standard (BIS), zone of parental discretion, and harm threshold (HT) are presented as limitations on parental decision making.

The third chapter will discuss disagreements between parents and medical teams. This includes a review of the literature analyzing the underlying nature of intensive care conflict to identify cases that may become intractable. The complicating factors of physician bias, parental emotion, and the intensive care environment are highlighted, with an exceptional focus on the parent's emotional need to feel like a 'good parent' to the critically ill child. This chapter sets the stage for the discussion of media involvement, particularly for parents who do not feel their good parent needs are appropriately addressed within the shared decision-making model.

In the fourth chapter, I present how media use may be beneficial to parents of critically ill children. I then discuss media aspects of the Gard case, showing how the actions of well-intended parents can quickly escalate into global media events with consequences extending far beyond the child. The fifth chapter then discusses the harm that media involvement in critical

care disagreements can cause. This is discussed first as violations of the child's rights, then in terms of harm to parents and society.

My concluding chapter will reinforce my thesis that media involvement in disputes between parents and healthcare providers is harmful and should be avoided at all costs. I will discuss alternatives to media involvement, which include proactively addressing 'good parent' needs in the ICU, improving physician communication, and involving early third-party mediation. I also enforce the need for updated media ethics policies that address the ways in which personal information about critically ill children can be shared.

As pediatric intensive care capabilities advance and fewer children die quickly from illness, more parents will be asked to make collaborative choices regarding their children's lives. These parental choices will inevitably be both uniquely challenging and emotional. As parents evaluate applying their decision-making authority to the pediatric intensive care environment, healthcare providers are bound by their own professional obligations. As parents and healthcare providers disagree, some families will elect to utilize media technology. While elective involvement of media may offer benefits to parent and child, these must be weighed against the potential for media to cause additional and significant harms. It is of critical importance then that ethical reflection guides these discussions and that the child's holistic interests remain centered.

CHAPTER 1

The Rights of Children

Before I dive into the ways in which media exposure causes harm to the critically ill child, I will look broadly at the fundamental nature of the rights that the media risks violating. The following section begins with a historical review of child rights. Here, it is identified that child rights do not merely refer to the meeting of physical welfare needs. Instead, children have the right to ensure that more abstract concepts of psychological and developmental health, dignity, and privacy are protected. I take exceptional focus to the concepts of dignity and privacy, identifying how the various versions of these concepts can describe harm in both practical and existential ways. It is this discussion that leads us into the next chapter, where a discussion of those responsible for protecting child rights establishes the potential for conflict in decision-making.

Historical Rights of Children

The idea that children possess human rights is a relatively recent one. Historically, children were considered property of their parents with little consideration for interests separate from their family's needs. In fact, Aristotle described the ethical considerations for children as being no more substantial than what consideration we would grant to a parent's tooth or bone (Downie, 1997; Shmueli, 2011). While many children were loved and cared for, others faced unchecked harm ranging from unsafe labor to outright abuse (Kopelman, 1997). It was not until the late nineteenth century that Western societies began to consider the need to protect the rights of children. As activist authors such as Charles Dickens wrote about the plights of poor suffering children, an appeal was made to society's empathy. The growth of other social reforms, such as the Women's Rights Movement, sparked activists to advocate against physical child abuse.

(Kopelman, 1997). In response, laws limiting child labor and other forms of physical harm were passed (Wiesemann, 2016).

As a part of the global reaction to the human rights abuses of World War II, international documents were written, aiming to attribute fundamental inalienable rights to all people (Raymundo, 2008). The first of these, released by the newly formed United Nations, was the 1948 Universal Declaration on Human Rights (UDHR). Although as a declaration, the UDHR is not legally binding, it is important as much of its content was later incorporated into international human rights treaties, such as the International Covenant on Civil and Political Rights (ICCPR), the violation of which can be prosecuted in international court (United Nations, n.d.). The UDHR starts with the statement that "recognizing the inherent dignity and equal inalienable rights of all members of the human family is the foundation of freedom, peace, and justice in the world (1948)." It then follows through thirty articles that describe rights to which all humans are entitled, based on their "intrinsic dignity, consciousness, and reason." While some of the initial rights (such as the right to a nationality) can be applied to children, most relate to adult processes (UDHR, 1948).

In recognition that rights of special populations may have been missed, the United Nations released additional documents in 1953 and 1959 describing the Rights of Women and Rights of the Child, respectively (Wiesemann, 2016). While the UN Declaration on the Rights of the Child is meaningful as the first international consensus on how one must behave toward children, it was also quite brief. Most of the ten articles listed simply served to directly acknowledge that basic welfare rights listed in the UDHR also applied to children (Shmeuli, 2011). It is not until the 1980s that the human rights movement really began to recognize that children may have rights beyond the provision of basic care (Bridgeman, 2020). The 1989

Convention on the Rights of the Child (CRC) produced fifty-four articles detailing rights that

belong to all children. These rights can be categorized into those protecting survival and

development, those protecting the child's general best interests, those that promote future rights,

and those that require respect for the child's developing opinions and wishes (CRC, 1989;

Michaud, 2010). Here, there is formal recognition, not only that children possess rights in the

present, but that they also have actively developing future interests (Fienberg 1980).

<p align="center">**Basic Needs and Open Futures**</p>

Modern child rights can be broadly thought of in terms of those that provide for present

needs and those that handle future autonomy (Fienberg, 1980). Regarding welfare, there is a

requirement of adults to provide holistic care to children throughout their development (Report

of Special Rapporteur, n.d.). This means that not only do children have the right to have their

basic physical needs (such as food, shelter, and healthcare) met, but they also have the right to be

cared for as growing human beings. Children must be provided with safe environments in which

they can learn, play, and be supported in socioemotional growth (CRC, 1989). The emphasis on

children's trajectory of growth leads to the second kind of right, which is the promotion of future

interests.

Many of the rights outlined in the UDHR refer to an adult actor. Humans who have

reached a majority age are granted privileges (such as marriage and employment) to which

children are generally not permitted (Diekema, 2020). The rationale for this is that during

childhood, individuals undergo considerable growth in their capacity for autonomous rational

decision-making (Raymundo, 2008). Children, particularly young ones, simply lack the

neurological and cognitive development necessary to make well considered decisions (Diekema,

2020). Until they mature, others are responsible for making decisions regarding their welfare (Garrett, 2019).

It is, however, the natural trajectory of children that they grow up to become adults. The "right to an open future" philosophy states that to every extent possible, a child's future adult choices should not be unjustly limited in childhood (Fienberg, 1980). Examples of limitations include depriving actions like failure to provide a basic level of education necessary for social functioning and direct insults such as sterilization and emotional abuse (Fienberg; 1980; Garrett, 2019).

Dignity

In addition to ensuring basic needs are met, and that future rights are not unjustly limited, children also possess more abstract rights simply by virtue of being human. Perhaps the rights most relevant to this paper are the right to privacy and to a larger extent, to dignity. While major human rights documents such as the UDHR and the CRC reference the human possession of dignity as one of their primary rationales for possession of human rights, an exact definition is never provided (1948; 1989). The following section explores several concepts of dignity, first broadly, and then as they apply to children. These four initial concepts can be broadly divided into dignity that is innate, and dignity that is a descriptor of being.

There is first is the idea of group, or species-related dignity. Here, the concept of dignity is an undercurrent, granting unique ethical consideration to humans, simply by being *homo sapiens*. This species related dignity is primarily attributed to three theories. First, there is the Judeo-Christian doctrine that humans were created by God, in His image (Lindsley, 2016; Jonas, 2020). This personal connection to the divine grants rationale for providing humans with a

different moral status than that afforded to other animals (Jonas, 2020). Humans require ethical consideration because they possess in them something 'godlike' that is not found in other species (Lindsley, 2016; Jonas, 2020).

A second theory of species related dignity utilizes the philosophical writings of Immanual Kant. Kant believed that it is human beings' capacity for rational thought that distinguishes them from animals (Schroeder, 2008; Killmister, 2010; Jonas, 2020). In Kantian rule-based ethics, one must always behave in a manner respectful of a human being's capacity for rationality (Killmister, 2010; Timmons, 2012; Jonas, 2020). Specifically, Kant indicated that humans must never be treated as mere means to an end, because doing so disrespects the fact that they themselves, as autonomous rational beings, are ends worthy of dignity. (Schroeder, 2008; Killmister, 2010; Timmons, 2012; Jonas, 2020).

A final species related concept of dignity arises from feminist care ethics. Philosopher Eva Kittay noted that human beings are one of the only animal species that consistently provide care to the most vulnerable members (n.d.). While the tendency to raise and nurture one's young is seen in many animals, care for the sick, disabled, and elderly is largely unique to humans (Kittay, n.d.; Jonas, 2020). In these human relationships, we form attachments, where emotions (such as love, guilt, and embarrassment) can be felt (Timmons, 2012; Kittay, n.d.; Jonas, 2020).

Kittay's care philosophy states that human species related dignity is thus rooted in our capacity to care for one another. This care is both altruistic and self-serving, demonstrated by Kittay's idea that respecting human's dignity to treat each other with the respect of being "some mother's child" (n.d.). We treat each other with dignity then because we respect the potential for humans to be deeply and emotionally devoted to each other. Because someone else, also worthy of care, cares about the individual, to treat them as undignified would negatively impact the

whole interconnected structure of humanity (Kittay, n.d.). Dignity is grounded then in our unique and intrinsic ability to give and receive relational care (Timmons, 2012; Kittay, n.d.).

A second major way of considering dignity is to think of it as a descriptor of being. Philosopher Doris Schroeder identifies two adjective subtypes. The first is that of aristocratic dignity. Here, dignity is a way of describing a position of rank. To be dignified in this account is to behave in accordance with the expectations of one's rank (Schroeder 2008; Kilmister, 2010). A good king, for instance, behaves with dignity, because that is the way kings are expected to act. Although Schroeder distinguishes aristocratic dignity as separate from her second category of comportment dignity, they are quite similar. In comportment dignity, instead of behaving as one's position expects, dignity is reflected in behavior aligning with social norms. For instance, if one were to remove one's clothes and urinate in the middle of a crowded room, they would be breaking cultural tradition regarding appropriate social behavior. Such actions then would be described as undignified (Schroeder, 2008; Kilmister, 2010). A final way to think about adjective dignity is to consider it as a type of Aristotelian virtue. To behave with dignity is to behave as a good, virtuous person does (Kilmister, 2010; Timmons, 2012).

Although these two major categories of dignity vary from each other, they are interdependent. If we solely considered dignity to be an inalienable aspect of humanity, the concept would lose its moral power. Nothing anyone ever did could alter or take it away (Kittay, n.d.). Likewise, without descriptive formulations of dignity, we would lack explanatory power in which to define how one behaves with, or without dignity (Kilmister, 2010; Kittay, n.d.). Therefore, a more complete conception of dignity is both descriptive and prescriptive. Not only do humans possess dignity, but their dignity can be impacted (or injured) by the actions of both self and others. (Rodriguez, 2015).

These formulations of dignity relate to child rights in both present and future oriented ways (Rodriguez, 2015). Species-related dignity is a descriptive characteristic attributed to humans automatically upon existence. The fact that children are members of the human species grants them the right to the "god like" concept of dignity (Kittay, n.d.; Jonas, 2020). Conversely, the Kantian formulation views dignity as morally equivalent to autonomy. To respect an individual's autonomy is to treat them with dignity (Kilmister, 2010; Kittay, n.d.). This type of dignity helps to explain why we associate a lack of dignity with negative experiences of humiliation, guilt, and shame. If an individual is constrained from behaving autonomously, they may find themselves in situations that they themselves would not voluntarily desire (Kilmister, 2010; Kittay, n.d.). Not only can this result in the experience of negative emotion, but it may be construed as disrespectful to one's underlying capacities (Kittay, n.d.).

Young children do not yet have the cognitive capacity to make autonomous decisions in the way Kant referred (Kittay, n.d.; Jonas, 2020). As such, they are not personally held to the same exacting standards associated with aristocratic or comportment dignity. However, this can similarly be conceptualized as a species' destiny, or another kind of future right in trust. Following the expected path of human development, children will mature to adulthood. In adulthood, they will feasibly develop full capacity for rational decision-making. In the meantime, their interests are held in protection by fully autonomous beings (typically their parents). The mere fact that they have the potential (in fact, the high probability) of eventually reaching this level of rationality can be respected as a future right (Harvey, 2003). To treat a child as simply a means to an end then can construed as equally disrespectful to their present and future capacities.

There remains an important exception to the Kantian formulation of dignity. There are individuals who by virtue of cognitive disability, will never achieve autonomous decision-

making capabilities (Jonas, 2020; Kittay n.d.). Do these individuals then lack dignity? Are we free to place them in humiliating situations because they will not know any better? Dignity for the disabled is accounted for by both the god-like conception of species dignity, and Kittay's care ethic. For those who believe all humans were created in the image of God, cognitive capacity does not matter. That dignity is innate to all humans regardless of capability (Kilmister, 2010; Lindsley, 2016; Jonas, 2020). This idea gives us an initial rationale but discounts the viewpoint that the dignity of mentally disabled people can be harmed (Kilmister, 2010; Kittay, n.d.).

Kittay's care ethic developed as she considered the dignity of her severely disabled daughter. In this, she considers two possibilities. The first is that while the cognitively impaired may not be able to express negative feelings as able-bodied humans do, we cannot discount that they may still experience them (Kittay, n.d.). If an action would make most people feel undignified, she states that we can also assume that in some way, the cognitively disabled would experience distress. For instance, lying uncovered naked on a hospital bed would likely make a person feel embarrassed by their involuntary exposure of something that socially we tend to keep private (Kilmister, 2010; Kittay, n.d.). Even if the cognitively disabled is unable to process the social conceptions of things like privacy, they may still feel physical distress from being exposed to the chilly air in a strange, atypical manner (Kittay, n.d.).

For Kittay, a key part of caregiving then is seeking to appreciate that ways that uniquely human experiences, such as positive and negative emotionality, may exist, even when expressed in differently abled bodies (n.d.). Secondly, the fundamental stance of care ethics states that because the disabled are human, they fundamentally deserve to be treated with the respect of being "somebody to someone" (Kittay, n.d.; Timmons, 2012). In this way, care ethics is quite

like the Christian 'Golden Rule," which instructs people to do unto others as they would have them do unto themselves (Encyclopedia Brittanica, n.d.). Because the disabled exist in the world, they impact others. This impact is reflected in the meaning they give others, simply by virtue of existing and requiring care (Kittay, n.d.). If we would not wish for ourselves or our loved ones to be treated in a certain way, we should reflect that impulse in our actions toward others (Kittay, n.d.; Kilmister, 2010; Timmons, 2012).

Privacy

Much like dignity, the right to privacy is a complex one. While basic definitions indicate that privacy is the mere 'right to be left alone,' the practice of this can be interpreted in several separate ways. Broken down, privacy can be seen in terms of an access issue and a control right. Access privacy merely relates to the ease with which others can obtain personal information. What "personal information" contains is also a debatable topic. Personal information can be defined as a component of one's body (as when nude or otherwise vulnerable), property, or environment that is not readily accessible to others. Access privacy can also relate directly to informational facts about one's person that may cause embarrassment or even social harm if publicly made known. Examples of this kind of information include sensitive medical history, releasement of which may subject an individual to discrimination and ostracism (Shmueli, 2011).

Privacy control as a human right relates to the individual's ability to regulate access to personal information. Some information is presumed private by virtue of other rights (such as property rights) or individual actions (such as choosing to lock one's door). Breaking the lock and entering regardless would thus be in violation of the individual's attempted expression of privacy control. Other personal information, such as one's medical records is legally private

unless the individual grants express permission for access to be shared (Steeves, 2006; Shmueli, 2011).

A child's right to privacy is complicated. While the Convention on the Rights of the Child lists states that children have a right to protection from "arbitrary or unlawful" violations of privacy, most children lack the cognitive capacity to make judgments about what safe disclosure entails (1989; Diekema, 2020). Furthermore, the intimate nature of parent-child relationships means that in young childhood, virtually all confidential information is readily accessible to the parents without limitation. Parents must have easy access to data points regarding everything from health to physical location in order ensure the child's basic needs are met and they are kept safe from harm. Instead, the right to privacy is both a present need and a future oriented right. As children get older, perception of ownership, particularly over one's body, develops. Likewise, information that is necessary for parents to see (such as their child's naked body) changes. Not only is developing a sense of privacy important for teaching children how to protect themselves from harm, but it is also a key component of learning how to participate in a trusting relationship (Shmeuli, 2011).

Privacy, or specifically the idea that one has the right to choose how one's personal information is exposed, is essential to trust. As children develop socially, they learn how to interact with others. The choice to disclose personal thoughts, feelings, and information is a building block to participation in human relationships. If all things were known to all people, social structures would lose much of their underlying power. In many ways, exercising one's right to privacy allows individuals to control and stratify their social world. In fact, experiencing violations of privacy in minor ways (such as a peer sharing information told in confidence) is a natural part of social development. As children experience negative emotions such as

humiliation, they begin to learn judgements about what is appropriate to disclose and when. There is also an important reciprocal 'golden rule' lesson is learning how to respect the trust (and therefore privacy) of others (Shmueli, 2011).

Unfortunately, there are also forms of privacy rights violations that cause lasting damage. In childhood, examples tend to be those that cause significant lasting harm to present or future rights. A commonly cited scenario is the use of genetic testing for non-essential needs. The choice to access the child's genetic information for reasons other than the early intervention or treatment of a severe disease is said to violate not only the child's right to privacy (through the elicitation of unknown personal information) also but the child's future right to decide for themselves whether they wish to know about their genetic predispositions. This unsolicited knowledge may not only alter the way in which the child lives their life, but it also may cause deeply challenging emotions such as anxiety. If this knowledge is inadvertently disclosed to others, the child may also be made vulnerable to discriminatory treatment lasting into adulthood (Garrett, 2019).

The key distinction then between privacy intrusion typical of growing social relationships and human rights privacy rights violations lies in the situation's scope and significance (Steeves, 2006; Garrett, 2019). Who released the information? Was the exposure intentional? How much of an impact does the violation have on the child's ability to exercise present and future rights? Finally, once disclosed, can the child be expected to recover from negative emotional and/or social effects?

While parents are traditionally seen as the natural protectors of their children's rights, the legal right to parental decision making is granted on several important assumptions. These assumptions are fiduciary, conditional, and subject to revocation if responsibilities fail to be met.

In the next chapter, I will discuss adult responsibilities toward children. Although primary surrogate responsibility is usually attributed to parents, there are instances where this responsibility is shared. I focus on pediatric medicine, in which responsibility for child medical decision making is collaborative between parents and healthcare providers. In unpacking the ethical responsibilities of parents and pediatric healthcare providers respectively, I identify scenarios in which parental authority may be permissibly overruled. By detailing three bioethics theories, namely best interest standard, harm threshold, and the zone of parental discretion, that are commonly applied in overruling parental authority; I prepare for a discussion of pediatric intensive care disagreement.

Chapter 2

Families and Healthcare Teams

Modern families come in all shapes and sizes. The term 'family' may encompass single parents, parents of the same or opposite gender, relatives, and non-biologically related individuals taking primary childrearing responsibility (AAP, 2014). Regardless of their composition, childrearing families have many social responsibilities. As most children are not developmentally capable of ensuring their rights are met, families have primary responsibility for child welfare. When children become sick, families must seek external resources for improving their health. Pediatric medicine is a discipline that cares exclusively for the healthcare needs of children. A cornerstone of pediatric medicine is the philosophy of providing family centered care. In family-centered care, the physician partners with families in customizing care to the child's individual needs. Ideally, this leads to a shared-decision model, in which the physician provides and collaborates on options for treatment (AAP, 2012; AAP, 2014).

Although family centered care encourages physician adaptability to a diversity of family choice, there may are times when the physician and family are unable to agree on a plan of care Abbott, 2001; Forbat, 2015). When this occurs, the physician is bound by their professional ethics to ensure basic child welfare is protected (AAP, 2014; Jenny, 2018; Swan, 2020). The following section offers an overview of pediatric shared decision-making and parental and physician responsibilities. There is then a presentation of three frameworks commonly utilized in overruling parental decision-making in favor of protecting child-welfare.

Rights and Responsibilities of Families

As biological progenitors, parents have direct evolutionary interest in the success of their offspring (Wiesemann, 2016). Not only does the process of conception, pregnancy, and

childbirth bestow a line for bonds of genetic kinship, but it also positions the newly born infant in direct proximity to at least one adult who can theoretically provide for its needs. It is because of these genetic ties that parents are socially required to support the fulfillment of their child's human rights (Downie, 1997; Wiesemann, 2016). These rights include both those that provide for physical welfare and those that honor the child's future adult needs (CRC, 1989). A failure to meet these needs may result in the removal of the child from the parents' care and legal repercussions (Bridgeman, 2020).

Far beyond simply being the most logical facilitator for a child's rights, parents are given primary decision-making responsibilities because they are thought to be the people who know their children the best (Diekema, 2004). The psychological theory of attachment states that to emotionally mature, children must form trusting attachments to other people. In a trusting parental relationship, the child is utterly secure in the knowledge that their needs are addressed. Within this loving family dynamic, the child has a nonjudgmental and supportive confidant who knows them intimately (Shmeuli, 2011).

This knowledge, which is compounded through daily care and interaction, grants the parent particularly intimate insight into the child's uniquely developing thoughts, wishes, and needs (Harvey, 2003). With this insight, parents are thus able to make decisions not just in promotion of their child's basic interests but also in a true surrogate manner, feasibly with educated consideration of what the child's developing values may entail (Diekema, 2004; Navin, 2017). It is also through this regular interaction that the parent gains an incentive of their own. The child-parent relationship is a deep and reciprocally emotional one. Not only is meeting the child's needs an extrinsically imposed responsibility but promoting the child's wellbeing is intrinsically important as parents are receiving object of the child's love (Downie, 1997). It is

important to note that even although family rights acknowledge that the parent-child relationship is often emotionally meaningful to the parent, when parent and child rights conflict, there is a legal expectation that as the vulnerable minor, the child's best interests will always be prioritized.

Liberty in child rearing according to one's own judgement is a relative privacy right. So long as the child's rights are being respected, Western parents are granted a generous amount of discretion in childrearing decisions. The concept of a family possessing rights is thus conditional and based on fulfillment of parental responsibility. Far from children being mere property of their families, parents are their children's fiduciaries, responsible for safekeeping present and future rights until a time when the child can function independently (Wieseman, 2016).

