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Approaches to parental demand for non-established medical treatment: reflections on the Charlie Gard case

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Abstract

The opinion of Mr. Justice Francis of the English High Court which denied the parents of Charlie Gard, who had been born with an extremely rare mutation of a genetic disease, the right to take their child to the United States for a proposed experimental treatment occasioned world wide attention including that of the Pope, President Trump, and the US Congress.

The case raise anew a debate as old as the foundation of Western medicine on who should decide and on what standard when there is a conflict between a family and the treating physicians over a possible treatment. This paper will explore the different approaches of the British and American courts on the issue and the various proposals from that of John Rawls in his *A Theory of Justice* to a processed-based approach for resolving such disputes.

INTRODUCTION

As carefully crafted as the opinion of Mr Justice Nicholas Francis in the *Gard* case proved to be, it left commentators unsatisfied. A widespread criticism, captured in an article by Michael Dougherty in *The National Review* was for the state to ‘get out of the way of the parents trying to act in the best interests of the child’.¹ Although he conceded the parents could be adding to the suffering of the child by taking Charlie to America for an experimental therapy and agreed that such a choice ‘may be the wrong decision,’ in Dougherty’s view, it should still be ‘their decision’.

Dougherty’s stand was the popular response to the question of ‘Who should decide?’ It fails, however, to propose any rationale for the decision. It provided no norms, no standards and no guidelines for the parents. Their motive could equally well be indifference to the suffering of the child as concern for his well-being. Furthermore, even good, loving parents

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may make a decision antithetical to the best interests of an infant from a misunderstanding of the patient's medical condition, overwhelming anxiety, fear or unrealistic expectations. Parents may also rely on hope for a miracle which can displace all other arguments. Such a stance allows little role for reasoned assessment of the benefit–burden ratio.

Questions of 'who should decide' and 'on what standard' are as old as the reflections on the role of medicine. The treatise in the Hippocratic Corpus entitled *The Art* defines medicine as having three roles: 'doing away with the sufferings of the sick, lessening the violence of their diseases, and refusing to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless'.² In Book III of *The Republic* Plato admonishes, 'For those whose bodies are riddled with disease, [Asclepius] did not attempt to prescribe a regimen to make their life a prolonged misery'. Plato concluded 'Medicine isn't intended for such people even if they are richer than Midas.'³

The *Gard* case provides a useful opportunity to reflect on how we approach disputes about whether medicine is, in fact, powerless. In our reflections, we will contrast the standards used by British and American courts, consider the financial implications of the American approach and point towards a process-base approach and communication as alternatives to litigation.

DIFFERING STANDARDS IN BRITISH AND AMERICAN COURTS

Conflicts between families and physicians, as the *Gard* case illustrate, continue to challenge medicine, the courts and society. As we noted in an earlier article, British and American approaches to these questions are widely divergent.⁴ The British have a more unified system for setting standards than prevails in the USA where 50 independent state legislatures and judicial systems as well as Congress and a federal judiciary set standards. In Britain, cases of great importance are heard in the High Court whose 108 members are appointed by the Crown from among the most respected lawyers in the England and Wales. Once appointed, High Court judges hold office until a mandatory retirement age which is presently set at age 70. In the USA, 90% of the state judges are subject to some form of judicial election. Only eight states have lifetime tenure or tenure until a mandatory retirement age.⁵ Independent judicial assessment is not the mark of politically elected judges.

As Mr Justice Francis made clear in his opinion in the *Gard* case, under British law disputes between families and physicians are not to be resolved on the personal predilections of the presiding judge or the reasonableness of the arguments put forth by the family or the physicians, but on 'the independent and objective judgment of the court' on the best interests of the non-competent patient.

In the USA, there is no such uniform norm. As is seen in the clashing standards of the courts of final jurisdiction of New Jersey, Massachusetts and New York responses on how to resolve such disputes vary widely. New Jersey in *Quinlan*⁶ favoured allowing the family of a now unconscious young woman make the decision on her behalf. The Massachusetts' Supreme Judicial Court (SJC) in *Saikewitz*⁷ spurned that standard. It insisted that a probate court judge could—through the old English doctrine of 'substituted judgment'—discern

what a never competent 67-year-old patient who had spent his entire life in a state mental facility would want when he was dying of leukaemia. New York's highest court, The NY Court of Appeals, when confronted in *Storar*⁸ with a case of an elderly man profoundly mentally compromised from birth, rejected as 'judicial fantasy' the SJC's reliance on substituted judgment. In doing so, New York's highest court ruled that no one—physician, parent or judge—no matter how well intentioned may deprive a patient of life-saving treatment. To make its position unambiguously clear, the New York court required that before life-sustaining treatment may be withdrawn, there had to be 'clear and convincing evidence' of a preference of the patient, when competent, to forego life-prolonging medical interventions. Under that standard all minors and the vast majority of the population who have never written an advance directive or expressed a firm opinion on what, if any, medical treatments they would want if terminally ill, must, if incompetent, undergo 'all treatment for a condition which threatens [their] life.'⁹