Shared Medical Decision Making in Family Centered Care

Although primary social responsibility for child decision-making is usually granted to the child's parents, there are scenarios in which it may be shared among other non-related adults. These adults tend to have special expertise in a particular area of child-rearing and have often been enlisted by the parents to help meet the child's needs. Teachers, for instance, are the experts in formal child education. Decisions regarding academics are often made in partnership between parents and their child's educators. Likewise, parents rely on pediatric specialized medical teams for their child's healthcare needs (AAP, 2012; Hill, 2019).

This partnership between medical teams and parents is encouraged through a theoretical healthcare model known as family centered care. Family centered care developed out of adult medicine, as providers began to reject traditional paternalistic practices in favor of direct patient involvement in decision-making. As most children are unable to make decisions on their behalf,

pediatric medicine adjusted patient centered care to involve collaboration between healthcare workers and the child's surrogate decision-makers (AAP, 2012).

Family centered care builds from concept that patient/family perspectives are "essential components of high-quality clinical decision making" (AAP, 2012). Its primary function is the promotion of shared decision making between parents and healthcare providers. In shared decision-making, the parents are encouraged to share unique features of their family, such as culture and religion, with their child's medical team. The medical provider then partners with the family in providing necessary medical information in a manner that the family comprehends. Together, parents and providers make healthcare decisions on behalf of the child (AAP, 2012; Hill, 2019).

Family centered care may take many forms. It may be as simple as promoting an atmosphere in which the family is encouraged to ask questions and directly participate alongside medical staff in their child's caregiving (Hill, 2019). It may also involve working collaboratively in adapting medical care plans to meet family priorities and goals for treatment (AAP, 2014; Hill, 2019). Emphasizing family centered practice has been positively associated with improved patient anxiety, increased confidence in medical teams, decreased length of hospitalization, and decreased incidence of medical errors (AAP, 2012; AAP, 2014; Hill, 2019)

Clinician Responsibility in Shared Decision-Making

The family-centered care model requires that clinicians move away from traditional paternalistic practices by integrating the unique needs and wishes of the patient and their family into the care plan (AAP, 2014). This change in theory not only transitions the traditional physician role from that of all knowing guardian to that of partner, but it also fundamentally

redefines what it means to be an ethical physician. In 1987 the American Board of Pediatrics

(ABP) proposed a list of characteristics and responsibilities of the pediatric clinician (Fallet,

2017). These tables have been updated several times to their most recent (2003) formulation of

physician responsibilities(Hussler). All characteristics have the following principles:

Fundamental Principles

1.Primacy of patient welfare	The physician's primary motivation must be the patient's welfare.
2. Respect for patient autonomy-	Children who are developmentally capable of participating in their care should be encouraged to do so. In all other cases, the physician should aim to partner with the surrogate decision maker to make decisions on behalf of the patient's interest
3. Consideration for social justice	Physicians must aim to be equitable in the distribution of healthcare resources.

1. AMA, 2001; Hussler, 2003; Fallat, 2017. 2. AMA, 2001; Hussler, 2003; Fallat, 2017. 3. AMA, 2001; Hussler, 2003

Professional Characteristics

Honesty and Integrity
Reliability and Responsibility
Respect for Others
Compassion and Empathy
Self-awareness and Knowledge of Limits
Communication and Collaboration
Altruism and Advocacy

AMA, 2001; Hussler, 2003

1. Honesty and integrity-Communication must always be honest and straightforward. Patients

and families deserve honest information, including prognostic uncertainty. Assumptions should

not be made about what is "too much" for the patient or their family to understand. Patients and

families should always be made aware of potential conflicts of interest (AMA, 2001; Hussler, 2003; Fallat, 2017).

2. Reliability and responsibility-Physician's actions are accountable to children, their families, and society at large. They must disclose and accept responsibility for errors. They must also be open to discussing all possible consequences and alternatives with patients and their families (AMA, 2001; Hussler, 2003; Fallat, 2017).

3. Respect for others. Physicians must always act with respect and regard for individual worth and dignity. Physicians must maintain professional boundaries in relationships with patients and their families. This includes managing and disclosing conflicts of interest (AMA, 2001; Hussler, 2003; Fallat, 2017).

4. **Compassion/empathy**-This requirement emphases the physician's ability to recognize and understand that children's and family members' reactions to pain, discomfort, and anxiety may differ from that of the physician. The physician must trust reported distress and react accordingly (AMA, 2001; Hussler, 2003; AAP, 2014; Fallat, 2017)

5. **Self-awareness and knowledge of limits-** The physician must be mature enough to acknowledge when a problem requires knowledge and/or experience that they themselves do not possess. Asking others for consultation or assistance is necessary in these situations. Families should also receive assistance when requested in seeking secondary opinions. Physicians should adopt an attitude of continued learning throughout their careers (AMA, 2001; Hussler, 2003; Fallat, 2017).

6.**Communication and collaboration**-This involves the recognition that the best patient care occurs when multiple perspectives and experiences can respectfully work together. This includes

involving patients, families, and other healthcare team members in developing individualized plans of care (AMA, 2001; Hussler, 2003; AAP, 2014; AAP, n.d.; Fallat, 2017)

7.**Altruism and advocacy-** The welfare of the patient must always be the primary motivating factor in patient care. Physicians should advocate and care for the health and well-being of all children regardless of their background or ability to pay (AMA, 2001; Hussler, 2003; Fallat, 2017).

Physician Obligations in Disagreement

Not only must pediatric physicians embody these professional standards, but they also must figure out how to do so when there is disagreement. Professional groups such as the American Academy of Pediatrics have produced guidance documents to assist physicians in troubleshooting conflict with a child's surrogate decision-makers (2018; AAP, n.d.). These documents address various topics ranging from guidance in caring for children of different culturess to addressing parental refusals of care (AAP, 2018; Jenny, 2018).

While these documents all emphasize the importance of facilitating collaboration, they also recognize that there are occasionally scenarios in which the interests of the child patient and their family may be at odds (AAP, 2014; AAP, 2018; AMA, n.d.). In the most egregious scenarios surrogates may intentionally be abusing or neglecting their children's needs (Asser, 1998; Jenny, 2018.) In others, surrogates remain loving and well intentioned, but still wish to make choices that the physicians see as unacceptably harmful (AAP, 2018.)

In the United States, physicians are mandated reporters. When there is suspicion of abuse or neglect, physicians are both legally and ethically required to make a report to Child Protective Services (Asser, 1998; AAP, 2018). Key, however, is that a report does not necessarily enable

the physician to proceed against the surrogate's wishes (AAP, 2018). While hospitals may have processes in place for specific life-threatening scenarios (such as a Jehovah's Witness parent refusing a life blood transfusion), these processes typically require emergent appeals to the court system(Asser, 1998; AAP, 2018; Swan, 2020) If the court system is unable to be reached in sufficient time, the physician is ethically required to act with good faith and perform emergency interventions on behalf of the child's welfare(AAP, 2014; Fallat, 2017; Jenny, 2018). As soon as the child is stabilized, the physician must contact legal channels for ongoing management and treatment (Asser, 1998; AAP, 2018; Jenny, 2018; Swan, 2020).

In situations where abuse or neglect are not obvious, but the physician strongly feels the surrogate is not appropriately or adequately addressing the child's needs, education, mediation, and compromise are still encouraged (AAP, 2014; AAP, 2018; AMA, n.d). Only when all mediation efforts have failed, and compromise is not possible, do guidance documents require that pediatric physicians primarily consider the welfare of the child. Interventions may facilitate referral to other medical providers for additional opinions, consulting an institutional ethics committee, or in significant cases, escalating through the court systems (AAP, 2014; AAP, 2018; AMA, n.d.).

There are several different theoretical frameworks for evaluating which surrogate decision-making cases require intervention. The following section discusses three of the most referenced frameworks. Through a brief discussion of best interest standard (BIS), harm threshold (HT) and the zone of parental discretion (ZPD), advantages and practical limitations will be identified.

Best Interest Standard

Best interest standard (BIS) is one of the most cited frameworks in pediatric bioethics. As a standard, it has been integrated into the language of both medicine and law, not only in evaluating the limits of parental authority, but in guidance for general surrogate decision-making. According to BIS, when making decisions on behalf of children, a direct consideration for the child's best interests should be the primary focus. Loretta Kopelman, a primary proponent of BIS describes the standard in utilitarian terms. When seeking to apply BIS, one must "pick the option that most informed rational people of good will would regard as maximizing the child's net benefits and minimizing the net harms" (Kopelman, 1997). In other words, the ethically appropriate decision is the one which maximally promotes the child's wellbeing (Wilkenson, 2015).

The standard is both prescriptive and descriptive, offering both a way to define the application of child rights as well as providing a threshold for intervention (Kopelman, 1997). As an aspirational framework, BIS functions well. Critiques are most common in practical applications. First, BIS is too vague to be widely applicable. It is not clear what 'best interest' means. Given the world's plurality of cultures and belief systems, "informed, rational people of good will" may, and often do, disagree on ethically appropriate action. Evaluating the best interest will thus always depend on the decision-maker's underlying values, experiences, and bias (Kopelman, 1997; Diekema, 2004).

Hence, a second criticism of BIS is that it asks the surrogate to isolate consideration of a child's interests without external context (Diekema, 2004; Lantos, 2017; Kopelman, 1997).

Decision-makers often have complex ethical considerations. Parents may have other children, with whom the best interests of one may directly conflict with the best interests of another. Additionally, they may have other important duties to consider aside from the child. The parental decision-maker may consider obligations to other family members such as elderly parents or spouses and external commitments such as those made to an employer (Downie, 1997). Outside of the family, the principle of justice requires that pediatric medical and law makers consider the needs of all children without unfair preference for one over the other. BIS in its basic (and most common) formulation lacks sufficient guidance for decision-making in complex scenarios (Diekema, 2004).

Finally, BIS is criticized for its primary word choice. The word "best" implies supremacy over all other choices (Diekema, 2004; Birchley, 2010). It does not allow for the possibility that there may be choices far short of optimal that still fulfill one's ethical obligation. In forcing the pediatric surrogate decision maker to hold the child's optimal rights as prima facie exclusive, we create a standard that is incredibly challenging to uphold. It is common for a scenario to have multiple ethically permissible options (Lantos, 2017; Navin, 2017). In child-rearing alone, there are many parental choices one views as less than optimal, that will not warrant external intervention. Choices may also be interdependent, with the "best" option for fulfilling one child's right placing other rights at odds (Birchley, 2015; Navin, 2017; Lantos, 2017). For instance, it may be argued that the best possible nutrition for children involves feeding them expensive organic foods. A parent may, however, be unable to afford both expensive organic foods and a home. While failing to provide the "best" food, would per BIS be a mis-consideration of the child's welfare, one could certainly argue that the most appropriate parental decision may be ensuring both shelter and suboptimal nutrition is provided (Navin, 2017). What happens then if

all 'best' options are not practical? BIS again lacks the guidance for prioritization in such scenarios.

With so many cons, why is BIS so popular? The strongest arguments in favor of the framework support its role in aspirational goal setting. While the "best" interest of a child may not ever be practically achievable, striving to be 'best' can still be useful in shaping priorities and decisions (Kopelman, 1997). This again links back to Kopelman's utilitarian defense of BIS. Much modern application of BIS language is seen in social policy and family law. BIS is often applied legally in custody disputes, where a valid argument may be made on behalf of both parents. Aiming to promote the 'best' outcome (or in utilitarian terms, the most possible utility) may be particularly useful in decisions regarding in which there may be several acceptable options, or limited resources (Kopelman, 1997; Wilkenson, 2015).

Here, BIS may instead be best seen to guide complex evaluation of competing priorities while keeping focus on the child's basic rights. While competing interests and values may exist, BIS language keeps the discussion away from "best interest of everyone involved," by instead requiring the surrogate decision maker to grant primary ethical focus to the needs of the vulnerable child (Kopelman, 1997).

The Harm Threshold

With BIS functioning most optimally as a guidance principle, pediatric bioethicists sought to identify a practical framework for determining state intervention. One popular framework, known as the harm threshold (HT) focuses exclusively on conditions necessary for overriding pediatric surrogate authority. Per the HT, intervention is required when a surrogate's decision-making places the child at risk of serious harm (Diekema, 2004).

Much like the word 'best' in BIS, HT has been criticized as being overly vague. How is one to define harm? Douglas Diekema, primary author of HT, notes that to warrant intervention, harm must be both substantial and imminent. Substantial harms are further refined as threats to the fulfillment of basic needs (Diekema, 2004; Birchley, 2015). Diekema's idea of basic needs develops from John Rawls' conception of primary goods, in which goods are "the things a rational man requires to do what he wants" for his welfare, growth, and development. In children, this can be further developed into the things that "enable children to embark on the process of self-discovery, self-determination, and self-fulfillment" (Birchley, 2015).

While harms to basic human welfare (health, food, shelter, etc.) may be straightforward to identify, the inclusion of future oriented harms remains vague, particularly regarding the imminent requirement. Furthermore, even within welfare harms, interpretation of the substantial and imminent clauses is up for individual judgement (Bester, 2017). It is feasible that intervention may be required both in cases of direct actionable harm, as well as harm caused by neglect. Neglect harms are committed by omission, either directly or via refusal of necessary interventions, such as medical care (Lantos, 2017; Bester, 2017; Jenny, 2018).

Despite all these potential areas and causes for child harm, HT's guidance focuses primarily on the very latter scenario in which a surrogate has refused a medical intervention (Wilkinson, 2015; Birchley, 2015). Unfortunately, even in this situation, HT lacks practical guidance on how to stratify the multitude of harms that may be present (Birchley, 2015; Lantos, 2017). Much like in BIS, where considerations for others' interests are not ethically relevant, in HT, harm matters only regarding the child in question.

Zone of Parental Discretion

With HT's vague and narrow scope, pediatric bioethicists continue to search for a more widely applicable intervention threshold. While Lynn Gillam's Zone of Parental Discretion (ZPD) continues to focus primarily on medical situations, it overcomes many of challenges seen in HT through a further refinement of its basic principles. ZPD begins with the following ethical assumptions:

1. Parents have an ethical right to make decisions for their children based on their own conception of the good life (Gillam, 2015). (In this, Gillam allows for good faith cultural variation in interpretations of "best interests" and "harm.")

2. Parents are not morally obligated to maximize the well-being of their children (Gillam, 2015). (Effectively removing both the "best" requirement as well as the interpretation of the child's interests as ethically independent of the family dynamic).

3. The limit to parental authority lies at the point at which significant harm is likely to be caused to the child (Gillam, 2015).

The third assumption appears similar to the HT; however, in further detail ZPD requires that two types of harm be considered. First, like HT, ZPD requires that there be an evaluation of the parental surrogate decision. The decision itself must cause harm, either via direct action or omission/neglect. Second, and unlike HT, there must also be a secondary evaluation of all other harms that may accrue via intervention (Gillam, 2016). This caveat is important because it allows for a more generous and holistic formulation of harm, such as parental emotional needs or separation of the child from the family unit, to be evaluated in the decision to pursue legal intervention (McDougall, 2013; Gillam, 2015).

ZPD allows that more than one ethically important value may be considered in pediatric decision-making. If BIS requires one look at maximum benefits and HT requires one to evaluate worst possible burdens, ZPD requires an evaluation between all possible benefits and burdens (Gillam, 2015). A second major aspect of ZPD is that it requires the bioethicist to include context of the decision in question.

As previously discussed, both medicine and child-rearing often function in shades of grey (Mcguire, 2019). Reasonable, well-meaning people may approach decisions with different beliefs, values, and biases. While there are certainly egregious instances where singular "best decisions" or "significant harms" will be apparent, most scenarios will have several ethically valid options. ZPD asks the ethicist to place decisions in one of three categories.

In scenarios where there are multiple ethically valid options, there may be arguments that some decisions are better than others. If one were to follow the BIS, only the best possible option would be valid. If one were to follow the HT, all options, including those that are perhaps somewhat (though not significantly) harmful would be ethically valid. In ZPD, a 'zone' between the best possible option and potentially harmful options is defined. With an allowance for the importance of autonomy and cultural variation in surrogate decision making, all decisions that fall within the "zone" are ethically permissible (Gillam, 2015).

ZPD is particularly useful in promoting shared decision making when cases involve prognostic uncertainty. The ethical decision in question may not have an easily predicted impact. Instead, one must weigh what information is known, and that which is likely to occur with that which is unknown yet possible. A common example of this is choosing whether to attempt to resuscitate an extremely premature neonate. Resuscitation may bring about benefits, but it may

also cause harm. The parents' underlying values will alter how they choose to weigh potential outcomes in this 'grey zone' (Wolfe, 2022).

Ultimately there is no one perfect framework. Although BIS is often used in legal cases, medical providers find it difficult to implement in the shared decision-making model. While BIS is often thought to set too high of a standard, HT has been criticized as requiring only the bare minimum. At first glance ZPD seems like an improved HT, however it fails to weigh the possibilities of inadequate parental knowledge. Just because a decision is within the ZPD does not mean that the parent received adequate information to make an educated choice.

If these pediatric bioethical frameworks accomplish anything, it can be said that they provide contextual background with which to sort through ranges of acceptable options. Unfortunately, the use of different frameworks can lead to different outcomes. A healthcare provider who primarily uses BIS may be unwilling to collaborate on anything less than the 'best' choice. Likewise, a parent who believes they are making a decision within the scope of parental authority may feel strongly about having the final say. When parents and healthcare providers approach decisions from different ethical viewpoints, conflict may occur. The following chapter discusses pediatric intensive care conflict in more detail. It is through detailing of emotion, bias, and the "good parent" that the stage is set for discussing how unresolved conflict can escalate to media involvement.

Chapter 3

Pediatric Intensive Care Conflict

Unfortunately, there are times in which medical teams and families experience conflict. Disagreements are particularly common in the intensive care unit, with almost half of pediatric intensive care families reporting some conflict during their loved one's hospitalization (Abbott, 2001; Forbat, 2015). Intensive care unit conflict, which is defined here as "a difference of opinion affecting decision making or actions between parents and healthcare workers over a distinct issue impacting critical care treatment" is exacerbated by the nature of the intensive care environment (Spijkers, 2022).

As critical care medicine has advanced in technological capability, very sick patients who would have previously died early in their illness are now able to be kept alive for prolonged periods (Miller-Smith, 2019; Nuffield Council, n.d.). This life saving equipment is often cumbersome, with tubing and wires limiting family access for things like holding and hugging. Patients are physiologically fragile, meaning that physical interactions may be limited to essential interventions (Lisanti, 2017). This fragility and its consequent alterations in interaction is often intimidating to families who may be overwhelmed by their loved one's appearance. (Baia, 2015; Miller-Smith, 2019).

Critically sick patients are frequently cared for in tandem by subspecialty teams, meaning that families may receive serious and conflicting information from multiple sources (Miller-Smith, 2019). Due to the nature of shift work, families are often denied consistency in staffing. This lack of consistency requires them to repeatedly orient strangers to their loved one's preferences. There is an expectation and requirement of trust here, that each new individual caring for their child can meet their needs (Bridgeman, 2020). Amidst this novel environment, the family centered model of care expects that shared decision making will take place. The

typical shared decision-making model implies that family has time to reflect and collaborate with staff in the integration of values into patient care. In the intensive care unit, however, decisions often must be made urgently without much time for complete education or value reflection (Abbott, 2001).

 Communication breakdown occurs when there is ineffective passage of information from the medical team to the family (Abbott, 2001). This may result from a physician's issue in composing, a family's issue in decoding, or both. In life threatening situations, physicians may find it mentally challenging to simultaneously initiate patient interventions and interact with the patient's family. At the same time, stress and emotion associated with witnessing a loved one's illness may make it challenging for families to rapidly comprehend and make decisions with complex medical information (Abbott, 2001; Kruse, 2017).

The most common causes of intensive care conflict are disagreements regarding a patient's ultimate state of health and disagreements regarding treatment decisions. This conflict is often worsened by multiple players (such as subspecialty teams or large families), prognostic uncertainty, and negative family emotions (Do Vos, 2014; Spijekers, 2022). Underlying bias on behalf of both families and medical teams contributes to fundamental disagreements regarding care plans as well as more abstract concepts such as suffering, futility, and the child's best interests. (Mohrmann, 2006)

Ethical Frameworks and the Charlie Gard Disagreement

Best interest standard was used by the British court to justify supporting Great Ormond Street Hospital (GOSH)'s petition to withdraw life sustaining therapy and allow Charlie Gard to die (2017). Specifically, Mr. Justice Francis made the following declarations:

Great Ormond Street Hospital V Yates & Ors [2017]

"i. Charlie, by reason of his minority, lacks capacity to make decisions regarding his medical treatment;
ii.   It is not in Charlie's best interests for artificial ventilation to continue to be provided to and it is therefore lawful and in his best interests to be withdrawn;
iii. it is lawful and in Charlie's best interests for his treating clinicians to provide him with palliative care only
iv.   It is lawful and in Charlie's best interests not to undergo nucleoside therapy. Provided always that the measures and treatments adopted of the most compatible with maintaining Charlie's dignity."

In these declarations, GOSH and the British court system make several assumptions regarding the nature of Charlie's interests. First, prior to listing these judgements, GOSH lawyers presented details regarding the nature of Charlie's disease (GOSH, 2017). It was made clear that Charlie had a progressive irreversible mitochondrial disorder for which there was no known cure. Given the nature of his disease and the inability to improve his medical condition, GOSH stated that his present state of reliance on intensive care technologies such as mechanical ventilators amounted to medical therapy without just cause (Wilkinson, 2017; Truog, 2019).

In other words, because Charlie could not survive his illness, continuing to provide mechanical ventilatory support forced him to undergo uncomfortable treatment without rationale.

Likewise, trialing nucleoside therapy was instead likely to cause additional pain, both via the trans-Atlantic trip to America and through uncertain side effects. The assertion was that both continued intensive care therapies and experimental treatment were futile (as they were unable to achieve a curative state) and cruel (in that they caused Charlie to suffer) (Caplan, 2017; Troug, 2019). Therefore, it was in Charlie's best interest to remove painful futile therapies, apply palliative (symptom relieving) treatments only, and allow Charlie to die from his disease (Caplan, 2017; Wilkinson, 2017; Troug, 2019).

Charlie's parents had quite different ideas about what his best interests involved (Caplan, 2017; Wilkinson, 2017; Troug, 2019). While they agreed with GOSH that Charlie's present life dependent on mechanical ventilators was 'not one they would hope to keep,' the Gards did not believe that his underlying disease state was irreversible (GOSH, 2017; Troug, 2019). Instead, they hoped that experimental nucleoside therapy could at most, improve Charlie's health to the point that he would not die, and at the least, slow disease progression so that he could have a better quality of life. Although they recognized that transport to America and participation in nucleoside therapy could both cause Charlie additional harm, they felt strongly that any harm he might undergo could not be worse than the harm of losing one's life (Waldman, 2018).

The Gards and GOSH then differed dramatically on how they viewed Charlie's interests (Caplan, 2017; Waldman, 2018). While the hospital staff accepted his disease process as terminal and wished to avoid what they saw as needless suffering, the Gards did not see Charlie as dying (Waldman, 2018). Any suffering that he might then undergo would, to their viewpoint, still not be as bad as dying without trying all options. Although the use of BIS was in line with the common language of British child rights law, examining the details of the Gard case raises the question of if 'best interest' is what either party was focused on (Caplan, 2017; Waldman, 2018).

From a humanitarian point of view, it is hard to argue that the best interest of anyone is to die. And yet, when we look closer, GOSH is not arguing for inducing Charlie's death, as death is accepted as an inevitable fact. Charlie has a terminal illness; therefore, regardless of intervention Charlie was going to die. Instead, the question for GOSH is what suffering Charlie should be made to experience in the process of dying (Caplan, 2017; Waldman, 2018). Conversely, because the Gards did not see Charlie's death as inevitable, they held a different threshold for what experiences are 'worth the pain.' Intensive care interventions were not happening to him, causing pain without purpose, they were instead happening for him, so that he could have a chance at life (Sharman, 2004; Xafis, 2015).

Although BIS was the language used, it appears as though both the Gards and the British court system were forming their arguments on something much closer to the theories of ZPD and HT. First, was enrolling Charlie in experimental nucleoside therapy within the zone of parental discretion? ZPD is an appealing framework for the Gard case, as there are several "gray" hypotheticals to consider. It states first that parents are allowed to make their own value judgements based on their conception of a "good life" (Gillam, 2015). While the Gards agreed with GOSH that Charlie's present quality of life was poor, they did not share their certainty that his current state of illness was uncurable (Caplan, 2017). The value then of continued intensive care therapies was judged differently between the hospital staff and the Gards. Both ZPD and the family-centered care model allow this, as parents can apply their values to their child's situation (AAP, 2012; AAP, 2014; Gilam, 2015).

The limit of ZPD lies in the idea of harm. According to ZPD, parental discretion should be limited to the point in which parental choice causes "significant" harm (Guillam, 2016). The question then really relates to what kind of harm Charlie faced. GOSH's legal team endorsed

harm of commission (Caplan, 2017; Waldman, 2018; Yeung, 2021). First, in going to America for experimental nucleoside therapy, they asserted Charlie's parents would be subjecting him to harm by commission. That is, they assert that the harms Charlie would undergo in moving to America and participating in a clinical trial would be as, if not more harmful than his present state. The potential suffering this would cause far outweighed any benefit he could hope to achieve (Caplan, 2017). Of a lesser, but still morally relevant harm, was continuing to provide intensive care therapy, such as mechanical ventilation to Charlie. Here, another value judgement has been made, in which continuing to life is effectively judged to be a 'fate worse than death' (Caplan, 2017; Tate, 2020)

Charlie's parents had a different concept of harm. They were primarily concerned with harm by omission (Wilkinson, 2017; Yeung, 2021). While they agreed that Charlie's current life was undesirably bad, they felt that it could be improved (GOSH, 2017). To fail to transport him to America then would be to fail to provide him with a chance at a hopeful recovery. It was at this point that GOSH and the Gards found themselves at an impasse. One party felt that there was nothing left to do but facilitate a painless death, whereas the other felt that the benefit of any chance outweighed the risks. Both sides were convinced they were doing the 'best' for Charlie, and both aimed to reduce the likelihood of what they saw as the most significant harm (Caplan, 2017; Wilkinson, 2017; Choong, 2019).

The following section will discuss physician and family bias, respectively. I will focus on how experience, cultural socialization, and underlying emotion can contribute to intensive care conflict. Physician bias will be presented as a variable that can contribute to shaping a healthcare provider's opinion of a child's best plan of care. I will then discuss the emotional impact of critical care hospitalization on families, bridging how inappropriately supported needs may lead

the parent to involve external parties, such as the media, in intensive care conflict. I will return to Charlie in the media chapter, discussing how media involvement introduced several ethically relevant harms that were neglected by both GOSH and the Gards in their evaluation of Charlie's interests.

Physician Bias

The shift to family centered care takes physicians from a historically dominant position of solely determining best interests to a partnership in which they are required to guide parents through the discernment of their own values and wishes (Lantos, 2019). While an ideal world would make this an equal partnership, the very nature of the intensive care environment creates a situation fraught with the potential for power differentials. Families often experience significant stressors, which they must cope with in order to participate in critical decision-making. The physician, by virtue of his own underlying values and experiences, also cannot be a neutral party (Stokes, 2017; Drach 2020). Regardless of intention, physician bias affects the narrative of information presented to parents (Wilford, 2014).

Physician bias can take many forms. Existing multi-variate studies regarding physician decision making have shown that provider characteristics such as age, gender, religious background, and geographic location, correlate with how aggressively providers recommend and provide end of life therapies (Larochelle, 2009; Racine, 2016; Lantos, 2019; Hinkka, 2002; Miccinesi, 2005). Other studies have examined the impact of medical culture on quality-of-life evaluations. It is apparent that the physician's specialty, where and how they were trained, and the subculture of the unit in which they practice all affect how providers view quality of life (Racine, 2016; Hinkka, 2002; Miccinesi 2005; Stokes 2017; Shapiro 2011; LaRochelle, 2009) For instance, a physician specializing in palliative care medicine may have very different

priorities than a surgeon. Likewise, a pediatrician practicing in a large academic center PICU, may view longitudinal outcomes differently than one who practices in a community hospital.

Miller-Smith suggests that the very ethos of pediatric critical care medicine requires one to strive to beat odds, no matter how slim (2019). Children for whom the outcome, regardless of effort, will involve disability or life limitation provides a frustrating reminder of the physician's underlying fallibility. In these scenarios, physicians report feeling "lost," "defeated," and "afraid they have somehow failed the family and patient to whom they were expected to heal" (LaRochelle 2009; Arzuga 2015; Miller-Smith 2019; Racine 2016). Physicians also report having complex feelings of guilt when counseling families about life-sustaining measures for children who may survive with new neurological disability (LaRochelle, 2009; Drach 2020; Wilfrond, 2014). This concern is particularly strong among cases of children who will require extensive medical support and technology (such as feeding tubes) throughout their lives (Drach, 2020; Wilfrond, 2014). Physician disability bias has been well documented, with physicians consistently rating quality of life of "severely impaired children" as being lower than the ratings from both the parents and the patients themselves (Racine 2016; Wilford 2014; Payot 2011; Haward 2017; Saigal 1999; Lantos 2019; Janiver 2014).

One proposed explanation for the disproportionately negative quality of life evaluation is the presence of an exposure bias. Children with disabilities may be medically fragile, requiring hospitalization for procedures and illness management (Miller-Smith, 2019). For pediatricians who mostly or exclusively practice in the inpatient setting, patients with disabilities are only seen when they are experiencing a situation requiring admission (Wilfrond, 2014). Inpatient providers are also less likely to have positive exposure to patients with disabilities outside of the hospital, where they may obtain great fulfillment and pleasure in their lives.

Repeatedly only seeing patients and families during periods of significant illness and high stress may cause providers to assume that the level of suffering seen during hospitalization is a constant, rather than transient, condition. The exposure bias suggests why healthcare providers with personal exposure to significant illness and/or disability may be less conflicted in promoting aggressive treatment. These physicians may have a better-rounded perspective of what everyday life may look like in adapting to the care of a medically complex patient. (Hinkka, 2002).

Family Expectations and Bias

As physicians bring both personal and professional backgrounds to intensive care decision-making so do parents. If physician bias impacts how and what information is presented, likewise, family bias and background will impact how information is understood (Lipstein, 2011). Unlike physicians, parents are at a disadvantage by virtue of environmental and situational novelty, as well as their own emotional investment in the intensive care process. When surveying parents of pediatric ICU patients, it was reported that 71% lack personal experience with any loved one receiving critical care (Meyer, 2002). While not studied, it could be estimated that even among those with experience, even fewer parents have been the primary decision-makers for intensive care patients (Meyer, 2002; Janiver, 2014).

To approach ICU shared decision-making, parents must rely on applying knowledge that may be rapidly cobbled together via medical team discussion, social resources (such as the anecdotal experience of family or friends), and self-research (Lipstein, 2011). Resourcefulness in seeking, comprehending, and applying information, and the ability to cope with the ramifications of these uniquely stressful decisions is impacted by the parent's underlying background (Lipstein, 2011; Baia, 2015). Parents who come from backgrounds of poverty, low education,

and poor social support are disproportionately reported as affected by intensive care conflict (Lean, 2018; Spijkers, 2020). The underlying causes of this are complex and compounding.

First, it is important to acknowledge that parents who experience socio-economic disparities often also belong to historically disenfranchised populations. African American and Native American families may have been raised with a cultural mistrust of healthcare systems (Kotalik, 2016; Sullivan, 2020). This mistrust, which developed as a response to ancestral or personal experiences of exploitation, can impact the way in which families approach healthcare institutions (Mosley, 2012; Sullivan, 2020). Parents are socially and emotionally conditioned to be protective of their children (October 2014). When cultures have been raised to be skeptical of medical providers, there may be particularly strong barriers to collaborative efforts (October 2014; Hinds, 2009; Sullivan, 2020). If this context is missed by the healthcare team, parental efforts at protection may misperceived as outright denial of or resistance to curative efforts (Mosley, 2012; Sullivan, 2020).

Poverty can exacerbate the potential for conflict by introducing additional parental stressors (Spijekers, 2022). Parents of intensive care patients may worry about the cost of hospitalization as well as the ability to care for their child's needs after discharge (Page, 2020). Those working multiple jobs may not be easily accessible or visible to the team. Working families often are not able to take time off to be constantly at their child's bedside. Not only can this lead to significant anxiety but absent parents may be missing collaborative opportunities, such as team rounds. Subspeciality consultants, who may only round once a day very well may be passing information to families via second and third hand, without the real-time chance to address concerns. Concurrently, as families are not with their child, medical teams may form falsely negative assumptions about the absent parent's concern for their child. Even when

present, these parents may face negative judgement, brief explanations, and a decreased willingness to help from staff (Xafis, 2015; Haward, 2019).

Parents may have difficulty connecting and forming trustful bonds when medical providers come from different cultural and socio-economic backgrounds. Parents lacking formal education, as well as non-native speakers, may struggle to comprehend complex terminology (Xafis, 2015; Haward, 2019). Likewise, the medical team may jump to generalizations about capacity for comprehension, either talking above the parent's understanding or inadvertently belittling their intelligence (Xafis, 2015; Spijekers 2022). Although interpreter services have become increasingly accessible, they do not always cover all languages and dialects. Additionally, requiring interpreters for verbal interaction means that non-English speaking parents often miss casual explanations and pleasantries that contribute to building mutual trust (Xafix, 2015; Miller-Smith, 2019).

Diverse backgrounds may also impact the way that parents view the responsibilities of parenting. Parents may be unsure how to adapt their parenting practices to the needs of the critically ill child. Religious traditions may provide hope for recovery as well as promote coping. Families with strong spiritual ties may view outcomes as being "out of our hands" and "up to God" (Miller-Smith, 2019). Others may find that rituals such as prayer provide tangible ways that they can contribute to their child's healing (Desai, 2016; Miller-Smith, 2019). Faith communities may provide families with great support, however certain religious traditions may shape family ideals regarding appropriate medical care (Desai, 2016; Malom, 2019). Communities with prominent religious leaders may choose to involve members outside the family in the shared decision-making process (Malcom, 2019). Families with more secular beliefs may choose to place faith in medical technologies and interventions. Here, belief in the

power of science to 'overcome' nature may contribute to resistance in accepting negative outcomes (Kirshbaum, 1996). Both secular and religious families may wish to supplement or even substitute traditional medicine with alternative culture-based remedies (Desai, 2016; Miller-Smith, 2019).

Finally, parenting a child in the intensive care unit often brings about powerful emotions. Not only are parents asked to make decisions in a novel and stressful environment, but they are required to do so while supporting a critically ill child. As parents participate in and witness the hospitalization of their children, they may be faced with strong emotions such as grief, anxiety, and loneliness (Meert, 2005; Miller-Smith, 2019). Much research has been done into the impact of emotions on parental coping in serious illness (Sharman, 2004; Lisanti, 2017). In recognizing that intensive care parents may be struggling, we can begin to discuss how poorly supported needs can contribute to intractable conflict.

Parental Emotion

The healthy parent-child relationship is a special and intimate one. Parents observe their children throughout every phase of their life. The child is dependent on adults to meet all their needs. As the new parent responds to needs such as feeding and comforting their infant, they become deeply aware of their child's dependency on them (Harvey, 2003.) The resultant relationship is a protective one, in which the parent begins to associate fulfillment of the child's needs with fulfillment of the parental role. Meeting the child's needs is what a parent is supposed to do (Shmeuli, 2011).

The child learns that his parents are the people who have always been there and develop security in the fact that their needs are met. In return, the child gives the parent attention and

affection. The baby smiles and laughs back at her father's face. The toddler prefers the company of his mother to all other adults. The experience of the child's affections provides the parent with positive reinforcement to continue to meet their child's needs. This affection, which quickly becomes reciprocal, leads both parent and child to develop bonds of love (Downie, 1997; Shmeuli, 2011.) As the child grows older, they develop personalities. Parents begin to appreciate their child's unique quirks and talents. They may start to establish hopes for the adult their child may become (Hellman, 2008; Baia, 2015). A child who shows athletic talent may lead to a parent dreaming about raising a sports professional. A child with a passion for writing may be imagined as a famous author. In these hopes, the parent continues to gain positive incentive and purpose in their caregiving role (Meyer, 2006).

When a child experiences critical illness, the parent is faced with new possibilities and fears. Not only may they have to suddenly give up their dreams of the adults their children may become, but they must also face the possibility that their children may not grow up at all (Meert, 2005; Miller-Smith, 2019). The requirement of intensive care admission means the child is at risk of not surviving. Those children who do survive may sustain lasting physical and psychological repercussions (Meyer, 2006; Miller-Smith 2019).

Studies researching the impact of childhood critical illness on parents have ranged from extreme prematurity to childhood trauma and cancer (Meyer 2002; Baia, 2015; Lisanti, 2017). Regardless of disease process, parents of critically ill children report experiencing similar emotions. Intensive care admission introduces the possibility that the child will die (Miller-Smith, 2019). Unlike one hundred years ago where childhood death was common, modern first world countries expect that children will outlive their parents. The possibility of child death is thus thought of a strange unnaturally one (Meert, 2005). Even if the child does not die, there

remains the real possibility that life for the child will not return to the condition they were in prior to their hospitalization. Children may survive their intensive care admission with new fragility, neurological impairment, physical disability, or technological dependency (Meyer, 2006; Miller-Smith, 2019). These possibilities and the fear of the unknown lead parents to experience both anxiety and grief (Hellman, 2008; Xafis, 2015; Miller-Smith, 2019).

Anxiety is compounded by the novel nature of the situation and the environment (Janvier, 2014; Xafis, 2015). Unlike other childrearing problems, for which the parent may be able to troubleshoot based on the advice of friends or family, intensive care parents likely do not know any other parents of critically ill children (Janvier, 2014). Instead, they are forced to be dependent on the opinions and guidance of strangers. It is maybe then not surprising that many ICU parents report feeling isolated and lost (Xafis, 2015).

For perhaps the first time in their parenthood, parents may not be able to give the child what they need (Meyer, 2006). Not only is the parent unable to fix the child's underlying illness but with complex equipment and underlying fragility, parents may not even be able to actively participate in their care (Sharman, 2004; Meyer, 2006; Hellman, 2008). Instead, people such as nurses assume traditional roles such as changing diapers, bathing, and feeding (Meyer, 2006; Hellman, 2008). This may lead to feelings of guilt and shame, exacerbated by the commonly stated parental concern that they have somehow fundamentally failed as parents in not protecting their child from reaching their present state (Hellmann, 2008; Lean 2018).

Magical thinking is the belief that one's thoughts, actions, words, etc. influence the progression of events in the world; despite logical evidence to the contrary (APA, n.d.). As parents struggle to accept realities, they never thought possible, regression to child-like magical thinking often occurs (Lipstein, 2011; Miller-Smith, 2019.) Not only do many parents blame

themselves, but unrelated factors (like "I didn't take him to the playground when he wanted") may become causally attributed by the parent as a need for parental "punishment." In this internalization of responsibility for the illness, the parent's urgent desire to "make everything better" for the child increases, and distress at the inability to do so compounds (Miller-Smith, 2019.)

The intensive care environment, which stays busy day and night with its constant beeping monitors and bulky equipment, may increase sensations of surrealism and timelessness (Latour, 2010; Lisanti, 2017; Lean, 2018; Miller-Smith, 2019). These thoughts are further exacerbated by physical stressors such as lack of sleep and poor, infrequent nutrition, both commonly reported by parents of hospitalized children (Baia, 2015; Xafis, 2015; Miller-Smith, 2019). Beyond these often-illogical attempts to rationalize the present circumstances, parents report a kind of shell-shocked otherworldly experience of stress. Phrases like "feeling like walking in a fog" or "being stuck in amidst a strange and unimaginable place" are quoted in studies that evaluate parental experience (Hellman, 2008; Latour, 2010; Miller-Smith, 2019). One such account, by author Vicki Foreman describes experiencing the hospitalization of her extremely premature twins as "slippery" in which the boundaries between reality and nightmares blurred (Miller-Smith, 2019).

Despite the potential for these challenging emotions, the shared-decision model of pediatrics expects that families still actively participate in decisions regarding their children's care. When the coping mechanisms of pediatric critical care parents are studied, a common thread is the need for parents to feel as though they are "being good parents to their children" (Hinds, 2009; October 2014). The idea of being "good parent" to a critically ill child, while subject to individual, cultural interpretation, has demonstrated several general consistencies. Parents want their children to be seen for the individuals that they are. Although the child may

not be able to interact with the medical team, parents want their children to be cared for as the uniquely special people they know them to be. Many parents thus view a shift in their responsibility from direct care to being the "advocate" for their child's needs. A "good parent" is one who feels that their role as child's parent is respected. This may be respected through direct care for the parents' needs, patience with questions, or through encouraged participation in comforting and in physical care (Hinds, 2009; October 2014; Spijkers, 2022).

As external stressors and emotions further strain parents, the pediatric intensive care environment becomes rich with the opportunity for conflict (Abbott, 2001; Forbat, 2015; Spijkers, 2022). While the shared decision-making model expects parental participation, a parent who wishes to feel like a good parent may react to collaborative efforts with suspicion, mistrust, anger, or fear (Hinds, 2009; October, 2014). Physicians, who bring their own biases and emotions in turn may be frustrated and react with subpar patience or compassion (Spijkers, 2022). Failure to compromise not only delays important decision-making on behalf of the child, but it creates an environment where family appeals to external resources, such as the media or the court system, may seem appealing (Choong, 2019; Kubheka, 2020).

Chapter 4

Media Benefits

The previous chapter identified common sources of intensive care conflict between parents and healthcare providers and included a discussion of how intrinsic and extrinsic factors present in both parties contribute to conflict development. After identifying that physician bias can alter the way patient information is presented, the chapter explored how parental background can combine with incident-related stress to alter how information is received. Finally, the reviewed literature evaluating how parents make decisions in the intensive care unit was reviewed.

In these studies, a recurrent theme was reported by parents of critically ill children. This theme, or the underlying motivation to "be a good parent" to their child, tends to have several generalized components. A "good parent" is one who is treated like an integral member of the care team (Hinds, 2009, October 2014). They are kept informed on present treatment and anticipated diagnoses, options, and outcomes (Hinds, 2009; Latour, 2010; October 2014). As a member of the team, the "good parent" feels like an effective advocate (Kirschbaum, 1996; Meyer, 2002; Hinds, 2009; October 2014). When concerns are brought up, they are taken seriously and considered as valuable information (Kirshbaum, 1996; Hinds, 2009; October 2014).

Most importantly, the "good parent" needs to feel as though they have gotten their child to a place where they can receive "the best" care (Xafix, 2015; Miller-Smith, 2019). This optimum care is interpreted by parents not just in terms of physiological outcomes, but in compassionate and individualized attention paid to the needs of their child (Kirschbaum, 1996; Sharman, 2004; Bridgeman, 2020). Loving parents see their children as uniquely important (Miller-Smith, 2019). A child requiring critical care has a reasonable risk of not surviving. When

parents disagree with critical care teams, it is most often regarding the child's best interests (Mohrmann, 2006; Do Vos, 2014; Spijkers, 2022). Parents who are unable to feel like "good parents" within their child's current care may begin to look elsewhere for an environment that satisfies that need (Choong, 2019; Kubheka, 2020).

Historically, this process occurred via word of mouth, typically as parents of sick children connected with each other at the hospital. The very dissatisfied or concerned parent relied on these word-of-mouth recommendations to seek alternative treatments, providers, or institutions (Xafis, 2015; Miller-Smith, 2019). Modern parents, however, have other options. As media technology has advanced, information regarding alternative resources is at their fingers. Not only can parents use media technology to rapidly gain information, but the increasing popularity of social media opens entirely new possibilities for including external parties in critical care disagreements.

It is in these growing possibilities that current bioethics literature lacks guidance. Media use can be beneficial, but it can also cause significant harm, not only to the rights of the critically ill child, but to the family and the healthcare system at large. The following chapter unpacks these issues, starting first with a review of modern media channels with a concession granted to the potential benefits that media use may have for the critically ill parent. The chapter concludes with the case example of Charlie Gard's media campaign, preparing for an in-depth discussion of the multiple ways that media exposure may cause harm.

What is Media?