That judicial abrogation of an individual's right to be free of an unwanted medical intervention was promulgated in the name of the state's protection of vulnerable patients by the same New York court that in a landmark 1914 opinion by Justice Benjamin Cardozo in *Schloendorff v. Society of New York Hospital* declared: 'Every person of adult years and sound mind has the right to determine what shall be done with his own body and any touching of one's person by another without consent or legal justification was a battery'.¹⁰

Cardozo's words were presaged more than a century ago in *Southern Pacific Railway v. Botsworth* where the US Supreme Court declared:

No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to have the possession and control of his own person, free from all restraint and interference of others unless by clear and unquestionable authority of law.¹¹

The combination of the doctrine of self-determination and the legal requirement of informed consent allowed the competent patient to decline any unwanted medical procedure. That right was extended to the non-competent in a series of legal cases in the USA beginning with the New Jersey Supreme Court's 1976 opinion in *Quinlan* and culminated in the 1990 US Supreme Court's opinion in *Cruzan*¹² that recognised the right—subject to an individual state's evidentiary standards—of an incompetent patient to decline any and all unwanted medical interventions. That negative right to decline medical interventions quickly morphed into a claim for the patient's positive right to demand and to receive whatever medical intervention was desired.^{13,14} The claim applied to the self-determination of the individual patient (competent or non-competent), and it was extended in *Quinlan* to include family members, that is, to a relative who had decision making authority for an incompetent patient.

FINANCIAL IMPLICATIONS

The financial implications of the expansion of right claims was explored in a discussion in *The New England Journal of Medicine* among Norman Levinsky, the then Chair of the Department of Medicine at Boston University,¹⁵ Lester Thurow, Dean of the Sloan School of Business at MIT,¹⁶ and Victor Fuchs, an economist at Stanford University.¹⁷ Dr Levinsky's

thesis was that physicians were ‘required to do everything they believe may benefit each patient without regard to costs or other societal considerations’. He went further in his position to comment that, ‘In any decent, advanced society there are rights to healthcare’. In his words, ‘In such a just society the physician who withholds care that is in his power to give because he judges it is wasteful to provide it to a particular person breaks faith with his patient’. Levinsky explained that he was not seeking to prolong life under all circumstances, just where physicians and patient or surrogates believe to be in the patient’s ‘best interests’. Levinsky insisted on a single mindedness in the physician-patient relationship: ‘The doctor’s master must be the patient’.

For Thurow, such indifference to cost presaged fiscal insolvency. Contributing to the problem, he observed, is that ‘most Americans are simultaneously egalitarians and capitalists’. As capitalists they believe that individuals should be allowed to spend their money on whatever they wish. And as egalitarians, they believe everyone in society should have access to whatever healthcare is available. Americans, he maintained, ‘do not have the political ability to say ‘no’ to any person dying from a treatable disease’. Nor as capitalists are they willing to limit what those who can afford healthcare receive. The confluence of the two values, Thurow concluded, means that no society can afford to provide everything to everyone. In his view Americans are going to have to learn to say ‘no’ to requested medical treatment, not because there is no value in the treatment, but because in economic terms, ‘the marginal costs exceed the marginal benefits’.

Victor Fuchs insisted that the warnings against rationing of medical care ring hollow. In his view we do and always have rationed healthcare—just as every nation has and must do. Moreover, he noted, medical care is hardly unique in this respect. We ration automobiles, houses, restaurant meals, etc. Since no society, no matter how wealthy can meet everyone’s medical desires, Thurow proposed limiting medical care to that in which the marginal costs equal the marginal benefits. He warned that if medicine does not do so, some third party will take on that task. Managed care was tried and, while it did for a time control costs, it failed politically. The default position now is the market place, which, as Fuchs notes, is both ruthless and unyielding. You get only what you can pay for.

POSSIBLE WAYS OF RESOLVING FAMILY-PHYSICIAN DISPUTES ABOUT TREATMENT DECISIONS

John Rawls’ *Theory of Justice*¹⁸ provides an insight into how we might proceed in cases of family requests for treatment believed inappropriate by the medical team such as the *Gard* case. He proposes a theory of ‘justice as fairness,’ in which what ought to be done is determined by asking: What would we agree to if, operating behind a ‘veil of ignorance,’ we did not know what role we would play in life: rich/poor, doctor/patient, judge/incompetent terminally ill person. What a person would agree to for each position, not knowing whether he occupied it, Rawls asserts, is the fundamental minimal demand of justice. What, indeed, would one want if one were afflicted with a rare genetic disease for which there is no known cure? The literature¹⁹ suggests that a dying individual, if competent, would want a procedure that would not be unreasonably dragged out, would not distress one’s family and would not

fail to safeguard the right to decide whether to struggle for yet another morning or slip gently into that good night.