Media refers to the wide variety of channels used to deliver information to society (Market Business News, n.d.). The content of media varies from current events to educational

information, and entertainment. Modern media can be divided into three primary categories, namely broadcasting (or "mainstream"), print, and internet/social media (Market Business News, n.d.; Global Digital Insights, n.d.). The oldest of these categories is print media. "Print" encompasses books, magazines, journals, and newspapers (Market Business News, n.d.). Traditional newspapers tend to be vetted by journalists and editors to accurately report events and information of social importance. Conversely, tabloid prints tend toward sensationalist entertainment, with a focus on scandal and less on the provision of fact (Choong, 2009; Market Business News, n.d.).

While print media requires that one be able to read, broadcast media simply requires that one be able to listen (AAP, 2016). Broadcast encompasses both television and radio, with radio being the most wide-reaching and easily portable of the two. Historically both television and radio broadcast news at scheduled intervals, with the time in between devoted to entertainment and advertisement. This has evolved over the past forty years into what is now referred to as the 'twenty-four-hour news cycle' (History, 2009). Now instead of interval updates, entire shows are dedicated to presentation and subsequent commentary of public events.

Although the internet is the latest of the media categories to develop, its popularity is rapidly outpacing both print and broadcasting (AAP, 2016; U.S. Census Bureau, 2022). Between 2002 and 2020, United States revenue for newspapers and video rentals decreased 52.0% and 88.5% respectively (MediaTracks Communications, n.d.). Meanwhile, daily internet use is growing exponentially (AAP, 2016). In 2019, daily internet use was reported in 4.02 billion people. In 2022, this number increased by over a billion users, with 5.07 billion reporting daily use. The typical internet user aged 18-29 years old reports spending an average of six hours and thirty-seven minutes per day engaging with internet applications (Global Digital Insights, n.d.).

One of the biggest contributors to the internet's success is the concurrent invention and popularity of "smart," or internet capable telephones. Over six billion of the world's people report owning smart telephones with more than 90% of these individuals indicating their primary usage is spent interacting with social media (Barrett, 2019).

"Social media" is a term referring to the wide range of internet-based applications that enable individual users to create and share informational content directly with others (Barrett, 2019). Not only can the internet be used to rapidly access virtual versions of print and broadcast media, but the rise of social media has shown that it can also be a source of its own type of information (Mackey, 2016). The internet's growth in popularity thus represents a cultural shift in how information is disseminated and received (Mackey, 2016; Barett, 2019). The nature of broadcast and print media produces a divide between those who present information and the passive audience receiving it. Internet and social media transition the audience from the role of passive recipient to that of an active seeker, processor, and in the instance of social media, producer of information it finds most valuable (Barrett, 2019).

Media's Benefits

Media's lasting and ever-evolving presence in society suggests that many individuals benefit from its use. One of the largest benefits is accessibility to information (Barrett, 2019). Before the invention of print (and far before the invention of broadcasting devices), individuals gained information via word of mouth. Not does word of mouth require effort on behalf of the individual, but it requires a certain social standing. What information you found out was dependent on who you knew, who you saw, and what they felt was relevant to share. Word of mouth also lacks standardization (Barrett, 2019). Anybody who has played the childhood game

of 'telephone' quickly learns how easily information can be distorted when it passes through several listeners.

With the invention of print media, a more standardized source of information was made available (Kubheka, 2020). While still limited to those of social standing who could read, once printed, information was less subject to individual distortion. Unfortunately, as a tradeoff, this type of information dissemination was dependent on the speed of printing and distribution of written materials. As broadcasting technology was invented, this process sped up considerably. Not only were people simply able to 'tune in' to listen to the media, but information was made accessible to a wider audience, regardless of their capacity to read (History, 2009; AAP, 2016). While traditionally broadcast information was limited to certain times of day, the past forty-years has increased availability to the current '24-hour news cycle' (History, 2009). Now one can listen to current events at any hour of the day.

Still, information obtained via broadcast media is limited to what broadcasters find newsworthy. Information obtained from these sources is simply what the broadcaster chooses to present. The invention and increasing popularity of the internet has changed all of this. Now, users have access to both new and archived information from a variety of sources. The growing use of smart phones means that individuals can search for and obtain information virtually anywhere (Barrett, 2019).

Families of sick children report that this easy accessibility to information helps them feel like more equal partners in their child's care (Barrett, 2019; Choong, 2019; Kubheka, 2020). A parent may not think of questions until after their child's healthcare provider has left. They may also feel as though the provider does not have enough time to help them completely understand what is going on. With the internet, parents can read, learn, and research at their own leisure

(Bridgeman, 2020; Bryan, 2020). This arguably results in individuals who are better informed to participate in the shared decision-making process (Moore, 2019; Kubheka, 2020).

Media also provides a means of connection (Barton, 2018; Choong, 2019). Parenting a critically ill child is often isolating (Meyer, 2002; Xanfis, 2015; Miller-Smith, 2019). Not only are parents not likely to know other parents in similar situations, but they may not know of any other children with their child's particular illness. Introducing oneself to other parents in the hospital, much less asking them in depth questions about treatments and outcomes, may feel uncomfortably intrusive. Internet and social media allow parents to connect with parents of other sick children who are open to, and desire interaction (Barton, 2018; Barrett, 2019; Choong, 2019). Through online support groups, parents can learn of others with their child's condition. They also can quickly gain guidance from others on how to be involved in their child's unique parenting needs. Such support groups may offer advice on everything from advocating for different treatment options to helping one's child cope with side effects of medical therapy (Konrad, 2007; Narramore, 2008; Barton, 2018; Bridgeman, 2020). Not only does the media help build a sense of community, but it also creates a space where introductions seem less difficult and less awkward (Barrett, 2019). In this new source of community, valuable networking and emotional support can occur (Barton, 2018; Choong, 2019).

Media also helps facilitate communication with family and friends (Barrett, 2019; Kubheka, 2020). Pediatric tertiary care centers are often located in large metropolitan areas (Pesata, 1999; U.S. News and World Report, n.d.). Families may travel far outside their communities for specialized critical care (Pesata, 1999; Shepard, 2011; Syad, 2013). Once at the hospital, intensive care units often have visitor restrictions, limiting face to face interactions to one or two caregivers (Carnevale 2005; Macdonald 2012). Social media allows families to

provide centralized updates without the time commitment (or emotional stress) of verbally reporting information over and over (Barrett, 2019; Kubheka, 2020). It also allows for a chance via video chatting and other technologies for family members unable to commute to the bedside to still interact with and provide comfort to both child and family (Barrett, 2019).

Media use can also have beneficial effects for families involved in critical care disagreements. In 2019, bioethicists Bryanna Moore and John Lantos reviewed twelve highly publicized cases in which a child's parents chose to involve the media in disagreements regarding their critically ill child. Moore and Lantos examined direct interview quotes from parents both during and after the cases that indicated their motivation for using media. From these quotes, they identified seven overarching themes (2019). These are discussed critically below.

1. **To change the medical team's decision**

Most critical care disagreements occur because parents and physicians disagree about the best course of action for the child (Mohrmann, 2006; Do Vos, 2014; Moore, 2019; Spijekers, 2022). When parents feel as though the medical team is going to proceed (or withhold) an action they disagree with, parents may involve the media to garner additional pressure toward their preferred course of action (Moore, 2019).

This has occurred in two main situations. The first is where the parents desire a treatment that the hospital team feels is harmful or otherwise contraindicated. Examples include the case of Amelia Rivers, in which the hospital denied listing the patient for an organ transplant based on her multiple underlying medical conditions. Without a transplant, Amelia would die. Parents

appealed Amelia's case to the media, and as the result of substantial public pressure, the hospital changed their organ transplantation policy (Moore, 2019).

The second sort of situation is where the healthcare team wishes to provide a treatment that the parents disagree with. The case of Oshin Kiszko is one in which his parents wished to forgo chemotherapy. While the medical team appealed to child protective services and the court system to provide treatment due to medical neglect, Oshin's parents used the media to bring attention to (and then stall) court proceedings. Ultimately, proceedings were stalled to a point where chemotherapy was no longer considered medically appropriate, and Oshin died (Richards, 2018; Moore, 2019).

While these are two different scenarios, the underlying mechanism is the same. In both situations, parents have appealed to the media to change the medical team's opinion by virtue of public shaming (Choong, 2019). In the first scenario, media attention led to public outrage that any child may be denied lifesaving transplantation simply because they have medical comorbidities. In the second situation, Oshin's parents used the media to evoke shame in a more philosophical way-namely the idea that a medical team could override the deeply held wishes and beliefs of loving parents wishing to raise their child as they see appropriate (Moore, 2019).

It is interesting to note that while the media was a useful tool in inducing shame change for these two cases (though arguably without the outcome Oshin's parents desired), in numerous others, extensive media coverage has been unsuccessful in changing the underlying medical decision (Hurley, 2017; Wilkinson, 2017). While I will discuss Charlie Gard in further detail in the sections below, his is a prime example of a case that that despite having attracted copious social attention, the medical team (and court system)'s decision remained unchanged (Wilkinson, 2017).

2. **To be heard**

Of course, not all parents will want or need a decision to be changed. Others may disagree about a proposed plan of care but be more upset about circumstances affecting or contributing to the disagreement (Gilbert, 2018; Choong, 2019; Moore, 2019). Commonly reported as a contributor to this distress is the feeling that their child's clinicians did not listen to or take the concerns of the parents seriously, often to some detrimental outcome (Nuffield Council, n.d.; Moore, 2019).

The case of Jahi McMath is one such example. Jahi's parents reported expressing concern that their daughter was bleeding too much following a tonsillectomy. Despite their efforts to get the surgeon to come to the bedside and reexamine their daughter, security was called on the family for being "too aggressive." They were reassured that her bleeding was normal after her procedure. Soon after her father was taken away by security, Jahi suffered a cardiac arrest due to exsanguination (Gilbert, 2018; Shewmon, 2021). Publicized controversy ensued as Jahi was declared brain dead. While Jahi's family was resistant to the medical team's diagnosis of brain death, longitudinal interviews with her family state that much of their resistance was rooted in the fundamental disrespect and discrimination they felt (Gilbert, 2018; Moore, 2019).

Media quotes taken initially from Jahi's family demonstrated hurt and mistrust. They stated, "It was like he (the doctor) thought we were dirt" and "No one was listening to us, and I can't prove it, but I feel in my heart if Jahi was a little white girl, I feel we would have gotten a little more help and attention" (Gilbert, 2018; Moore, 2019). Given that the medical team had falsely assured them that the bleeding was normal, Jahi's family also found it difficult to understand that their child, who had met death by neurological criteria (and therefore was still warm, making urine, and breathing via ventilator) was legally dead (Moore, 2019; Shewmon,

2021). After all, her mother stated that when the emergency was present "none of them knew more about her than me. Not one. I was smarter than all of them when it came to her" (Moore, 2019). For families who do not feel heard, the media's far-reaching accessibility provides an appealing outlet for the parent's emotions, thoughts, and experiences to be heard on a loud and global scale (Moore, 2019). Years later, Jahi's grandmother was quoted reflecting on the family's media campaign wondering "Would we have fought so much if the hospital had (just) been a little more compassionate (Gilbert, 2018)?"

3. **To feel empowered and gain or regain control**

Just as parents wish to be heard, some may also seek to feel empowered. Parents of critically ill children often report feeling a loss of control. Not only does the intensive care environment necessitate an often-substantial alteration in the way that a parent can participate in the physical care of their child, but parents are also required to trust a team of strangers to provide things that they themselves cannot (Sharman, 2004; Meyer, 2006; Hellman, 2008). Exacerbating this stress is the very real potential that despite efforts, these trusted strangers will fail, and the child will not survive (Miller-Smith, 2019).

Ideally the parent feels like a valued partner in their child's care. Unfortunately, many families still perceive an imbalanced power-dynamic within the shared decision-making model (Kotalik, 2016; Sullivan, 2020). Medical providers have knowledge, technology, and treatment possibilities that the parent not only may not be aware of, but for reasons unclear to the parent may or may not be applicable for the individual child (Xafis, 2015; Haward, 2019).

Sharing a child's story on the media opens the parent to connections and resources that may not have been possible to obtain any other way (Barton, 2018; Choong, 2019) Parents are

largely alone in the ability to disclose personal information about their children. Regardless of conflict, hospital systems and medical teams are limited by patient privacy laws in what they can disclose. In this sense, engaging media may feel like 'doing something' that only a parent can do to impact a situation that otherwise feels out of control (Meyer, 2006; Moore, 2019). The following two case quotes directed at their child's media exemplifies the way that coverage can create a sense of empowerment:

> "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 (Moore, 2019)."

> "Your efforts are working. The company cannot continue to ignore us. They cannot continue to ignore the fact that they and they alone have the power to save Josh. We will succeed. It is a war of attrition, and we are stronger **(**Moore, 2019)."

4. **To buy time**

Media campaigning may be a parental attempt to stall away dreaded outcomes of child death (Moore, 2019). The goal of 'buying time' may or may not be intentionally stated. Underlying motivations range from hope and optimism to anticipatory grief, denial, and underlying mistrust. In many cases, multiple elements are present together. For instance, families who engage media to 'buy more time' may be hopeful that public attention (again via the power of shame) deters their child's medical team from prematurely withdrawing life sustaining interventions. In this, there may be an underlying thread of both optimism and denial that if the child can be kept alive for long enough, there may be spontaneous improvement (Meyer, 2006; Lipstein, 2011; Miller-Smith, 2019).

In this optimism, there may also be elements of anticipatory grief. Without a doubt, the death of a child is one of the most devastating things that can happen in parent's life (Meert, 2005; Myer, 2006). When death seems possible, or even imminent, using every effort (including the media) to 'stall' it's occurrence may very well speak to an aspect of the parent's grief processing. The cherishing of each day, while easily perceived as stalling, can be deeply meaningful in helping parents learn to cope (Meert, 2005; Moore, 2019). One parent of a terminally ill child who used media coverage to impact her child's care spoke about her relationship with time, exclaiming that "Every day is such a gift and each month you are blessed with should be celebrated!" Not only does the media coverage potentially help to maximize length of life, but it can also provide a venue for families to feel like they are contributing positively to their child's legacy (Moore, 2019). This will be discussed in more detail in the next point.

It is also essential to mention that families with the concern that their child's life sustaining interventions can and will be abruptly 'pulled' without consent may be speaking from a place of significant trauma. This may be particularly apparent in families from cultures that have experienced historical medical harms, as well as in those whose personal healthcare experiences have led them to doubt the medical team's intentions (Mosely 2012; Kotalik, 2016; Sullivan, 2020). Moore and Lantos quote one such parent as stating "I just want to spend time with my son. I want to let him die naturally without someone coming up and saying that we are going to cut him off on a certain day (2019)." In these cases, the media is employed by the family as a kind of accountability watchdog, supervising and deterring medical teams from making decisions that may be unfavorably perceived by the public (Moore, 2019).

5. **To generate discussion or raise awareness about a particular condition or issue**

In modern society, critically ill children are statistically rare (Miller-Smith, 2019). Some of these children's families utilize the media as a form of altruism, as to prevent other children from undergoing similar experiences (Moore, 2019; UDOT, 2022; WTAE, 2022). This usage is particularly common among children who have become sick or injured as the result of "freak" accidents (Javed, 2022; UDOT, 2022). In publicizing their child's journey, parents hope to teach other families the things they may wish they had known about prevention (Moore, 2019).

A recent example of the latter is the case of Kennedy Mitchell, a toddler who became critically ill after ingesting the popular child's toy "Orbeez.' Kennedy's mother contacted the toy's manufacturer and the media to warn other families that the toy is dangerous to young children (WSAZ, 2022). This type of media use is also prevalent among families of children with rare diseases that do not receive much research funding. Parents may elect to use their child's story as poster child in order to demonstrate the devastating effects of disease and thus generate public pressure for research (Barton, 2018). Media use in both cases may be linked to the concept of building a legacy (Barton, 2018; Moore, 2019; Boles, 2021; Cahlan, 2022; WTAE, 2022).

Critically ill children, regardless of etiology, may not survive their illness (Miller-Smith, 2019). Of the children who die in the intensive care unit, the majority do so within the first few years of life (Meyer, 2006). It is natural for parents to have hopes and dreams for their child's lives. When these lives are briefly lived, dreams change (Meert, 2005; Meyer, 2006; Miller-Smith, 2019). Parents may instead dream that their children's illness has a lasting meaning in the world (Boles, 2021; Cahalan, 2022). This legacy can be built through the types of attention

discussed above, or it can simply be felt in having large groups of people aware that their child lived and was loved (Meert, 2005; Meyer, 2006; Miller-Smith, 2019; Moore, 2019).

Charlie Gard's parents used the money raised for his treatment to form a foundation for research of mitochondrial illness. In doing so, they stated, "We feel that the foundation will be a lovely legacy for Charlie, and we hope you will all continue to support us in honouring the life of our little warrior as he helps other poorly children and their families" (Moore, 2019; The Charlie Gard Foundation, 2021).

6. **To feel that they have done everything possible for their child**

Not only can media attention help parents feel empowered at the time of illness, but it can act as a means of coping with the emotional stress accrued in the intensive care unit. Making decisions on behalf of one's critically ill children is a high-stakes experience. Many decisions have unknown outcomes. Other times, the decision may be between two undesirable choices. Finally, in some scenarios medical teams may inform parents that they do not believe that there are any curative therapies left.

Some parents may fear decisional regret (Moore, 2019). What if there was a therapy that they were unaware of? Would they be left forever wondering 'what if I?" Others may deeply feel that a "good parent" is the one who leaves no viable option, however unlikely, unexplored. Here, there is a sense that doing something, anything, may be better than "watching their child die." Media used by these parents then acts as a beacon of hope, through which someone may hear of their child and offer a novel solution (Moore, 2019).

7. **For financial gain**

Parenting a critically ill child is expensive (U.S. News, 2020). Not only do parents face the prohibitive costs of intensive care therapies, but they must deal with numerous ancillary expenses (such as hospital transportation, parental food, and missed wages) (Lean, 2018; Spijkers, 2020). Crowdfunding, or social media to raise money, has become one of the most used ways for individuals to seek medical expense assistance (Moore, 2019; Kubheka, 2020). Websites, such as "GoFundMe" provide detailed instructions to individuals seeking to raise money. These campaigns are open not only to those that the family knows, but the entire internet. Complete strangers may (and often do) give substantial amounts of money to particularly poignant cases (Barrett, 2019; Kubheka, 2020).

GoFundMe provides guidance to families seeking successful medical campaigns. In return for hosting campaigns, GoFundMe keeps a percentage of the funds raised (Barrett, 2019). Crowdfunding is particularly appealing not only because it helps raise money for care that parents may not otherwise be able to afford, but once set up, it does so independently. Donations are given through a singular secure page and progress can be easily tracked (Barrett, 2019; Kubheka, 2020). The ease of crowdfunding can give parents time to spend with their child that they may have otherwise spent overworking or stressing over finances (Barrett, 2019; Moore, 2019).

The above sections have discussed in detail the ways in which media involvement can be beneficial to the parents of critically ill children. While focused mainly on parents' emotional needs, several of these benefits could benefit the sick child. Feasibly a parent whose emotional needs are met is one who can best provide emotional support to their child. By helping parents feel as though they are fulfilling the "good parent" role, they may in fact, be able to be better

parents. After all, a good parent is often described as one who can advocate for their child's needs. This advocacy is an essential part of the shared decision-making process.

The potential benefits of media are not unimportant. Unfortunately, short of building a child's legacy or gaining attention/funding for medical treatment, very few of these benefits directly address the needs of the child independent of their parent. The child may not wish for the same kind of legacy that their parents envision (Kubheka, 2020). Equally, they may not be developmentally or cognitively capable of conceptualizing such wishes. Finally, the fact that most of the benefits cited serve to directly meet the needs of the parent may mean that the parent is challenged in accurately foreseeing or weighing potential risks to the child.

Charlie Gard's Media Campaign

While Charlie Gard's case is not the first-time parents have appealed to the media, his case was a unique first in the way that his parents' campaign efforts rapidly multiplied and morphed into causes far beyond their intentions. Although Charlie's parents wished to change the minds of medical teams and court systems, the use of Charlie's story and imagery quickly grew in the media, turning him instead into a poster child for political and social causes quite beyond the interests of Charlie himself. This section is dedicated to the facts of Charlie's media coverage, highlighting its escalation to threats and violence against those directly involved. The following chapter will then discuss how this coverage harmed Charlie, his parents, and society.

Charlie's parents initially utilized electronic media to educate themselves about Charlie's disease. It is through their internet searches that they first learned about nucleoside experiments conducted in the United States (Montgomery, 2019). When his parents presented their findings to Charlie's medical team, the internet provided both initial contact information and a means for facilitating trans-Atlantic discussions between medical teams. It is through these channels that

Great Ormond Street Hospital (GOSH) prepared to establish an in-hospital clinical trial for

Charlie (Wilkinson, 2017; Hurley, 2017).

Unfortunately, while preparations for a British branch of the trial were coordinated,

Charlie's condition worsened. At this point, Charlie's medical team deemed him unlikely to

benefit from nucleoside therapy and aborted trial efforts (Hammond-Browning, 2017; Wilkinson,

2017). Although his parents shared concern for Charlie's decompensation, they maintained hope

that nucleoside therapy could slow disease progression. As GOSH appealed to the British legal

system for permission to discontinue Charlie's life sustaining therapies, the Gards countered with

requests to transfer Charlie to the United States for trial participation there (Wilkinson, 2017).

It is during this first of many court trials that Charlie's parents started their media

campaign. They established a variety of social media accounts (Facebook, Instagram, and

Youtube) as well as a personal website for sharing their perspective of Charlie's story. Not only

did the Gards share details (such as their experience of diagnosis and explored treatments) of

Charlie's medical journey, but they uploaded numerous pictures and videos of him (Wilkinson,

2017; Richards, 2018).

While their motivation for sharing the details has never been directly disclosed, as the

Moore/Lantos study indicates, it was likely multifactorial (2019). The Gards were deeply

devoted to their son's care. Interviews throughout their legal battles show that the Gards saw

themselves as fierce advocates, fighting for any possible chance of improving Charlie's life

(Richards, 2018). Besides the fact that the Gards wanted to change GOSH's opinion, they also

hoped to influence the court's opinion. Without the cooperation of GOSH and/or the court

system, they were unable to get Charlie the treatment they desired (Hammond-Browning, 2017;

Wilkinson, 2017). Sharing details and images not only allowed them an unfiltered means to

process and share their story, but it also allowed them to show Charlie as they saw him; namely a very loved little boy whose parents felt ignored and abandoned by their medical team (Wilkinson, 2017; Richards, 2018; Moore, 2019).

In addition to their desire to advocate for Charlie, the Gard's media campaign had a practical component. As GOSH was now unwilling to conduct nucleoside trials, Charlie's parents desperately needed to raise money. The United Kingdom provides socialized healthcare via their National Health Service (NHS), meaning that most healthcare expenses are subsidized in taxes (BMJ, 2020). While receiving intensive care therapies in the United Kingdom, Charlie's medical expenses were paid for. By desiring transport to the United States, the Gards' financial circumstances were set to change dramatically. They would be responsible not only for the costs of transporting their critically ill child to the United States, but once in the US, they would be responsible for all hospital costs to include intensive care admission and experimental nucleoside therapy (Hammond-Browning, 2017; BMJ, 2020).

Unlike the United Kingdom, the United States requires that patients cover via medical expenses themselves (either via paid insurance plans or out of pocket) (BMJ, 2020). While there are socialized programs in the United States (such as Medicare and Medicaid) that offer subsidized insurance for vulnerable populations such as impoverished children, as a non-United States citizen, Charlie would be ineligible to participate (Hammond-Browning, 2017; BMJ, 2020). The Gards' out of pocket expenses therefore had the potential to be extraordinary (Moore, 2019). As they braced for these costs, Charlie's parents chose to utilize the crowdfunding website, GoFundMe (Hurley, 2020). It is on this website that the Gards were advised on how to conduct a successful crowdfunding campaign. According to GoFundMe guidelines, the most lucrative campaigns are those in which emotional appeals are made. The website encourages

prospective campaigners to upload pictures, videos, and frequently updated medical details (Hurley, 2020).

Charlie's parents enthusiastically followed this advice. The images they shared of Charlie were carefully selective and emotionally appealing. Virtually all the pictures and videos uploaded were taken from early in Charlie's life before his disease progressed (Choong, 2019). In them, Charlie appeared thin but not otherwise ill. Even hospital imagery emphasized normalcy, showing him cuddled by parents and sleeping in a crib surrounded by stuffed animals (Choong, 2019.) Parental updates were frequent and heartfelt, expressing frustration at the situation and hope that if Charlie could only receive nucleoside therapy, he may yet recover.

Initial court proceedings were covered by regional media as a public interest story highlighting a local family's struggles to care for their sick child. As an interested public searched the internet for case details, the Gard's social media was quickly discovered. Here it served not only as a direct avenue for the curious, but also as a stream of images and videos (Hurley, 2017). Although both television and print media eventually worked directly with the Gards for commentary, they relied on social media as a source for Charlie data. As the GoFundMe guidelines predicted, pictures and the parent's emotional perspectives attracted a rapid and deeply invested following. Within six months the Gard's GoFundMe raised more than 1.3million pounds (Kubheka, 2020).

While the Gard media campaign started on electronic social media, it rapidly spread to all aspects of media coverage. The twenty-four-hour news media and tabloid publications thrived off soundbites and catch phrases taken from the Gard pages (Hammond-Browning, 2017; Wilkinson, 2017). In addition to its public interest appeal, aspects of the Gard case attracted the

attention of various political and social causes, specifically right-wing 'right to life,' disability

justice activists, libertarianism, populism, and anti-socialist concerns (Hurley, 2017; Das, 2018).

Political and social leaders such as United Kingdom Prime Minister Thersea May, United

States President Donald Trump, and Catholic Church figurehead Pope Francis all publicly

expressed their opinions on the case, via video and on their own social media pages (Hammond-

Browning, 2017; Hurley, 2017; Choong, 2019). As celebrities became involved, they utilized

their own following power to attract attention to the case while using aspects of the case to draw

attention to their own causes (Hurley, 2017). Pope Francis, for instance, used his personal twitter

account to proclaim that "To defend human life, above all when it is wounded by illness, is a

duty of love that God entrusts to all." Within a day of the pontiff's tweet, internet searches for

Charlie Gard increased by two hundred and eighty-five percent (Garrison, 2017).

Whereas television media and newspapers tended towards highlighting celebrity opinion

in the context of larger movements, a second following emerged in development of a large online

grassroot movements (Das, 2018). A particularly large group, containing approximately sixty-

two thousand active members was founded on Facebook (Richards, 2018). This group which was

composed primarily of middle-aged women and called itself Charlie's Army, shared updates

provided by the Gards, as well as links to mainstream media coverage (Das, 2018; Richards,

2018).

Charlie's Army group posts had a decidedly populist, or anti elitism/anti-establishment

view (Das, 2018; Richards, 2018). Charlie's story was often portrayed by group members as

being yet another instance of the social 'elite' (in this case, the NHS) inappropriately interfering

with and harming the rights of ordinary citizens (Das, 2018; Choong, 2019). Members of

Charlie's Army often shared their own experiences, either as parents or patients, in which they

felt harmed by the healthcare system (Das, 2018). This mistrust of the healthcare system was also manifested in posts questioning or outright denying the grim medical details (Richards, 2018). Characteristic posts included ones that rejected photos of a grossly swollen immobile Charlie as "chunky baby fat" that "will slim down as he begins walking," and those that questioned reports that Charlie was receiving morphine as "over aggressive" therapy that was "poisoning" (Das, 2018).

As court cases proceeded through multiple escalations of appeal, GOSH conducted its own media campaign, via carefully constructed statements which defended the medical team's position in withdrawing life sustaining therapy. In contrast to the Gards' lengthy and detailed emotional posts, GOSH's media statements were brief, generalized, and constrained, enforcing their position that Charlie was suffering via continued therapy and that withdrawal of life sustaining technology was in his best interest (Hammond-Browning, 2017). These statements were taken by groups like Charlie's Army as proof that the NHS was being intentionally evasive in what they saw as evidence that the healthcare system was harming (or even killing) sick children (Das, 2018; Richards, 2018).

In fact, both grassroots groups and mainstream media coverage of the Charlie Gard case was notably characterized by two components-the presentation of misinformation as fact and the use of emotionally charged rhetoric (Richards, 2018). The first of these is the fact that much of media coverage of the Gard case involved the presentation of opinions of the uninvolved and uninformed as factually relevant information (Richards, 2018). Although social media groups often shared personal stories of illness, none of the cases shared Charlie's rare disease (Das, 2018). Celebrity opinions of leaders such as Trump lacked medical, legal, or scientific backing and yet their viewpoints were presented over and over by mainstream media as relevant

(Richards, 2018; Choong, 2019). Even the so called 'expert witnesses' were limited by constraints of court proceedings and patient privacy laws; meaning that the few who possessed first-hand knowledge were unable to freely share it. Intent on feeding the public's desire for information, non-involved content experts could only share best estimates (Choong, 2019).

Limited by patient privacy laws and the need to maintain a professional image, GOSH could only release vague generalized statements (Choong, 2019). These aspects mean that the most direct media information came from Charlie's parents themselves. Even though the Gards were well informed as to the nature of Charlie's illness, they were also biased by their emotional investment. Using them as the sole source of reliable information meant that the media was left presenting an often-unequal biased picture as fact.

Secondly, all forms of media used sensationalist language in reporting Charlie's story. As demonstrated by "Charlie's Army," militant analogies were common (Richards, 2018; Choong, 2019). Although illness narrative commonly refers to the patient as "fighting" a "battle" with their disease, Charlie's Army took the analogy a step further (Choong, 2019). Not only was Charlie seen to be fighting against his disease, but he and his parents were victims fighting in a much larger populist war (Dresser, 2018; Richards, 2018). Charlie's case exemplified for many not only their personal experiences and anxieties but also larger fights-against cruel healthcare systems, socialized medicine, and "the right to life" (Hurley, 2017). Through publicized use of emotionally charged language, such as "baby murder" and "holding hostage," media coverage incited in many a call to action (Richards, 2018; Choong, 2019).

Petitions were written, the most popular of which contained over 115,000 signatures (Richards, 2018). Protests were hosted by social activist groups such as the pro-life Americans United for Life in major cities around the world (Hurley, 2017). Some of these events, conducted

directly outside of GOSH and British court houses became ugly, with murder accusations and expletives shouted at those entering (Richards, 2017; Das, 2018). Protesting also took a personally aggressive turn, as GOSH physicians, judges, court officials, and the Gards themselves became the victims of anonymous harassment and death threats (Das, 2018; Choong, 2019). The reach and aggression of these threats impacted both those directly involved in Charlie's case as well as individuals peripherally associated (such as other patients and families seeking medical care at GOSH) (Choong, 2019).

In the end, despite all the media attention, protesting, and fundraising, GOSH's position was upheld in every one of the Gards' legal appeals. With his parents' consent, Charlie's life sustaining technology was removed, and he died (Hammond-Browning, 2017). Charlie's death was globally mourned with celebrities and state figureheads expressing condolences. "Charlie's Army" page flooded posts detailing emotions of shock, horror, and sadness. The page, which has since dissolved, persisted for years, with members sharing virtual memorials to Charlie and discussing details of more recently publicized family/medical team disagreements (Richards, 2017; Das, 2018).

While the Gards shut down most of their social media sites, they used their GoFundMe campaign funds to convert their personal family website into a foundation (Kubheka, 2020) Today, the Charlie Gard Foundation is one of the leading groups involved in raising awareness and advocating research for mitochondrial diseases. The Gards themselves remain active, advocating for changes in the British legal system and providing monetary, medical, and legal resources for parents facing similar medical-family disagreements. While it is admirable that the legacy his parents have chosen to focus on remains centered on the disease that took his life, it also is not entirely unsurprising. As Charlie's case grew in the media, his parents remained

singularly directed in their role as parental advocates. Although they accepted funding and attention from the causes that adopted Charlie, they themselves did not advocate for or participate in any of them. There then remains much to be said about other impacts of Charlie's media campaign.

While Charlie's parents started their media campaign with the singular goal of advocating for Charlie's interests, his case explosively grew beyond Charlie himself. Without his parents' express intent (or even necessarily their agreement with the causes), Charlie became a poster child. His name and image have become synonymous for many, not with the loved child he was, but with the social and legal turmoil surrounding his death. In the process, all those directly involved, including his loving parents, underwent invasions of privacy, harassment, and violence threats. Not only did these people experience psychological harm, but the nature of media involvement itself threatened to harm the legal processes established for arbitration of such conflicts.

This chapter began by acknowledging the ways in which media coverage may benefit children and their families involved in family-medical care disagreement. The details of Charlie Gard's media coverage were then presented in detail. Through this case, it has been demonstrated that well intentioned and loving parents who chose to utilize the media may be unable to control the direction in which coverage evolves. Once media coverage begins and society at large becomes emotionally invested, potential benefits become shadowed by real harm. The forthcoming chapter is dedicated exclusively to media harms. As I build upon previous chapters' introductions to child and family rights, I highlight the ways in which unfettered media involvement potentially leads to rights violations. The Gard case is integrated throughout this discussion highlighting how media coverage damaged Charlie, his parents, and society.

Chapter 5

Media Harms

In previous chapters, I discussed the disagreement between Charlie Gard's parents and the Great Ormond Street Hospital (GOSH) intensive care staff. In doing so, I showed that typical of family-medical team disagreements, Charlie's parents and his doctors disagreed about the nature of both his disease process and his best interests (Caplan, 2017' Wilkenson, 2017; Troug, 2019). Although the language of best interest standard (BIS) was used by the British court system, I identified more so that GOSH and the Gards were concerned with crossing a threshold of harm. Charlie's medical team believed his condition to be terminal regardless of intervention. Their position then was the need to avoid harms of commission, or inflicting suffering for futile purposes (Caplan, 2017; Troug, 2019; Yeung ,2021). Conversely, Charlie's parents believed that experimental nucleoside treatment could improve Charlie's quality of life (Waldman, 2019; Yeng, 2021). When GOSH decided not to host a clinical trial in London, Charlie's parents wished to take him to the United States. Their concern was that of harm by omission, that they would cause Charlie more harm by failing to provide treatment (Caplan, 2017; Waldman, 2019; Yeung, 2021). The Gards involved the media in their disagreement both to apply public pressure as well as to raise money for treatment (Hurley, 2017; Wilkenson, 2017).

Both the Zone of Parental Discretion (ZPD) theory and the Harm Threshold (HT) state that an evaluation of harm must include relevant details as well as a consideration of the harms that may come about as the result of intervention (Diekema, 2004; Gillam, 2016). For Charlie's case, this means that an ethical judgement of interests must include a holistic perspective of all foreseeable outcomes, to all relevant stakeholders. As a child's welfare depends on his environment, the stakes of his parents are morally relevant (AAP, 2012; Gillam, 2015). In this paper, I have built the claim that Charlie's parents and the British legal system failed to consider

a major variable, namely the harmful impact of media involvement. While this paper does not question the judgements made of the Gard case, Charlie's case details have been used to demonstrate the powerful ways that media involvement can cause both benefit and harm.

I have already discussed the numerous ways that media can be seen as beneficial, particularly to parents. The following chapter discusses the harms of media involvement, set in the context of the Charlie Gard case. Here, I name ways that media causes harm to children (via invasions of privacy and violation of dignity) and family (via privacy violation, misinformation, and the creation of barriers to the shared decision-making process). I also include a discussion of larger social impacts, which include the potential for social media to perpetuate disparities and alter healthcare allocation. This section concludes by bringing the harm discussion back to the child, via a reiteration of the family centered care model of healthcare.

Harm to Child-Loss of Privacy

Most of Charlie Gard's short life was spent in the media spotlight. Not only did his parents share photographs and videos of his image, but they invited the world to share in the details of his medical life (Wilkinson, 2017; Richards, 2018). Through his parents, the public learned not only about his genetic disease, but also about his day-to-day existence (Richards, 2018). We learned that he could not eat, breathe, or move on his own. He was dependent on a mechanical ventilator and a nasally inserted feeding tube (Hurley, 2017; Wilkenson, 2017). Charlie's parents asserted that he was interactive and 'loved being tickled (Lantos, 2017; Richards, 2018).' Brain scan data and healthcare reports told us that this was unlikely (GOSH, 2017; Wilkenson, 2017).

Not only was Charlie's life shared, but its most basic details-the things he loved, the pain he experienced, were subject to vigorous media debate (Hurley, 2017; Wilkenson, 2017). Every moment was shared. Although it is not doubted that Charlie's parents shared his life with the intention of saving it, little has been said about the potential repercussions of media coverage. Charlie was not likely to survive, however if by some miracle he lived, he would have grown up with personal details-his genetic information, his medical care, even his baby pictures out in the world (Dresser, 2018). What harm would that cause?

Although Charlie's case occurred on an abnormally large media scale, we can look to the research on social media and children for potential consequences. Modern society has embraced technology. Today's parents grew up with the expansion of social media. As media technology increased, teenagers and young adults began to integrate it into their daily lives. Now that many of these individuals have reached adulthood and become parents, their children have become another aspect of life shared on social media (Brosch, 2016; AAP, 2016; Sorenson, 2020).

Analysis of social media usage shows that 98% of parents on popular media site Facebook routinely posted photographs of their children (Brosch, 2016; Sorenson, 2020). The top three categories of pictures shared were those related to daily life, outings, and special events. Daily life comprised spontaneous moments in the child's life, with a particular focus on their preferences, mannerisms, and humorous interactions. Outings and special events included holidays, milestones (such as the first days of school) and other major events in the family's life (Brosch, 2016; Sorenson, 2020). For many families, this digital presence begins even before birth, through virtual ultrasound photographs, pregnancy stories, and gender reveals (Brosch, 2016; Sziron, 2018; Sorenson, 2020).

In 2014, the University of Michigan's C.S. Mott Children's Hospital performed a national poll of parents of children ages 0-4., seeking to identify how modern parents were integrating their parenting practices with social media technology. They found that in addition to photographs, parents, particularly mothers (56% of the polled) shared detailed information, such as anecdotal stories and personal advice regarding their parenting practices. Despite this regular use, over 75% of the parents polled reported routinely being concerned about the social media practices of their peer group. Of the items of concern, 56% identified information that a child might find embarrassing, 27% 'inappropriate' and 51% containing personal identifiers (Brosch, 2016).

Of the subcategories of concern identified, the most common involved sharing nude or seminude images. While these were typically taken during bath time, polled parents expressed concern that child predators may find and be able to exploit said imagery. Other categories included things that could be considered humorous at the child's expense-such as making silly faces, acting 'adult-like,' and bathroom related accidents. The final type involved children who were dirty: covered in food, mud, paint, or feces. Of the Motts study sample over 67% reported at least once sharing a photograph or video from the above category. While children are young, these images may not be upsetting to them, however as they become older, they can be a source of distress (Brosch, 2016). Research performed by the Family Online Safety Institute stated that one out of ten parents have reported that their older children have asked them at least once to remove something they posted online (Family Online Safety Institute, 2015; Brosch, 2016).

Although there have not been more recent studies, one could hypothesize that as media has become increasingly mainstream and new technologies (such as video blogging) have emerged, the frequency of sharing potentially concerning information is even higher. While this

"sharenting" practice may feel innocent and routine to parents, there are potentially negative

consequences (Brosch, 2016; Oswald, 2016; Sziron, 2018). The first of these is that media use

allows free access to a child's personal information. Once shared, parents are limited in who has

access to information and how it is used. Not only can nude photographs provide fodder for child

predators, but a parent's general social media sharing can be used as a resource for illicitly

accessing children in real life (Brosch, 2016; Hunter, 2022). Sharing information in this way not

only violates the child's right to privacy, but it introduces potential, harm to their fundamental

welfare (MSU, 2018; Sziron, 2018).

Children are not only at risk for physical harm. Identify theft, or the use of personal

information such as social security numbers for financial gain, is increasingly prevalent in

children. Currently identity theft impacts approximately 1.25million children (about the

population of New Hampshire), or one in every fifty, annually. While historically child identity

theft is committed by someone who knows the child personally, parental media sharing has

provided a new avenue for strangers to access sensitive information (Hunter, 2022). The misuse

of this information can negatively impact children well into adulthood (Brosch, 2016; MSU,

2018; Szrion, 2018). Unlike adults (who have access to things like credit reports), parents do not

typically monitor their child's personal information. Subsequently, child identity theft may not

be detected for years, at which point the child's long-term financial ramifications may be

significant (Hunter, 2022).

Finally, virtual information sharing can contribute to psychological harm (Family Online

Safety Institute, 2015; Brosch, 2016; Van der Vellen, 2017). Not only may a child feel

embarrassment or shame from parental postings, but they may become targets of cyber bullying.

Cyber bullying is an unwanted aggressive behavior that takes place online, characterized by

repetition and the perception of a power imbalance (MSU, 2018; Stop Bullying, 2021). This behavior can include negative, hurtful, threatening, or humiliating commentary, spreading rumors, purposeful exclusion, and the exposure of secrets. Bullies can be a child's peers or adults (Stop Bullying, 2021).

While traditional bullying occurs between people who know each other, cyber bullying may be perpetuated by strangers. Cyber bullying is uniquely challenging, because as children integrate social media into their own lives, bullying can occur constantly on one's smart telephone, following the child wherever they go. Unlike in person bullying, cyber bullying may be anonymous, making it hard for parents to detect, and even harder to stop. Victims of bullying tend to have lower academic performance and higher rates of anxiety, depression, and suicide (Stop Bullying, 2021).

Although cyber bullying can occur with any degree of media involvement, children who reach 'celebrity' status are at particular risk. Child celebrities, such as Charlie Gard, have their lives intentionally exposed on a global scale. Through the sharing of select private details, the public can make generalized assumptions about lives that they do not personally know. Research on the impact of television "reality show" participation noted harshly negative online commentary targeted at children as young as four years old. Not only did this virtual commentary make fun of the child's physical characteristics, but it attributed negative personalities such as 'annoying,' 'horrid,' and 'bitch' (Oswald, 2016).

While this study was recent and the children have not yet grown up, one must wonder about the potential lasting impacts of this commentary. That which may have simply been a difficult day or a developmentally normal temper tantrum has been elevated to the level of personality trait. What happens when you grow up with the reputation of being 'stupid,'

'annoying' or a 'bully'? What happens when colleges or prospective employers have access to a litany of poor childhood behavior? How will future choices be limited by a reputation obtained in childhood (Oswald, 2016; Sziron, 2018)?

In short, media exposure violates not only the child's right to privacy, but also their fundamental rights to have present and future welfare protected. When information is shared, children are placed at risk of physical, psychological, and financial harm (Brosch, 2016; Oswald, 2016; Sziron, 2018). This harm can be damaging in childhood and in the child's future adult life. In this sense, privacy violation can be seen as both a threat to present welfare as well as a potential limitation of the child's right to an open future (Sziron, 2018).

Harm to Child-Loss of Dignity

"What basic interests can he have left other than respect for his humanness, his body, the sort of
respect and care we believe to be due to any human body?"

By the end of his life, Charlie Gard was significantly disabled. He could not see, or hear, in fact, he could not even move or breathe independently (Hurley, 2017; Wilkenson, 2017). There are those who would suggest that because of his disabilities, he was unable to experience the negative impacts of any human rights violations (Kittay, n.d.). Subsequently, this argument follows, it is more permissible to focus ethical attention instead toward the emotional needs of his more able-bodied parents. Not only do I fundamentally disagree with this position, but I claim that it is because of, not despite his disability, that attention to human rights is of the utmost importance.

One of the most of these rights is the right to dignity. What dignity could Charlie have? As a human being, he meets the Judeo-Christian criteria for species related dignity. He also

qualifies for Kittay's care ethics. It is the latter of these that I wish to focus on the most. Charlie was not just a human being; he was a human infant. As both a human AND as a child, he required and deserved care. This care is not only physical welfare, but the consideration of holistic needs (CRC, 1989).

Kittay's ethics develop care related dignity in two important ways. The first is that the human right to dignity is perhaps easiest to understand in terms of its violation, or things that cause a state of indignity. There are things that, regardless of cognitive ability, we do not consider acceptable treatment of a human. The rationale for this is that while an individual may not be able to articulate complex feelings of disrespect, they may still experience (or have the capacity to experience) negative sensations and emotions (Kittay, n.d.; Jonas, 2020). It is this potential to be negatively affected by others that matters. The rationale, she then states, is that as humans, we can consider how certain things would make us feel. It is this capacity for empathy, coupled with the capacity for relationships in which we formulate a social schema of acceptable interpersonal behavior. If an action places one in a state that we would not wish for ourselves, it is something we must seriously consider before doing (Kittay, n.d.; Timmons, 2012; Jonas, 2020).