What would not be desired would be a full adversarial hearing with competing witnesses, opposing counsel and the trauma of a courtroom proceeding added to the already stressful process involved in an end-of-life treatment decision. Such a route, which would plunge both the family and physician into the unwelcome, cumbersome and costly arena of litigation, would be likely to result in the unnecessary continuation of treatment by the physician and suffering for the patient and family.

The New Jersey Supreme Court in *Quinlan* foresaw that result and sought to obviate it by locating the decision-making mechanism within the family-physician group, subject in difficult or novel cases to ratification by a hospital ethics committee. It did so because it believed that decisions on ‘the nature, extent, and duration of care [were] primarily the physician’s responsibility’.²⁰ Shifting the role to the courts was judged to be ‘a gratuitous encroachment on the medical profession’s field of competence’ and ‘impossibly cumbersome’.

Critics such as Robert Truog object to the use of hospital ethics committees as having an institutional bias²¹ He insist that families must have access to due process including a ‘jury of one’s peers’. Truog agrees that ‘the legal system is particularly unwieldy when it comes to questions involving clinical decision making, and acknowledges that the pace of the judicial system is measured in terms of months and years, whereas clinical medicine evolves over hours and days’.²² He is seemingly unaware that in the American legal system petitions for injunctive relief are heard not by a ‘jury of one’s peers’ but by a single sitting judge. Nonetheless, he continues to plead for due process by a jury of one’s peers as the only equitable way to resolve family-physician disputes about treatment decisions.

WRANGLING IN COURT: THE AMERICAN EXPERIENCE

The highly publicised case in Florida of Terri Schiavo serves as a warning to those who postulate the wisdom of bringing family-physician disputes on appropriate end-of-life care to court for due process and unbiased resolution.²³ That case involved state and federal courts, the Florida legislature, the Governor of Florida, the US Congress and the President of the USA. It began in 1990 when Terri Schiavo suffered a cardiac arrest. Several years later Terri’s husband and her parents took conflicting positions on her medical status and the request of her husband for the withdrawal of Terri’s ventilator. The husband and the treating physicians believed Terri was in a persistent vegetative state (PVS). Her parents believed she was alert and responsive. An autopsy noted severe neuronal loss and cortical blindness that supported the diagnosis of PVS.²⁴ The legal conflict dragged on for 7 years through multiple state and federal courts, the Florida legislature, the US Congress, some 14 appeals and 4 denials of *certiorari* by the US Supreme Court. The legal and political quagmire finally ended when for a fourth time the US Supreme Court declined to hear an appeal on the case.

The timing of death in an intensive care unit (ICU) setting is a personal matter: a value choice—not a technological imperative. For the incompetent patient, it is most aptly acceded

to by those who, in the words of New York's Court of Appeals' in *Eichner*, 'knew and loved the patient personally.'²⁵ Developments in medical technology may have made the issues more problematic, but questions of life and death and of who should decide are not new; they have been determined within families, under physician guidance, since the dawn of medicine. Except for rare and readily circumscribed circumstances—when there is no next of kin, when there is a dispute among family members or an intractable conflict between the family and physician or when there is evidence of malevolent motives or medical negligence—there is no need for judicial intervention. When as in the *Gard* case there is an irreconcilable dispute between the family and physicians, the British system has a long history of relying on a highly qualified judiciary for resolution. The different structures and the emphasis on 'autonomy' in the American legal system make the American judicial system a less apt locus for resolution.

The debate in the USA on how best to resolve family-physician disagreement about care for patients at the end-of-life has occasioned an intense debate in the literature.²⁶ The so called 'futility' debate began with the report in 1990 on *Baby L*, in which physicians at Boston Children's Hospital refused a parental request for ventilator support for a neurologically devastated 23-month-old infant.²⁷ The term 'futility' proved impossible to define with any agreed on precision. It met its demise as a short hand way to resolve family-physician disputes on end-of-life treatment within a decade with the publication by Helft and colleagues of an essay on the rise and fall of the futility movement.²⁸ Even some of those who had actively participated in the 'futility' debate came to conclude that futility is a failed concept in medical decisions making whose use should be abandoned.²⁹

PROCESSED-BASED APPROACH FOR RESOLVING DISPUTES

That attempt at resolving family-physician disputes was soon replaced in American bioethics with a process-based approach first seen in a Texas case, *Hudson v. Texas Children's Hospital*.³⁰ That approach demonstrated that there was a way out of the conundrum American medicine seemingly faced of being forced to accede to family demands or engage in an adversarial process by challenging family's demands in court. *Hudson* involved a full-term infant named Sun, who was born with thanatropic dysplasia, a severe genetic form of dwarfism that frequently results in early death from respiratory failure. At delivery, the physicians, unaware of the fetus' medical status, resuscitated the infant and placed him on a ventilator. A subsequent evaluation revealed the baby had 'a lethal and incurable genetic deformity'. The team of neonatologists and bioethicists at Texas Children's determined it would be unethical to continue ventilator support on an infant they believed was 'slowly suffocating'. The mother did not accept that assessment. As she puts it, 'He just needs to finish growing'. Further, she informed the doctors, 'The sun that shines in the sky, not a man, fathered her child and would decide its fate'.³¹

Unlike most states where the only alternative to following a family's care plan was to challenge it in court, a 1999 Texas statute³² authorises a 'processed-based approach' whereby physicians and hospitals may withdraw life-prolonging interventions even over family objections if the actions were approved by an ethics committee and no other facility could be found within 10 days willing to treat the patient as the family wished. In the

Hudson case, 40 hospitals declined to accept the child on transfer. Ultimately, a Probate court ruled that under the statute the hospital was authorised to withdraw treatment. Once provided with judicial approval of the reading of the Texas statute, the treating physician's withdrew the patient from the respirator.

In their analysis of the statute's effectiveness, Robert Fine and Thomas Mayo observe that in the first 2 years of its existence, Baylor Medical Center invoked the law's provisions six times.³³ Each of those cases was concluded without the need for judicial involvement. Further, as those authors observe, while there is still no agreement on a definition of medical futility, the statute reserves that determination for an ethics committee judgment. The committee's judgment is constrained by communal standards because a healthcare institution may not withdraw treatment if another facility is willing to provide it. It is only when no qualified physician has been identified who is willing to provide the requested life-sustaining treatment that it may be withdrawn. In light of the general success of this approach in keeping disputes about medical treatment out of court, policy statements from multiple professional societies now recommend a process-based approach. Some professional societies, however, still use the argument of 'futility' in cases involving potentially inappropriate interventions.^{34,35}

THE IMPORTANCE OF COMMUNICATION: INSIGHTS FROM DOSTOEVSKY

A process-based approach provides more communication to parents, families, physicians, an ethics committee and other healthcare providers.^{36,37} We might avoid these disputes through effective communication between parents and the medical team. John Lantos and William Meadow, both experienced neonatologists, provide a helpful framework for conversations with the parents in a chapter entitled 'Moral Psychology of Decision Making' in their textbook on neonatal bioethics.³⁸ Particularly useful is their analysis of several approaches to such conversations: (1) Provide the parents with objective information and guide them to a decision that reflects their own morals and values; (2) 'Broad shoulders' in which the doctor makes a recommendation and bears the burden of responsibility and (3) 'Shared deniability'.

The final approach uses Dostoevsky's insight that human seeks to avoid decisions that can result in lifelong doubt and guilt.^{39,40} Dostoevsky proposes that we prefer a situation in which no one bears direct responsibility for a decision. To achieve that outcome Lantos and Meadow adopt Dostoevsky's deflection of explicit discussion of options in favour of an approach whose goal is 'shared deniability'. Rather than the physician recommending the withholding of a proposed experimental therapy, particularly when the parents have explicitly indicated they want to try it, the attending physician reiterates the team's assessment that further interventions cannot reverse or improve the baby's condition. The physician informs the family that the team will honour the parents' request, but no additional aggressive measures will be instituted. The goal of care, the physician tells the family, will be focused on comfort of the infant and support for the parents.

If presented this way, one that does not require the parents to alter their choices, no new interventions—medical or technological—are proposed. The parents, who desperately want

to try any potentially beneficial treatment, are reassured that all options will be tried. They can also comfort themselves that when the child dies they are not responsible. The anticipated death, when it occurs, will be tragic for the parents, but not a tragedy of their doing. No one—parent or physician—was responsible for the outcome. In the *Gard* case, it was the extensive damage to Charlie's brain, not human choice, that resulted in the undesired outcome.

CONCLUSION

Although Mr Justice Francis handled the *Gard* case with consummate skill and care, the dispute went unresolved for nearly a year. Charlie endured months of aggressive ICU care his physicians at Great Ormond Street Hospital had sought to avoid. His parents endured a public conflict-laden prolonged dying process. In the end, neither patient or family, nor the medical community or society were well served by the process. We owe it to all involved to seek a better way of resolving such conflicts.

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