Indignities can take many forms. They can relate to physical care (such as leaving a person lying in their own filth), psychological interaction (such as subjecting an individual to circumstances that are humiliating), or more existential insults to one's being (Schroeder, 2008; Kilmeister, 2010; Jonas, 2020). It is the last two types that I argue are violated by media involvement. I have noted that media involvement violates the right to privacy. Not only does it do so in the general sorts of ways mentioned, but it has relevance when the privacy violation reveals a state of vulnerability.

Media coverage of pediatric intensive care conflict involves the widespread sharing of personal details and imagery of sick children. These children may be experiencing pain or discomfort. They may be in various states of consciousness, in which they may not even be aware that photographs are being taken. They often have medical lines and tubes placed in bodily orifices, and they are hospitalized, dependent on others for physical and emotional care. Even if they are not actively dying, they are not experiencing full healthy childhood living (Carnevale, 1997; Lisanti, 2017).

Western society considers suffering and death to be personal experiences. While some people do elect to share their journeys with others, others desire that their experiences be kept private. Not only does critical illness cause many people to consider the possibility of their own death, but they do so while feeling poorly. Medications, treatments, and even just hospitalization itself takes people away from their normal lives and puts them in a place where they may not feel like their best selves. As they experience physical pain and discomfort, they may also have negative emotions. Among many significant emotions, patients frequently report feelings of vulnerability, depression, anxiety, embarrassment, grief, and loneliness (Hupcey, 2000; Yang, 2016). Sharing images and details of individuals without their permission is not only considered disrespectful, but depending on who does the sharing, it may even be illegal. For instance, Healthcare workers in the United States are forbidden from sharing personally identifying details of their patients without their consent (U.S. Department of Health and Human Services, 2021). This is considered disrespectful because it fails to prioritize the personal needs and experiences of the patient and instead turns their information into an object to be used for personal gain.

In sum, media exposure of sick people, taken without their consent, violates dignity because it objectifies someone who is vulnerable (Yang, 2016; Kittay, n.d.). This is particularly

egregious in children, who possess a baseline vulnerability, even when healthy. Although sick children may not yet (or ever) be developmentally capable of higher-level expressions of negative emotion, they are certainly still capable of things like pain and suffering (Raymundo, 2008; Diekema, 2020). The exposure of these experiences, for individuals who cannot decide for themselves what should and should not be shared, should be a carefully weighed decision, with the focus of the decision centrally on the potential benefits to the child.

Widespread media cases like Charlie's require an exceptional focus on objectification, because once private details are released, there is no control over how they will be used. Charlie's parents released photos and videos initially intending to change court opinions and raise money for his care (Wilkinson, 2017; Richards, 2018). All indications are that these things were done with the goal of directly helping Charlie. Once public, however, the information the Gards released was used in a variety of ways (Hurley, 2017).

As I previously mentioned, Charlie's image and story were quickly adopted by several political and social activist groups. These groups adapted the details of Charlie's life to fit numerous agendas. While some of these (such as the 'Right to Life' movement), could be argued to have remote relation to Charlie's case, others like the populist/anti socialism movement merely utilized his situation as evidence for their own causes. Not only was Charlie's name, picture, and story used but, in several cases, merchandise with his imagery was sold to support not the Gards nor Charlie's needs, but instead to benefit these organizations (Hurley, 2017; Das, 2018; Richards, 2018).

I am alleging there is something particularly undignified about employing sensitive details about a child towards causes that neither he nor his parents ever subscribed. This use takes aspects of another person's suffering to reap benefits that they themselves cannot

experience. While there is a counterargument that Charlie's cause can somehow 'lives on' through the inspiration of others, I seriously question whether this rhetoric has value (Richards, 2018; The Charlie Gard Foundation, 2021). The question I think lies in what aspect of life can 'live on'? To quote the court ruling in the Oshin Kinzo case, "Oshin was not a cause. He was a little boy in a terrible situation (Richards, 2018)." In packaging one's individual experiences of suffering and death into a cause, we run the risk of reducing the memory of them to nothing but their suffering; in other words, making the tragedy in their lives the only legacy they have.

Although this paper has intentionally focused on the Charlie Gard case, it is important to recognize that however significant the loss of dignity was for Charlie, media impact could be even more substantive in different situations. I have argued that it does not matter if Charlie could have ever expressed negative emotions from his media exposure. Again, I believe this to be a basic truth. By considering human dignity within the care ethics framework, Charlie's humanity is enough of an ethical reason to avoid placing him in undignified situations.

Caring ethics requires that we think of people as we would like those we love to be treated (Kittay, n.d.; Timmons, 2012). Kantian ethics requires that we respect people as potentially autonomous beings (Killmister, 2010; Timmons, 2012; Jonas, 2020). At the end of the day, Charlie was a child who died of a tragic disease. While there are aspects of his existence that others may benefit from, fundamental respect for his dignity requires that we do not reduce his life's meaning to merely lessons. Other people do not exist in the world for us to gain meaning from. Dying children do not suffer merely for our benefit.

I do want to acknowledge however, that some would still maintain that an ethically distinctive line may be drawn. While I believe Charlie's humanness to be sufficient reason to avoid placing him in potentially humiliating situations, I can grant that some difference must be

considered in scenarios where the child is cognizant and/or survival into adulthood is expected. Cognitively intact children who are developmentally capable of developing and expressing wishes for media participation may create different ethical conclusions. For instance, an older child who feels passionately about helping other children in similar situations may be able to help contribute to their own media presence (Van der Vellen, 2017). Likewise, in this way, the critically ill child may be able to help decide for themselves what type of legacy they find meaningful (Boles, 2021; Cahalan, 2022). At the same time, the potential for a child to experience lasting negative impacts (perhaps through a reputation lasting into adulthood) of a significantly personal life experience leading to public conflict, must be considered (Van der Vellen, 2017).

If Charlie had lived, would he have done so with the lingering shadow of his parents' legal battle? More so, would he have grown up as a poster child, associated with causes that he himself may one day grow to oppose? The ultimate key to this is the ability to express one's wishes. For individuals who have not or cannot make these wishes known, it is undignified to make assumptions about what kind of meaning they want to attribute to their life. Respect for dignity, or the active consideration for and avoidance of situations others may experience or perceive negatively, always but particularly in vulnerable populations, should be paramount.

Harm to Families-Loss of Privacy

While a child's parents may be the ones choosing to involve the media in conflict, they may be doing so without fully understanding the degree to which they themselves may become the focus of media attention. Intrusions to parental privacy can be harmful, as parents must cope simultaneously with the difficult circumstances surrounding their child's illness and judgments being made regarding their character (Richards, 2018; Choong, 2019). In Charlie Gard's case,

his parents were the primary sources of information for the media. As their legal battles continued and media attention grew, Charlie's parents experienced a lack of privacy (Richards, 2018; Barrett, 2019; Choong, 2019).

This was particularly evident as their reactions to case proceedings became publicized. During one of the court sessions, GOSH lawyers presented MRI evidence showing that Charlie had experienced significant brain damage. As the information was presented to the court, Charlie's mother began to sob and his father loudly cursed the lawyer, proclaiming the information to be untrue (Richards, 2018). While undoubtedly both reactions were raw experiences of emotion, they were replayed and highlighted in news media across the world. In the media, these reactions were interpreted negatively as indicators of their underlying character, with the father's shouting labeled as an obstinance "smoldering fury" and both parents declared to be problematically 'in denial" (Hardman, 2017; Wootson, 2017). Indeed, even in the time immediately surrounding Charlie's death, the Gards were pushed to release statements, with global observations being made on their grief (Garrison, 2017; Wootson, 2017; Richards, 2018).

Although the Gards were supported by many followers, others were harshly critical of their decisions. Both parents were victims of harassment, receiving hate mail and death threats. In these messages, they were told, among numerous things, that they were bad parents who were only prolonging their son's suffering for their own gain. Assumptions then were made not only about their personal characters and relationships, but also about their motivation and dedication to the care of their child (Hardman, 2017; Wootson, 2017; Richards, 2018; Choong, 2019).

Once an impression is made in the media, it is difficult, if not impossible, to change. For a parent who sought media involvement out of a desperate desire to be a "good parent," negative assumptions made via selective media coverage have the potential to be psychologically

damaging. Are they still able to believe themselves to be a good parent if they are getting

relentless feedback to the contrary? How will others perceive their character in the future?

Impacts on privacy have the potential to be long lasting. Even though Charlie has died, the Gards

live on. Their reactions to their public struggle and ultimate loss have been documented in items

of public record (Hardman, 2017). Therefore, even as they rebuild their lives, there will be a part

of them forever associated, not only with their son, but with the way that they acted during one

of the most difficult and painful times in their lives (Choong, 2019).

Harm to Families-Negative Impacts on Shared Decision-Making

Media coverage of disagreements involving critically ill children can further damage the

shared decision-making model. As we have seen, family-medical disagreements often occur

when there is a disagreement about the best course of treatment (Do Vos, 2014; Spijekers, 2022).

Parents may seek media involvement for numerous reasons, notably because they feel that the

medical team is failing to listen to or respond to their concerns. The media (and society at large)

may be appealing as a listening ear, able to provide validation to feelings, and a recruiting tool,

gathering additional support for persuasion (Moore, 2019).

Unfortunately, as the Charlie Gard case exemplified, media can be polarizing,

misinformed, and biased. In the Gard case, the media's use of language served to deepen the

divide between Charlie's parents and his healthcare team. While sensationalist language, such as

'murder,' 'killing,' and 'hostage' was successful in garnering public interest, it also served to

further perpetuate an 'Us vs. Them' scenario in which one side was going to be right and the

other, entirely wrong (Das, 2018; Richards, 2018; Choong, 2019; Barrett, 2020).

As the case gained support by populist political movements, it served to further exemplify for many the ways in which so called elitist structures were inherently harmful. In this case, Charlie's medical team, GOSH, and the entire NHS were accused of intentionally seeking to harm children. The resulting narratives, which utilized themes of war, genocide, and justice served to paint one side as good and one as evil (Das, 2018; Richards, 2018; Choong, 2019; Barrett, 2020). As the public reacted to these themes, both healthcare providers and Charlie's parents faced harassment and death threats (Richards, 2018; Choong, 2019).

The reality of course is much greyer. As Charlie's parents were doing what they felt was in his best interest, likewise, was his medical team. If the medical team did not feel strongly that the proposed transport and trial would be against his interests, it is likely that they would not have fought so hard to prevent it. After all, the shared decision-making model of pediatric medicine stresses allowance for family discretion in medical decisions, so long as the decisions do not put the child at risk of undue harm. Whereas Charlie's parents were trying to fulfill their role as 'good parents,' Charlie's healthcare team was trying to meet their professional obligation to protect children from harm (AAP, 2014; Fallat, 2017; AAP, 2018; Jenny, 2018; Richards, 2018). Although Charlie's parents did not themselves verbalize the 'good/evil' narratives (and in fact, were consistently complimentary of the care that Charlie did receive), it is easy to see how their willing participation in media coverage could be misinterpreted by Charlie's medical team as an endorsement. Hence, media coverage (and the resultant polarity) served to further deepen what is already a wounded dynamic.

As Charlie remained hospitalized, his parents and his healthcare workers still had to interact with each other. Visiting the hospital was the only way in which his parents could spend time with their child. As Charlie continued to decompensate in the intensive care unit, his parents

certainly required emotional support and guidance (Abbott,2001; Forbat, 2015; Spijkers, 2022). Unfortunately, healthcare workers undergoing harassment may have been personally conflicted and therefore challenged in their ability to respond fully to the psychosocial needs of Charlie's parents. Likewise, the fear of personal media coverage (or legal involvement) may have led healthcare workers to avoid unnecessary interactions with the family at all (Choong, 2019; Kubheka, 2020; Spijkers, 2022). Finally, until the courts declared otherwise, responsibility for medical decision-making continued to be shared. While the Gard legal case was over one big decision (transportation and clinical trials in the United States), there were certainly smaller ones that still had to be made over the course of Charlie's hospitalization. Attempting collaboration under such already strained circumstances makes further shared decision making difficult, if not impossible (Hammond-Browning, 2017; Choong, 2019; Kubheka, 2020).

Further worsening this dynamic is the way that media coverage both facilitated and perpetuated the spread of misinformation. Charlie's parents were the primary source of information for the media (Hurley, 2017). Other parties involved (GOSH, legal teams, etc.), were limited by patient privacy laws in their ability to rebut accusations. All other sources of information (such as those provided by so called 'expert subject matter witnesses') lacked direct knowledge of Charlie's unique case and were composed primarily of conjectures. Accordingly, most of the information spread by the media was disproportionately biased from the start (Hammond-Browning, 2017; Richards, 2018; Choong, 2019).

This information was further distorted as Charlie's case was adopted by various agendas. Although there is not data that reflect what the Gards' views on said political and social agendas were, it is not remotely suggested that they started their media campaign because they saw Charlie as an example of NHS corruption, disability discrimination, or any of the numerous other

causes with which his situation was eventually linked. It is certainly possibly however that as organizations with these causes adopted Charlie and provided the family with both attention and funding that their underlying rhetoric was, at least to some degree, integrated into the Gards motivation for continuing. Not only then were they fighting for Charlie's life, but their fight meant something bigger (Dresser, 2018; Richards, 2018; Moore, 2019). This sense of validation is reflected in introduction statement of The Charlie Gard Foundation, which recounts not only the Gards' own legal battle but the way in which Charlie's fight was deeply meaningful and influential to larger causes around the globe (2021). While there is something to be said for the Gards' commitment to legacy building, one can also say that the motivation and support of these causes was a conflicting barrier, applying undue pressure on the Gards to 'win'-not only for Charlie but for everyone else as well.

In addition, this pressure, public participation via misinformation may be a source of false hope. Charlie's medical team stated that he was brain damaged. This brain damage was so significant that he could neither hear, nor see. He did not have the muscle strength to make large movements and the movements he did make were attributed to seizure activity (GOSH, 2017; Wilkenson, 2017). Nevertheless, Charlie's parents remained adamant that he was interactive, squeezing their hands and gazing into their eyes (Lantos, 2017; Richards, 2018). Whether this is medically factual or reflecting his parents' deepest hope is beside the point. What matters is that numerous people, many without medical knowledge who had never met nor examined Charlie shared their beliefs about his condition and ability to recover (Choong, 2019).

While most prominent and outrageous in online forums, like Charlie's Army (where members posted their beliefs that Charlie was an otherwise healthy child being poisoned or held hostage), public support for the Gards cause was widespread (Das, 2018; Choong, 2019). The

sheer fact that so many people participated in petitions and protests to allow Charlie transport and experimental trial in the United States shows that many people did sincerely believe that failing to receive nucleoside therapy was the only thing preventing Charlie from surviving (Das, 2018; Richards, 2018; Choong, 2019). Publicized accounts, both from Charlie's medical team and the Gards themselves indicate that Charlie's parents were originally quite pragmatic about his chance of recovery (GOSH, 2017; Waldman, 2018). While at the time of diagnosis, his parents believed nucleoside therapy to be a potential cure, as the legal cases proceeded, they conceded that due to the progressive brain damage, therapy may only marginally improve his quality of life (Wilkinson, 2017).

However practical however, the literature on parents of critically ill children reminds us, that when children are facing potential death, parents often retain some degree of magical thinking, in which any possibility of hope, however unlikely, is closely held (Lipstein, 2011; Miller-Smith, 2019). As Charlie's disease progressed and the likelihood of any benefit became increasingly slim, much of the public, who again had never seen or interacted with Charlie, perpetuated hope. Not only does this give the Gards a continued optimism that they might yet 'win,' but it makes death feel exceptionally sudden and cruel (Choong, 2019). This is evidenced in the Gards' statement, announcing the decision to transition Charlie to hospital. Despite living most of his life in the intensive care unit and months of legal debates surrounding the circumstances of his almost certain death, the Gards still called proceedings as taking place 'too fast' and 'too soon.' Although arguably no family is ever ready for the death of their child, receiving constant affirmations of hope from around the globe may very well have contributed to the sudden sense of death's immediacy (Choong, 2019).

The bolstering of unlikely hope links us to final parental harm; namely the creation of social barriers under which it would be almost impossible for the parents to change their minds (Dressler, 2018; Barrett, 2019; Choong, 2019; Moore, 2019). This is evidenced simply by the volume of attention focused upon Charlie and his parents. In addition to the support of political organizations and celebrity figureheads, the Gards raised over one million pounds to facilitate transfer to the United States (Waldman, 2018; Kubheka, 2020). If at any point in the case's proceedings his parents wished to change their minds about the best course of action, they would first have to answer the millions of people deeply invested, financially and otherwise.

The Gards saw firsthand, how verbally aggressive and militant some of their supporters were. Those who opposed GOSH referred to medical teams as 'murders,' 'baby killers' and much more (Das, 2018; Choong, 2019). Once that kind of attitude has been well established in public discourse, it would take exceptional moral courage to publicly change one's mind, and thus, include oneself among those so hated. They would also face the logistical nightmare of financially reimbursing the thousands of people who donated money for the specific purpose of getting Charlie nucleoside therapy. This point is not to doubt the sincerity of parents who choose to embark on media campaigns. Instead, I mean to make that argument that once the media (and via media, the public) becomes invested, parents are firmly committed to a cause that they may not be easily able to extricate themselves from. In this way, even if additional relevant information is discovered, parents are placed against a wall in which they can do what they feel is right as 'good parents' or they can choose to save public face, committed perhaps reluctantly, to an end.

Harm to Society-Crowdfunding

A key aspect of the Charlie Gard media campaign was the use of crowdfunding to raise money for transportation and medical care in the United States. While Charlie's case was exceptional in the speed and amount of money raised, the use of medical crowdfunding has become increasingly popular among pediatric and adult families alike (Moore, 2019; Kubheka, 2020). In the previous chapter, I highlighted benefits of crowdfunding. The internet allows for the breakdown of physical barriers, facilitating a sense of interconnectedness. Through emotional appeals, people can raise money, often from complete strangers moved by their situation. Not has crowdfunding proved to be a successful way to raise money, but the easy design of websites requires minimal effort on behalf of campaigners. Once a campaign page is established, it basically runs itself, allowing time that may have otherwise been spent working extra hours to be reallocated to caregiving (Barrett, 2019; Moore, 2019; Kubheka, 2020).

Unfortunately, crowdfunding has several drawbacks that require ethical consideration. The first is that there is little to no formal process in place to confirm the validity of claims. The most popular medical crowdfunding website, GoFundMe, allows anybody to set up a campaign. This means that anyone can fabricate or exaggerate a sad story to appeal to the emotional goodwill of funders. Although GoFundMe does prosecute fraudulent uses of their platform, the lack of process vetting means that well-meaning donors experience some degree of risk (Barett, 2019; Kubheka, 2020). An effective criminal with a persuasive enough story may never be caught.

Even among those who have legitimate stories, there is no guarantee that money raised will go toward its stated purpose. In the Charlie Gard example, while his parents fully intended to use funds to pay for medical expenses, when he died, the money raised was not returned to

donors (Barett, 2019; Kubheka, 2020). Instead, the over 1.3 million pounds raised was used to form The Charlie Gard Foundation (2021). Although nobody seems to have complained about the reallocation of this money, the fact remains that its ultimate use was not as advertised. Apart from the potential for donor extortion, medical crowdfunding raises important questions about how healthcare resources are allocated (Mackey, 2017; Moch, 2017; Kubheka, 2020). Charlie Gard's case involved two different national healthcare systems. I will address each in turn.

In socialized healthcare systems such as the NHS, essential (aka lifesaving) healthcare is provided to citizens free of charge. When citizens choose to participate in non-essential/elective services, they must cover cost by either paying out of pocket or utilizing ancillary insurance plans or undergo long wait times. Importantly, healthcare that is deemed lifesaving or life essential is paid for. While some healthcare (namely elective care) is commodified, life-saving medication is not. Conversely, in the United States, almost all healthcare is commodified (BMJ, 2020). Emergent medical care is provided without first requiring payment, as mandated by the U.S. Emergency Medical Treatment and Labor Act (CMS, 2022). After the emergency is stabilized, patients are responsible for the cost of their care. Like non-essential healthcare in the U.K., American healthcare recipients can choose to pay either out of pocket or via insurance plans for services rendered (BMJ, 2020).

While these systems seem (and in many ways are) dissimilar, both have an important limitation. In neither country can a prospective patient demand to receive healthcare that is completely non-beneficial or harmful (AMA, 2001; Hussler, 2003; Fallat, 2017; Moch, 2017). While an extreme example, an individual with healthy limbs cannot walk into a hospital and demand an amputation, regardless of how much money he is willing to pay for it. What is different however, is that in the United States, if there is a slight possibility of benefit AND the

patient can find a doctor willing to endorse a therapy AND they are willing to pay for it, that therapy is typically allowed, under the premise that respect for patient autonomy should allow well informed individuals to decide what kind of risk they are willing to take. So long as the therapy is available and medically indicated, an individual is free to bankrupt themselves in pursuit of it (Moch, 2017; BMJ, 2020).

There are two overarching concerns here. First, while a similar attitude is present in the United Kingdom, it is nowhere near as libertarian. When clinical benefit is extremely unlikely, as seen in the Charlie Gard case, medical culture does allow for physicians to make paternalistic judgements about what risks a patient (or their surrogate) should be allowed to take (BMJ, 2020). While it is not the purpose of this paper to dwell on whether the Gards should have been permitted to transport Charlie to America, this fact is relevant to the point being made. In introducing crowdfunding of this financial magnitude into society, we run the risk of pushing healthcare commodification out of its existing structure and into one where patient financial willpower can exceed medical consensus (Mackey, 2017; Moch, 2017; Kubheka, 2020). But what about the United States? Crowdfunding in the United States runs into other problems. What happens when a particular therapy is a limited resource? Or more so, what if (like Charlie's nucleotide studies) it is still in experimental phases? First, I will address the possibility of limited resources.

As examined in prior chapters, physicians have numerous ethical obligations. Among these is to use their best medical judgement to decide appropriate use of treatment. When a resource (such as a medication) is in short supply, the physician is required by the ethical principles of justice and beneficence to make decisions about what patient stands to benefit the most (AMA, 2001; Hussler, 2003). As crowdfunding has grown in popularity in the United

States, some ethicists have expressed concern that it may shift this system away from the most need to the one who can pay the most. Why is this problematic? Apart from the real potential for individuals to experience suffering from lack of appropriate resources, a switch in driver to financial pressure takes away the value in having a physician make educated decisions. Instead of carefully considered allocations, individuals of the public, without requisite knowledge, or indeed personally relevant information can sway the allocation of resources towards those who are simply more successful at making emotional appeals (Mackey, 2017; Moch, 2017; Barrett, 2019; Kubheka, 2020).

Another concern is the potential to impact systems built to ensure safety standards. Modern experimental science has processes to ensure that products do not reach the public without being first rigorously vetted. And yet, for some with significant life limiting illness, the risks of a less tested treatment are outweighed by the potential benefit of living. The United States had a recent case, in which parents of seven-year-old cancer patient Josh Hardy wished for him to have access to an experimental medication. While there are ways for physicians of terminally ill patients to appeal for compassionate use, in Josh's case, the pharmaceutical company refused stating that they did not have the resources to facilitate human trials. Josh's parents then embarked on a media campaign, utilizing both social media and crowdfunding to shame and buy their way into use of the medication. After undergoing death threats, the company agreed to allow Josh to trial the drug, an endeavor that required that they pause other studies that were already in process. While Josh thankfully did not experience any negative impacts from the medication, he also failed to benefit and ultimately succumbed to his illness (Moch, 2017). A key component of Josh's campaign was the American 'right to try' movement,

namely that if a dying patient wishes to trial a treatment that may save their life, they should be allowed to do so (Mackey, 2017; Moch, 2017).

While there are valid arguments about what informed patients should be allowed to take as burden, they do not follow that a patient has the right to any possible treatment, without consideration for wider implications (Moch, 2017; Kubheka, 2020). The pharmaceutical company involved in the Josh Hardy case not only indicated that they were not ready to trial their drug in human subjects, but also stated that they lacked the resources to do so at this time. Although significant pressure and public shaming of the company (which the media asserted was 'allowing a child to die of a curable illness') got Josh the medication, this happened at significant expense to other trials in progress (Moch, 2017).

This is quite a dangerous precedent to set. Even if Josh's life could have been saved, it does not follow that the pharmaceutical company was ethically obligated to compromise safety processes or to stop other more established trials. After all, how many lives were negatively impacted by delayed or altered processes? How many people may have lived that now will not because a delayed medications was not released in time? Could (or should) everyone be like Josh? What would happen to our scientific processes if the power of emotional campaigning and money was allowed to be a relevant decisional factor? The potential impact on society is worth pause.

Additionally, we consider the potential impact of crowdfunding on healthcare systems and treatment allocation, it is worth mentioning that both the crowdfunding process and its platforms are not necessarily value neutral. While not officially marketing itself as a political entity, GoFundMe has published a list of causes they will not host on their site. Notable among these are campaigns that raise money for abortion services. If we accept that crowdfunding has

the potential to impact healthcare and what kinds of resources people can afford, supported

funding of some services but not others have the potential via selective pressure to prioritize

what kinds of situations are "worthy" of care (Barett, 2019; Kubheka, 2020).

Beyond the potential to discriminate against specific types of healthcare needs, there is

also the potential for crowdfunding to define which individuals get assistance at all. Data on

successful crowdfunding suggests that white, English speakers who were well educated and of

moderate socioeconomic host the most lucrative campaigns. The elderly, the impoverished, and

people of color's campaigns tended toward less attention and less money raised overall

(Kenworthy, 2020). This data suggests that crowdfunding may further perpetuate racial, ethnic,

and socio-economic disparities, by further shunting philanthropy from those who need it the

most (Kenworthy, 2020; Kubheka, 2020). In addition to these disparities, there remains the

concern that crowdfunding can lead to masking faulty social systems. If healthcare costs are so

extraordinary that people feel the need to resort to posting personal photos and details of their

loved ones to afford it, reaching for media attention may be a mere Band-Aid. Perhaps then, if

there is to be meaningful social change, the use of crowdfunding needs to be more closely

scrutinized for what it is accomplishing, and at what cost (Barrett, 2019; Kubheka, 2020).

Harm to Child

This chapter has discussed just a few of the many types of harm that media involve in

intensive care conflict may cause. After starting with harm to the critically ill child via violation

of rights to privacy and dignity, we switched focus towards harm to the family. Families can

experience violations of their own privacy as well as increased difficulties in collaborating with

their child's healthcare team. There was finally a high-level look at the negative societal impacts

of using media crowdfunding to finance healthcare services.

In conclusion, I want to reiterate the importance of looking beyond direct harm to the child. Pediatric medicine emphasizes the importance of family centered healthcare. The family centered care model states that the environment in which a child is raised directly impacts their welfare. Things that do not directly harm the child may ultimately do so indirectly (AAP, 2012). Parents with substantial emotional or financial burdens of their own may be strained in decision-making. Healthcare teams undergoing public harassment may struggle in providing compassionate care to parents. In stressing those directly responsible for the child's welfare, focus can easily slip away from the primary ethical obligation to consider the best interests of the sick child.

Chapter 6

Preventing Harm

This paper has been spent critically evaluating media involvement in pediatric critical care conflict. I started by discussing the rights of children. Of particular emphasis were the concepts of dignity and privacy. I then discussed who is responsible for protecting these rights. While parents are socially the primary surrogate decision makers, parental autonomy was presented as a conditional, fiduciary relationship, in which the child's present and future interests must remain central.

As these interests are preserved, parents may find themselves needing to consult topic experts. Pediatric medical teams offer specialty knowledge regarding the health of children. With this knowledge comes the ethical obligation to provide healthcare in a way that supports the child's rights. Pediatric physicians are encouraged to collaborate with parents via shared decision making in a family centered model of healthcare. Despite the emphasis on collaboration, there remain times where the pediatric medical team is obligated to overrule parental decisions contrary to the child's interests. Three common pediatric bioethics frameworks, namely the best interest standard (BIS), the harm threshold (HT) and the zone of parental discretion (ZPD) were presented as options for evaluating cases that may require an override of parental authority. The discussion then narrowed to family/medical provider conflict in the pediatric intensive care unit (PICU). Research regarding PICU conflict identifies poor communication and value discrepancies as leading factors contributing to disagreement. While some degree of disagreement is not uncommon, complicating factors such as physician bias and parental emotional strain can contribute to intractable conflict development. Here, the stage was set for a discussion of media specifically.

Parents use media technology in their intensive care disagreements for multiple reasons. While the potential benefits are many, I have made the argument that use may also cause significant harms, infringing not only on the child's rights, but negatively impacting parents, healthcare providers, and society at large. The recent case of Charlie Gard was used throughout the paper's entirety as an illustration of how media involvement of well-intentioned and loving parents can escalate into a situation that hurts many. While this closing chapter is not intended to provide a comprehensive analysis of all possible solutions, I do wish to conclude by offering a summary of several interventions that may help to mitigate harm. These interventions have been divided into those that prevent conflict, those that help to mitigate existing conflict without media involvement, and those that offer policy guidance and legal support once the media is involved.

Proactive Strategies-Parental Education on Safe Media Use

While illness certainly increases the vulnerability of the exposed, the potential for media harm is not exclusive to the critically ill. All children may undergo physical, psychological, and financial insults secondary to media use. As electronic technologies, such as smart phones have expanded, media access has become easier (Barrett, 2019). Much of the present literature focuses on protecting children from their own media use. Numerous studies evaluate the impacts of 'screen time' on cognitive and social development (AAP 2016; AACAP, 2020; AAP, 2021). Professional bodies, such as the American Academy of Pediatrics provide parents with guidance on ensuring children are protected from online predators and cyber-bullying (2016; 2021).

Little, if any, material is available to instruct parents on the potential dangers of their own media sharing. The first mitigation strategy then is increasing parental education. For parents that have grown up alongside the expansion of social media, sharing images of their

children may feel like a natural progression of their usage. As parents learn to protect their

children from their own media use, they should also be encouraged to look critically at the things

they choose to share.

Proactive Strategies-Improving Family Centered Care in the PICU

We have established that admission to the pediatric intensive care unit is a uniquely

stressful time for families. Parents are expected to participate in shared decision-making amidst

personal stress and role strain. By addressing parental needs, parents must be able to feel as

though they are being effective 'good parents' to their sick children. A second bundle of

interventions then are those that foster a supportive family centered care environment.

The Society of Critical Care Medicine (SCCM) published a meta review in 2017 of

evidence-based interventions aimed at improving the experience of families in neonatal,

pediatric, and adult intensive care units (Davidson). In this section, I offer a summary of

pertinent recommendations with notes regarding pediatric specific research. This is then

followed by a generalized discussion of opportunities for medical teams to enhance provider

training regarding the communication of uncertain prognoses, evaluation of self-bias, and

tolerance for diverse family values.

Society of Critical Care Medicine Guidelines for Family Centered Care

1.1. Family members of critically ill patients should be offered an open flexible family

presence at the bedside that meets their needs while providing support for staff and

positive reinforcement to work in partnership with families to improve family satisfaction

(Davidson, 2017).

1.2. Family members of critically ill patients should be offered the option of participating in interdisciplinary team rounds to improve satisfaction with communication and increase family engagement (Davidson, 2017).

SCCM cites one small single-center trial in the PICU that compared bedside rounds with private (medical team only) rounds held in an off-unit conference room. Families that experienced bedside rounds reported higher levels of satisfaction with their child's healthcare. In addition to building team trust and promoting collaboration, parents reported increased levels of understanding of tests and treatment plans, as well as improved perception of respect for the unique needs of their child/family. Overall parents preferred bedside case presentation, and 81% wished that all their child's future rounds occurred bedside (Davidson, 2017).

1.3. Family members of critically ill patients should be offered the option of being present during resuscitation efforts, with a staff member assigned to support the family (Davidson, 2017).

Historically, families were removed from the room during lifesaving resuscitation efforts (Bush, 2022). There is now a growing body of evidence to suggest that allowing families the option of remaining during resuscitation is associated with improved psychological outcomes (Davidson, 2017). Not only do families report feeling more confident that all efforts were made to save their child's life, but they also report decreased instances of complicated grief (Mangurten, 2006; Bush, 2022). Parents state beliefs as though their child was aware that they were there for them, and that in the end they were not 'abandoned' to die with strangers (Tinsley, 2008; Twibell, 2015; Davidson, 2017).

In instances where a child is successfully resuscitated, families have received personalized experience into what resuscitation efforts involve. This knowledge can then be used to help define future wishes and goals of care (Mangurten, 2006; Tinsley, 2008; Davidson, 2017). While initial research regarding family presence encountered resistance from healthcare providers who feared families would be distracting or otherwise interfere with resuscitation, minimal instances of disruptive behavior have been reported (Bush, 2022; Mangurten, 2006). Facilitated family presence, via the provision of a staff member dedicated to family support, is recommended by several major medical organizations, including the American Academy of Pediatrics, American Association of Critical Care Nurses, and the European Society on Pediatric and Neonatal Intensive Care (Davidson, 2017).

2.1. Family members of critically ill neonates should be offered the option to be taught how to assist with the care of their critically ill neonates to improve parental confidence and competence in their caregiving role and improve parental psychological health during and after the ICU stay (Davidson, 2017).

Parents want to be able to help their children. For what may be the first time in their parenthood, PICU families are limited in the physical care they can provide for their children (Meyer, 2006). Research on PICU conflict attributes a sensation of frustration and helplessness to parental stress. While there is limited research regarding parental participation in the pediatric ICU, several studies that suggest benefits in teaching physical caregiving to neonatal intensive care (NICU) parents. These studies particularly focused on hands on cares like diaper changing and soothing pain. Although parents reported minimal improvement in overall stress levels, they did indicate increased satisfaction and confidence in the quality of care their children were receiving (Bastani, 2015; Davidson, 2017). While SCCM acknowledges that the neonatal

population has a documented benefit, there is a need for further research regarding older children and adolescents (Davidson, 2017).

2.2 Family education programs should be included as part of clinical care as these programs have demonstrated beneficial effects for family members in the ICU by reducing anxiety, depression, post-traumatic stress, and generalized stress while improving family satisfaction with care (Davidson, 2017).

The Creating Opportunities for Family Empowerment (COPE) study was a multi-institutional initiative designed to address the negative psychological impact of PICU admission on children and their mothers. Participating mothers were exposed to three levels of training, taking place at various periods (early admission, transfer out of PICU, discharge home) during their child's stay. Program content ranged from written hand outs and audio recordings to interactive workbooks and developmentally appropriate activities to complete with bedbound children. Training was designed to provide mothers both with education about the emotional needs of the hospitalized child as well as training on how to help their child cope with things like anxiety and frustration (Melnek, 2004).

Nurses blinded to the study group consistently indicated that in comparison to the control group, COPE mothers were more interactive and attune to their child's physical and emotional care needs while in the hospital. COPE mothers reported less situational stress, decreased instances of negative mood state, and lower rates of post intensive care post-traumatic stress symptoms. When interviewed, participants indicated that they felt more confident and useful in their ability to help their children cope with hospitalization. Perhaps most importantly, children of COPE mothers displayed improved levels of coping with hospitalization with fewer long term psychological symptoms (Melnek, 2004). Not only do family based educational programs help

parents cope, but results seem to suggest the potential to benefit sick children (Melneck, 2004; Davidson, 2017).

2.3. Peer-to-peer support be implemented improve family satisfaction, reduce parental stress, and reduce depression (Davidson, 2017)

SCCM noted that most of the research on parent peer-to-peer support groups have occurred in the neonatal intensive care environment (Davidson, 2017). The majority of PICU related groups are designed to support bereaved parents after child death (Butler, 2019). While there is a strong body of evidence to suggest ongoing benefit during ICU stay for NICU parents, SCCM recommends that additional focused research be aimed at PICU families (Davidson, 2017).

2.6. Validated decision support tools for family members should be implemented in the ICU setting when relevant validated tools exist to optimize quality of communication, medical comprehension, and reduce family decisional conflict (Davidson, 2017)

While there are no decision-making tools specifically designed for families undergoing PICU admission after an acute injury or illness, there are several for families of chronically ill children (Boss, 2021; Henderson, 2021). Some of these, such as tracheostomy placement and advanced directive decision-making tools, could impact PICU parents. One such tool, Family Reflections, is funded by the United States National Palliative Care Research Center as part of a research study on family decision making at Johns Hopkins. On its website-based format, individuals are given a decision (such as tracheostomy placement) and are exposed to a variety of interviews from families who have made different choices for their children. Although the tool has a decided palliative care slant, it normalizes that a wide range of decisions can be considered

in the best interests of children (Boss, 2021; Henderson, 2021). Another series of validated

decision-making tools has been produced by the Courageous Parents Network (CPN). CPN has

decision making tools in a variety of media modalities (written, video, etc.). Not only do these

tools help families elicit their values and wishes regarding a wide range of healthcare decisions,

but they provide resources for family and sibling psychosocial support (Weaver, 2020;

Thienprayoon, 2023).

4.5. Family navigators (care coordinator or communication facilitator) be assigned to
families throughout the ICU stay to improve family satisfaction with physician
communication, decrease psychological symptoms, and reduce costs of care and length of
ICU and hospital stay (Davidson, 2017).

Lurie Children's Hospital of Chicago recently pioneered a full-time family navigator role

in their pediatric intensive care unit. This program, called PICU Support, provided training in

PICU specific technology, child bereavement support, and conflict resolution, to masters

prepared family counselors. Navigators checked in with both families and healthcare providers

during key times (admission, changes in acuity, discharge planning, etc.) in the PICU stay, with

the goal of ensuring that essential information was effectively communicated and understood by

all parties. Family meetings with subspecialty teams were facilitated weekly. Healthcare

providers were given weekly update forms that indicated holistic family concerns, stressors, and

needs. When needed, the navigator helped connect families with other hospital resources such as

social work, chaplaincy, and child life therapy (Lurie Children's, n.d.; Michaelson, 2020).

Ancillary resources, such as a PICU introduction guide, question prompt list, decision-

making tools, parent/team shared diary, and bedside communication update log (designed to

update families who were not able to stay consistently at the bedside) were also provided on an

individual needs' basis (Lurie Children's n.d.; Michaelson, 2020). The multi-modal nature of these resources was designed to address a variety of adult learning needs, as well as to facilitate ongoing opportunities for reflection and coping. Participating parents have been highly complementary of the program, with over 97% of participants ranking the PICU Navigator as 'useful' in assisting with parent emotion, decision-making, and healthcare communication (Michaelson, 2020).

5.4. Given the evidence of harm related to noise, although in the absence of evidence for specific strategies, ICUs implement noise reduction and environmental hygiene practices and use private rooms to improve patient and family satisfaction.

5.5. Family sleep needs should be considered, and families should be provided with a sleep surface to reduce the effects of sleep deprivation.

Recommendations 5.4 and 5.5 focus on the physical environment of the intensive care unit. Many parents express a desire to stay at their child's bedside throughout hospitalization (Hefley, 2005; Stremler, 2014; Miller-Smith, 2019). Unfortunately, many intensive care units are established for twenty-four-hour high intensity caregiving (Latour, 2010; Macdonald, 2012; Lisanti, 2017; Lean, 2018; Miller-Smith, 2019). Constant beeping, loud staff members, and overhead alarms have been shown to induce stress and anxiety in both patients and family members (Macdonald, 2012; Baia, 2015; Xafis, 2015; Kramer, 2016; Miller-Smith, 2019). Medical equipment is estimated to be the highest source of noise pollution with certain routine alarms hitting almost 80 dBA (the level of heavy city traffic). Although approximately 94% of these PICU alarms are estimated to be 'false', parents report experiencing heightened levels of anxiety each time they occur (Kramer, 2016).

Sleep deprivation, which occurs through frequent noise awakenings, prominent levels of light, and semi upright sleep on uncomfortable surfaces (such as chairs) further exacerbates these feelings (Hefley, 2005; Macdonald, 2012; Stremler, 2014). A multi-center study on the efficacy of PICU parent ICU sleep rooms showed significant improvement in reported parental stress among those who got comfortable, fully supine, dark room sleep (Hefley, 2005).

Facilitating Difficult Conversations

The above recommendations and studies focus on the needs of the parents. Although parents are expected to be equal partners in the pediatric shared decision-making process, there are still power inequities. Pediatric healthcare providers have specialty knowledge and technological interventions obtained via years of training. Parents have neither knowledge nor the technological ability to "fix" their child's critical illness. While they have special knowledge of the holistic needs of their children, parents also carry significant emotional burdens. These burdens are further stressed by the novel environment of the intensive care unit. Family centered care initiatives focus on bridging this equality gap through interventions aimed at improving parental knowledge, involvement, and communication (AAP, 2012; AAP, 2014). Other interventions targeted at making the intensive care environment more approachable address parent and child psychosocial needs.

The "good parent" is a well-informed advocate. While family centered care interventions can be helpful in making it easier for parents to integrate information into their child's daily care there is still a need to address the other half of the shared decision-making dyad. Communication failure is a major component of intensive care conflict. The third preventative strategy I will discuss is how healthcare providers can improve family communication.

Often conflict emerges not over what has been said, but how information is presented (Janvier, 2014). Parents involved in conflict often describe feeling as though important conversations are "rushed" without taking the time to listen to their feelings and opinions (Abbott, 2001; Meyer, 2006). While traditionally the task of 'breaking bad news' was delegated to new physicians in training, there is growing recognition that just as medical expertise is grown over training, facilitating difficult conversations is a technical skill requiring experience and finesse. Although trainees may be involved in these conversations, difficult information should come from the most experienced team members (Spijkers, 2022).

Parents of PICU children value regular and frequent updates of information (Abbott, 2001; Meyer, 2006; Latour, 2010). Given the stress of the environment and situation, this information is sometimes best retained through repetition and small chunks. This exchange of information, in language and mannerisms that parents can understand sometimes requires as much purposeful information seeking as it does information giving. Healthcare providers often work in shifts, meaning that clinical changes may occur while off service (Miller-Smith, 2019; Bridgeman, 2020). In preparing to have the conversation, the provider must first ensure they are current regarding all relevant events and data. Consulting with the most recent providers can help ensure the speaker is up to date. Particularly sensitive conversations may be best received from providers that the family has established personal rapport with. There should be a designated time for important conversation; where, if possible, phone calls and emergency interruptions are delegated to other providers (Meyer, 2006; October, 2014).

Mnemonics like SOBPIE have been designed to help medical providers remember to practice patience and empathy during decision making. Information should be given in brief periods with pauses allowing for reactions and contribution. Importantly, most of the mnemonics

emphasize the development of interpersonal rapport (Janvier, 2014). Only at the end are providers to provide the information, with time to regroup and focus back on emotional needs related to the conversation.

Situation. *"I'd like to talk to you about Charlie's health. Would you like to have the conversation here in his room or in the family conference room? Do you want to call anyone to be here with you?'*

> Is this the best place to have a difficult conversation? Is there sufficient privacy? Who does the family want present? Sometimes parents want to hear difficult information separately or in the presence of other support people like grandparents, siblings, and close friends. Parents should be addressed respectfully, and the child's name should be used(Janvier, 2014).

Opinions- *We are concerned that Charlie is having difficulty getting off the breathing machine. What have you noticed about that process? …. We have gotten to the point where we do not believe that Charlie will be able to breathe without the machine. There are a couple of options available...*

> Introduce the topic of conversation with the opportunity for families to provide their own observations. Importantly, providers should avoid the option of 'doing nothing.' Even when no medical therapeutic options are available, it is important to enforce that the child/family will still be supported (Janvier, 2014).

Basic human interaction- '*I can see this is a really difficult thing to discuss. Do you want me to get you some tissues? Are you ready to continue or would you like to take a few minutes to yourself?*

Sometimes healthcare providers are uncomfortable observing displays of emotion. They may rush to complete the conversation to 'allow the family privacy.' Instead of rushing, providers are encouraged to acknowledge the difficulty of the situation and offer practical comforts (Janvier, 2014).

Parents-*I'm so sorry this has been such a tough time. It sounds like you guys have been through a lot. Can you tell me about what is concerning you the most right now?*

Encourage parents to share and reflect upon their journey thus far. What is their perspective on the situation? Questions such as 'Can you tell me what about this concerns you the most? 'and 'What kind of things do you hope for xyz' can help providers in adjusting their presentation of information (Janvier, 2014).

Information- "*I'd like to talk to you in some more detail about what Charlie's test results have shown. Then, if you're ready, we can talk through some of the options.*

Vital information should not be rushed. By first focusing on the emotional needs of the parents, the stage is now set for presentation of data/options (Meyer, 2006; Janvier, 2014).

Emotions- *"I'm so sorry that this is happening to you. I was really hoping that Charlie's breathing would get better with that last medication'*

Providers should be prepared for a range of parental emotions in response to difficult news. Creating a safe space for families to experience initial reactions is important. Providers who have rapport with families may also find it appropriate to share their own emotions. While they should remain mindful to not let emotions create additional burden (as with families feeling the need to comfort providers), parents often report that

showing genuine emotion made them "feel like (they) cared" and "that they(providers) were really doing their best (for my child)" (Meyer, 2006; Hinds, 2009; Janvier, 2014).

Uncertain Prognoses

One of the most challenging situations for healthcare providers is to provide information when prognoses are unknown (De Vos, 2014; Prins, 2022). Physicians train for a long time to be experts in their field (Miller-Smith, 2019). With that said, each patient's condition is unique. There may be scenarios (such as rare congenital disease) that the physician has never encountered. Even among well studied conditions, there is often variable response to treatments (De Vos, 2014). New therapeutics are being discovered all the time. Some patients experience therapeutic benefits with minimal negative effects. Others may experience burdensome (or even life threatening) side effects. Still others will experience side effects with minimal to no improvement in clinical condition.

Communicating uncertainty can be uncomfortable for both parents and providers (De Vos, 2014; Miller Smith, m019; Prins, 2022). For the provider, they must first acknowledge that there are things beyond their knowledge (Miller-Smith, 2019; Bridgeman, 2020). For pediatric and neonatal intensive care providers, where the ethos of the specialty is saving children against odds this can be a particularly humbling conversation (Miller-Smith, 2019). Furthermore, if this acknowledgement is done incorrectly, parents may lose confidence in the qualifications of their child's healthcare provider (Bridgeman, 2020).

Studies observing PICU and NICU physicians discussing uncertainty have noted several informative patterns (Prins, 2022). In situations where death is not imminent, uncertain prognoses often have a particularly optimistic note. Parents are informed that while their child's

disease course may yet be unknown, there is boundless expertise and technology available to address whatever arises. It is only when tests fail to provide answers, or the child does not respond to therapeutics as anticipated that the tone changes. While there may be uncertain expressed for why things have progressed as they have, there is often certainty regarding the likelihood of negative outcomes. For instance, disability or death may be presented as near certainty (Prins, 2022). It is perhaps no surprise then that parents often report being surprised and upset by what they may perceive as a sudden switch in attitude.

When approaching uncertain prognoses, physicians are encouraged to be as honest and as neutral as possible. While hopes and anticipations for success can certainly be shared, such conversations should be put into perspective. Instead of merely citing statistics that families may not understand, outcomes can be discussed in terms of 'most likely,' or 'very best and very worst' (Prins, 2022). Ideally the conversation about uncertainty starts early in the child's hospitalization, with reassurance that as more information becomes available, the physician will update accordingly (Kruse, 2017; Choong, 2019).

As seen in SOBPIE, it is important that regardless of circumstance, the physician remains attuned to the needs and emotional receptivity of parents (Spijekers, 2022). Even when there is nothing medical to be done, there remain options for providing holistic care, symptom relief, and psychosocial support to families and children (Janvier, 2014). Parents do not only want to be kept up to date as shared decision-making partners, but they want to know that regardless of decision or outcome, their child and family will still be treated with respect and care.

Addressing Provider Bias

A final challenge in physician communication is addressing and acknowledging the influence of provider bias. The above information on uncertain prognosis discussed some of the ways in which challenging patient scenarios can stress the comfort zone of physicians (Miller-Smith, 2019). Similarly, intrinsic bias regarding patient quality of life may negatively impact family decisions (Hinkka, 2002; Miccinesi 2005; LaRochelle, 2009; Shapiro 2011; Racine, 2016; Stokes 2017). Family backgrounds introduce the potential for cultural value differences. Healthcare providers unfamiliar with the values of families may inadvertently assume the family shares the same values they do (Mohrmann, 2006; Spijkers, 2022). Likewise, when cultural values differ from the provider's experiences, negative assumptions may be made about the intentions of families (Wilford, 2014; Stokes, 2017; Drach 2020).

A common value difference between healthcare providers and families are the concepts of futility and suffering (Salter, 2019; Tate, 2020). A provider who feels that a patient is 'suffering' may not recommend treatments that they believe would worsen quality of life without any benefit (Tate, 2020). The term 'futile' is frequently used to describe these sorts of treatments. Of course, in a practical sense, these treatments may not be futile at all (Salter, 2019). They may very easily fulfill their technological purpose. A ventilator for instance, will continue to push air in and out of a patient's lungs. Dialysis will filter waste products from the bloodstream. Labeling such treatments as 'futile' when they really intend to mean 'not useful for this patient's overall goals of restoring health' may be confusing to families who have different perceptions of events (Janse, 2005; Mohrmann, 2006; Salter, 2019).

Charlie's parents believed there was possible physiological benefit from nucleoside therapy. They also did not believe that his current quality of life equated to pain or unbearable suffering. While Charlie's intensive care therapy was not what they desired, they saw it to the end of getting a healthy Charlie back home. Charlie's healthcare providers refused to provide nucleoside therapy, as well as other treatments like tracheostomy. Based on physiological evidence, they did not believe that Charlie would ever be able to return home. His continued life was equated with inacceptable suffering (Tate, 2020). In doing so, a situation was created where the only rationale alternative was Charlie's death. Not only was this option unacceptable to Charlie's parents, but any intermediary steps that might prolong Charlie's life were also deemed unacceptable.

Intensive care conflicts happen when there is disagreement over best interests. (Mohrmann, 2006; Lantos, 2017) Although current medical training has improved dramatically in teaching about the importance of diversity, there is an equal need to teach recognition of self-bias. While healthcare providers are certainly entitled (and in many cases obligated) to detect instances of harm, they must remain adaptable to family values. Only situations that cause imminent, substantial, and irreversible harm should be escalated, even then, the focus should be on facilitating compromise. In Charlie's situation, there was the early formation of an intractable impasse. With neither side willing to compromise their viewpoint, the development of actionable shared goals could not be achieved.

Conflict Mediation

Unfortunately, sometimes despite all preventative efforts, disagreement occurs. While conflict resolution strategies will need to be customized to the situation, there are several overarching recommendations. First, complex cases often benefit from the introduction of

additional neutral viewpoints. This can include consulting ancillary services such as palliative care or through the facilitation of second medical opinions.

There is also a strong recommendation in the literature for the involvement of conflict mediators. These can be impartial parties associated with the institution (such as a hospital wide ethics committee) or can be independent contractors such as lawyers and family counselors. The mediation process serves to help each party better articulate their interests and identify areas of common ground (Dubler, 2004). Most importantly, mediation is recommended early in the conflict (Choong, 2019). When conflict occurs, physicians may be tempted to continue to try and reach consensus through continued conversation and family meetings. Unfortunately, once trust has been disrupted, it can be difficult to get back. In the Charlie Gard case, mediators were brought in only during Charlie's last week of life. In a study of PICU providers, families, and nurses, almost 65% (63.4) of families and nurses perceived mediation efforts as happening "too late" (Kruse, 2017).

The later conflict mediation occurs, the less likely it is to succeed (Dubler, 2004; Kruse, 2017; Choong, 2019). At its core, mediation processes focus on seeking compromise (Dubler, 2004). When conflict persists for prolonged periods of time two things often happen. The first is that neither party desire any sort of compromise. Desires become deeply and stubbornly entrenched. The other party often becomes villainized and there is no desire to seek mutually agreeable solutions. Additionally, both parties (but particularly the child's family) are subject to emotional fatigue. Not only does no option (even the one wished for) become optimal, but the process of decision making itself drains emotional reserve to cope with the child's evolving needs (Dubler, 2004; Kruse, 2017).

Ultimately, some families may find themselves in a situation where no option will get them what they really wish for, and they are unable emotionally to make a choice. For instance, if a family deeply desires treatment to facilitate their goal of a healthy child and the child irreversibly deteriorates during disagreement, the family may find themselves lacking the emotional strength to make future decisions (such as implementing a do not resuscitate order or withdrawal life sustaining technology). While at this point, escalation to legal processes may become necessary, court proceedings can further prolong the distress of all parties (Dubler, 2004). Legal processes are long, harsh, and unbending. Rulings such as the Gard verdict that Charlie's life support could not be taken out of the hospital (on hospice) and withdrawn in the Gard's home, often eliminate intermediary options may be desired family centered methods of care. Optimal PICU conflict resolution then seeks first to employ as many non-legal options as possible.

Expansion in Journalism Policy and Protective Law

Until this point, I intentionally focused on the ethical responsibilities of parents and healthcare providers. I have done so for several reasons. The first is that in pediatric intensive care conflicts, parents and healthcare providers are the primary surrogate decision makers. I have presented the ethical responsibilities of both parents and healthcare providers, both separately and within a shared decision-making model. It is between these two groups that those most directly responsible for the welfare of the sick child must make decisions. Evidence on intensive care conflict shows that most instances of disagreement come from collaborative challenges. The most direct means then to mitigate negative media effects is to prevent scenarios in which the family feels they need the media to begin with.

I have presented the media as a conduit through which the public becomes peripherally involved in intensive care disagreements. While the section on media harms briefly discussed negative impacts of social media on healthcare structures, the bulk of this paper has shown the media as an external (and in many cases, unnecessarily burdensome) participant. There are more general arguments out there about the ethical responsibility of society in ensuring that children are protected. As that topic alone is worth several papers; I have chosen not to explore this in any sizable detail. While admittedly, the potential existence of this public responsibility does somewhat alter the media's role, I do not feel as though this substantially changes or outweighs the harm potential. The public's investment in protecting children does not grant excuses to harm the child (or family's) rights in the process of being watchdog.

With that said, I would be remiss if a discussion of potential interventions did not at minimum acknowledge macro level policy change. With the acknowledgement that there will be philosophical and political disagreement about the role of the public in private family/healthcare conflict, this section briefly discusses journalistic ethics and existing media policies before transitioning briefly into legal precedence for child protection in the media. Current child media policy focuses on two general categories. The first sort aims to restrict adult level content such as violence or sexual themes from shows and advertisements targeted at children. The second more relevant type relates to how children should be treated as they interact with (and are interviewed or displayed by) the media (AAP, 2016; AAP, 2021; Sorenson, 2020).

 In the following, I begin by highlighting two examples of the latter, comparing guidelines in the United States and United Kingdom, respectively. I then offer potential areas for expansion through a presentation of media reporting guidelines designed by United Nations International Children's Emergency Fund (UNCIF) to protect the child subject's human rights.

In conclusion, I discuss existing precedence for child media protection, as demonstrated through the scenario of child testimony in legal trials.

The United States Federal Trade Commission established the Children's Online Privacy Protection Act of 1998 (COPPA) to attempt to restrict inappropriate collection, use, storage, and disclosure of personal information for and about children on the internet. Of particular concern under COPPA is establishing legal boundaries restricting corporations from requesting personal data (either by direct request or via coercive strategies such as games) from children who may not be old enough to make judgements regarding safe use of their information (Federal Trade Commission, 2022).

Although the term 'child' is commonly defined in the United States as an individual under age eighteen, COPPA applies only to children under the age of thirteen. Personal information is defined as identifying information (such as name or social security number), contact information (home address, email address, or telephone number), and imagery (via photograph, video, or audio depicting the child's image or voice). Importantly, data is allowed to be collected, used, and stored, even in children under the age of thirteen, so long as the child's parent or guardian is given notice of COPPA and provides 'verifiable' consent. A variety of methods ranging from having a parent call a telephone number to sending an email notice of privacy policy are considerable acceptable consent (Federal Trade Commission, 2022).

The United States' approach has several flaws. First, the question should be raised whether the average thirteen-year-old child is mature enough to make decisions regarding the appropriate release of private information. Given that normal psychological development categorizes the teenage years as a time of impulsivity and vulnerability to peer pressure, a young teenager may easily be swayed into communications and interactions that put not only their

information, but also themselves at harm (Diekema, 2020). Additionally, it is concerning that the methods suggested for verifying parental consent are ones that could easily be overridden, either by a motivated child or by an adult who is not the child's parent or guardian. While verification of parental consent is an essential component of COPPA, the minimum requirements make it appear that the corporation and not the child is being protected.

Finally, there is the fact that personal information may be released about minors and used merely if the parent provides consent. While there may certainly be circumstances where the disclosure of information is safe and appropriate, the law reads that almost anything could be considered permissible with parental consent. In fact, barring bans on pornographic material, the United States lacks legislature limiting what personal information or content a parent may consent to release. Emphasis instead remains on the importance of obtaining legal consent for the protection of corporations. So long as consent is obtained, parents are legally able to disclose whatever they wish about their children.

The United Kingdom takes a quite different approach. There, the Office of Communications (Ofcom) has published guidance regarding the involvement of children in media programming. Ofcom Rule 1.28 to 1.29 state that journalists have legal and ethical responsibilities to protect child participants (n.d.). Unlike COPPA, Ofcom defines children as all individuals under the age of eighteen. When including a child in media programming, a consideration of welfare is required. Participation in media programming must not cause 'unnecessary' distress or anxiety. To ensure this requirement is met, OfCom recommends utilizing risk assessments for physical, psychological, and social health, as well as the employment of child development specialists for ongoing support and guidance (Ofcom Rule 1.28 to 1.29, n.d.).

Importantly, the requirement for 'due care to be taken in regard to physical and emotional welfare and dignity of people under eighteen' is noted to be "irrespective of any consent given by the participant, or by a parent or guardian" (Ofcom Rule 1.28 to 1.29, n.d.). It is noted that merely obtaining consent does not give the journalist ethical permission to proceed in a way that they themselves would judge as inappropriate. Rule 1.29 explains that journalists must be aware of the ways that a parent or guardian may be predisposed to perceive media participation in only a positive light without sufficient personal experience to make quick judgements of potential burdens. To combat this, an emphasis is placed on care and time in the consent process, in which both potential positive and negative outcomes are discussed at length. Of these outcomes, journalists are instructed to pay special attention to risks of attracting predatory attention and cyber bullying (Ofcom Rule 1.28 to 1.29, n.d.).

Although quite different in content from each other, both the United States and the United Kingdom recognize that there is at least to some degree a need to protect vulnerable children from media exploitation. The difference between the two countries may lie in underlying cultural attitudes. The United States is a country that heavily emphasizes personal freedom. The standard set by COPPA is the idea that a child's personal information cannot be released without parental consent. The harm COPPA aims to prevent then is that of the unmonitored violation of privacy (Federal Trade Commision, 2022). With the documentation of informed parental consent, there are very few limits to what a journalist can publish (Sorenson, 2020).

The United Kingdom on the other hand takes the approach that child welfare is a more of a shared social responsibility. Simply obtaining parental consent is insufficient if the journalist has reason to believe that participation in media will cause the child harm. A more holistic

offering of 'harm' is provided which includes violations to basic welfare rights (such as danger of physical harm) as well as future impacting rights (such as psychological damage via privacy violations, bullying, etc.) (Ofcom Rule 1.28 to 1.29, n.d.). Ultimately however, neither country provides any real policy guidance for when the parent is the one actively seeking and/or publishing information that may cause their child harm.

UNICEF has created a list of principles and guidelines for journalists to follow when interviewing or featuring children in the media(n.d.). The core principle is that reporting on children and young people should never put them at risk of compromising their basic human rights. From that core approach comes the following six principles for journalists to follow when interacting with children to create a media story (UNICEF, n.d.).

1. Respect the dignity and rights of every child in every circumstance (UNICEF, n.d.).

2. In interviewing (and reporting on) children, pay special attention to each child's right to privacy and confidentiality, to have their opinions heard, to participate in decisions affecting them, and to be protected from harm and retribution (UNICEF, n.d.).

3. Protect the best interests of each child over any other consideration, including advocacy for children's issues and the promotion of child rights (UNICEF, n.d.).

4. When trying to determine the best interest of a child, give due weight to the child's right to have their views taken into account in accordance with their age and development (UNICEF, n.d).

5. Consult those closest to the child's situation and best able to assess the political, social, and cultural ramifications of any reportage (UNICEF, n.d.).

6. Do not publish a story or an image that might put the child, their siblings, or peers at risk, even when their identities are changed, obscured, or not used (UNICEF, n.d.).

These principles are elaborated through specific guidelines for interviewing and publishing about children. Although many of the principles are merely further extensions of the above principles, the following three guidelines bear iteration.

1. Take exceptional care to avoid causing additional trauma. Avoid using stigmatizing language, imagery, or depictions that may cause a negative stereotype to be imposed upon the child by those who view the story (UNICEF, n.d.).

2. Permission must be obtained from both the child (if old enough) and the child's guardian. Both child and guardian must be made explicitly aware of the interview's purpose, story, and intended dissemination. Care should be made so that neither child nor guardian feels coerced into agreeing to an interview (such as incentivizing interviews, particularly among poor or disenfranchised populations) (UNICEF, n.d.).

3. When there is any doubt whatsoever as to whether a child is (or will be put) at risk via interview or media portrayal, reports should be made on the general situation rather than the individual regardless of how newsworthy the story (UNICEF, n.d.).

Unfortunately, media guidelines often remain just that. Journalists must balance the need to protect vulnerable subjects with the pressure to present stories that attract views. Once parents have elected to make their child's story public, it is often assumed that they have consented to any of the possible negative results of that decision. I have spent much of this paper arguing that this claim is not so straightforward. Not only do parents have conflicting emotions and needs of their own that make true informed consent almost impossible, but in many cases, they may simply be unaware of how the sequalae of their media campaign can negatively unfold. As with the Gards, a case that started with the intention of changing the medical team's mind and raising

money for healthcare can quickly grow into a global phenomenon, attracting the attention of celebrities and unrelated political agendas.

While the OfCom guidelines are somewhat more recent (2003), both OfCom and COPPA were composed in a time of different media technology. Neither country has updated its guidance to address newer developments, such as social media. As these technologies have quickly become primary sources of media use, there is a pressing need to update professional guidance regarding the ethical reporting of vulnerable populations. Not only must these guidelines be taught and integrated into professional training, but expansion in journalistic ethics must also be supported by law.

There is a legal precedent in both the United States and the United Kingdom that limits media exposure of children involved in court proceedings. This has been shown in domestic cases (such as child custody battles) and criminal proceedings. While the United States maintains the legal rights to a public trial and the ability to face one's accuser, when a minor is the one testifying, concern for the child's physical and psychological welfare has historically taken precedence. This means that although there may be media coverage of a legal battle, journalists are often restricted in publishing things like the child's face, name, and identifying details of testimony. Importantly, this precedence has been upheld, even in situations where the parent has given permission for media coverage. The argument in this case has been that frequently, when a child is involved in court proceedings, their parents have some degree of stake in the outcome.

While there has been limited expansion of this precedent to parent-medical team legal conflict, there are two notable exceptions, occurring in the United Kingdom and Australia. The first case, in the United Kingdom, involved an infant undergoing brain death testing. Parents had been resistant to the testing and were very concerned that the hospital planned to withdraw life

sustaining technology. The hospital evoked the British court system for authorization to withdraw mechanical ventilation. While the case was occurring, the judge restricted the release of both the child's name AND the name of the hospital in which they were receiving care for. Restrictions regarding hospital anonymity were rationalized in the judge's statement "I am anxious to everything I can to ensure the very difficult conditions in which staff are presently operating and not made worse by harassment of members of the public who only learn about the details of the case from the newspapers and respond in a wholly inappropriate manner" (Dryer, 2017).

The second case was that of Australian, Oshin Kisko. While his intensive care conflict involved parents wishing to withhold treatment, the media aspects of his case were initially quite like Charlie's. Distinctively however, the primary judge hearing his case, Justice O'Brian, issued an injunction limiting the extent to which media could cover the personal aspects of the trial. Not only did he prevent the public release of the hospital, or the names of medical providers involved in Oshin's care, but throughout the trial O'Brian also restricted both parental and media release of further images or recordings of Oshin (Richards, 2018). In doing so, O'Brian cited concern for Oshin's privacy, as well as the ongoing emotional needs of both his family and his healthcare team; stating that 'Oshin is not a cause, he is an individual little boy in a difficult situation." Although Oshin's parents did resume using social media for personal updates in the time after the legal case up until his death, the public involvement took a decidedly more restrained tone from the Gard case (Richards, 2018).

While these are but two situations among the many that have occurred in the time following Charlie Gard, these court proceedings demonstrate an interesting option of how legal proceedings can be adapted to include not only the details of the conflict itself but also a

consideration of the sequalae of media impacts surrounding conflict trials. Furthermore, they set a precedent that even when conflict escalates to the point of legal battles, there are ways in which the privacy and dignity of those involved can be protected from unrestrained media publicity.

Throughout this paper, I have discussed many ethically relevant aspects to pediatric critical care conflict. While I focused on the potentially negative impacts of media involvement in these conflicts, it would have been a disservice to the topic's complexity to discuss only media ethics. Instead, I have presented a comprehensive review of conflict components, starting with a high-level discussion of the origins of the ethical rights and obligations subject to media harm. I then transitioned into a review of the literature regarding pediatric intensive care disagreements.

Although the family centered care model of pediatric medicine encourages shared decision-making, decisions in the pediatric intensive care unit were presented as complex for both parents and healthcare providers. It was through a discussion of contributing factors to conflict that I then introduced the media as an appealing vector for families experiencing care disagreements. While I conceded that media use had many potential benefits, I argued that most of these directly benefited families, without considering potential harm to the child. Charlie Gard's case was threaded throughout as an exemplary case of escalating media harm.

While both pediatric critical care medicine and media technology have increased dramatically, the world of pediatric bioethics has thus far failed to address the ethically relevant ways in which the two fields intertwine. Although I have argued the ethical relevance of media involvement, this closing chapter shows that there is much research yet to be done. Addressing the impact of media involvement requires a multi-level approach. At the highest level, efforts should be made to avoid intensive care conflict from occurring. This involves conscious effort on behalf of medical staff to acknowledge parental stressors that may impede participation in the

shared decision-making model. Once conflict occurs, early intervention is necessary to promote

satisfactory resolution. Despite all of these efforts, it is inevitable that some conflicts will

escalate to the media. Once media has become involved, ethical guidance is needed at both a

policy and legal level to limit harm and protect all involved from further harm.

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