PERSONAL VIEW

“Do we murder Mary to save Jodie?” An ethical analysis of the separation of the Manchester conjoined twins

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“Everyone has the right to life so why should we kill one of our daughters to enable the other to survive?”* That question by the parents of conjoined twins, Mary and Jodie, who were so fused that any attempt to separate them would inevitably result in the death of Mary, stands as a challenge not only to their caregivers at St Mary’s Hospital in Manchester, England, but to all who confronted the vexing issues raised by their plight.

The case

A 34 year old white woman with no other children became pregnant. At four months of gestation ultrasound revealed conjoined twins. The treating physician on the Maltese island of Gozo recommended transfer to St Mary’s Hospital, Manchester where he had trained. Because of a long standing agreement between Malta and Great Britain the patient was transferred to the care of the British National Health Service.

On transfer magnetic resonance imaging revealed significant problems with the pregnancy. The smaller of twins was not expected to survive. The parents, because of their religious belief that “everyone has a right to life”, declined the option to terminate the pregnancy. The pregnancy was allowed to continue for 42 weeks before delivery by caesarean section on 8 August 2000. The combined birth weight of the infants was 6000 g. Both infants were immediately intubated. They were ischiopagus tetrapus conjoined twins linked at the pelvis with fused spines and spinal cords, and with four legs.

Jodie, the healthier of the two had an anatomically normal brain, heart, lungs, and liver. She shared a common bladder and a common aorta with Mary. Mary was severely abnormal in three aspects: brain, heart, and lungs. She had a very poor “primitive” brain. Her heart was vastly enlarged, very dilated, and poorly functioning. There was a virtual absence of functional lung tissue. Mary was not capable of independent survival. She lived on borrowed time, all of which was borrowed from Jodie.

There were three options:

(1) Permanent union until the certain death of both twins probably within 3–6 months or at best in a few years.

(2) Elective separation. In the hospital’s view this would lead to Mary’s death but give Jodie the opportunity of a “separate good quality life”. There was a 5%–6% chance of death at

separation. Jodie would subsequently require several operations for bladder and genital repairs. She had musculoskeletal abnormalities which would require future surgical intervention. Separation would allow Jodie “to participate in normal life activities appropriate to her age and development”.

(3) Urgent (emergency) separation. Prognosis would be markedly reduced in the event of Mary’s death or cardiac arrest of Jodie with mortality projected at 60% for Jodie, 100% for Mary.

Discussion

As Lord Justice Ward summarised the case in his opinion for the English Court of Appeal, the unique and crucial feature of this case was that though each infant had its own brain, heart and lungs, Mary depended on Jodie’s heart and lungs to sustain her life. That double duty would so tax Jodie’s heart that, if unseparated, it was thought that both infants would die within 3–6 months or possibly longer. The St Mary’s physicians were convinced they could successfully separate the twins and provide Jodie with a worthwhile life. The parents, devout Catholics from the remote Maltese island of Gozo, rejected the proposed surgery. They accepted the status of their daughters as God’s will and wanted to leave their daughters’ fate in God’s hands. They asked that no medical interventions be utilised to prolong the tragic fate of their children.

The medical, moral, and legal issues raised by this case of conjoined twins were complex and vexing. Though rare, about one in 200 000 live births, Siamese twins—to use the common and now somewhat disputable term—are well described in the medical literature. The first recorded pair dated back to twins born in Armenia in 945.¹ The best known conjoined twins were Eng and Chang Bunker who were born in Siam in 1811, hence the name Siamese twins. The first successful operation to separate a pair of conjoined twins was done as early as 1689 by a German physician named G Konig. Since then some 200 surgical separations have been reported, most of which have occurred since 1950.

*A 15 hour operation involving some 20 physicians to separate the twins was performed at St Mary’s Hospital on 6 November 2000. Mary died in the course of the procedure; Jodie survived the surgery.

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Conjoined twins are the product of a single ovum. They have the same chromosomal composition and sex and can be joined at the head, chest, abdomen, or hip. The most common type are those joined at the chest and involve a shared heart. Annas in a 1987 essay described the prospects for this category of twins as nearly “hopeless”.² At that time, if left attached, no twins with conjoined hearts survived for longer than nine months. Once separated, no twin with a shared heart condition has survived for more than a few months. In 1996 a survival of nearly a year was reported in the case of one of the Lakeberg twins who had shared a single six chambered heart with its sibling.³ That surgery was done at the Children’s Hospital of Philadelphia after the original treating physicians at Chicago’s Loyola Medical Center had refused to undertake the procedure because of the high risk of death to both the twins. The surviving twin was maintained in the hospital on negative pressure ventilation for most of the year of its survival.

These single heart cases, as did the twins at St Mary’s Hospital, required that one twin be sacrificed to save the other. The most well known of those shared heart cases occurred in 1977 at the Children’s Hospital of Philadelphia when deeply religious Jewish parents were told they would have to “sacrifice” one twin so that the other could live. The profound issues raised by that dilemma occasioned concern by all involved in the proposed procedure.⁴ The parents would not consent to the separation without rabbinical support. The Catholic nurses at the hospital refused to participate in the surgery without assurance from the archdiocese of Philadelphia of the moral acceptability of “killing” one twin to save the other. And the paediatric surgeon, Dr C Everett Koop (later the Surgeon General of the United States), refused to undertake the surgery without judicial approval and legal immunity from potential charges of homicide.

The rabbinic scholars used two analogies to justify the separation. The first concerned two men who jumped from a burning aeroplane. One man’s parachute failed to open and while free falling he grasped the leg of the other whose chute could not sustain the weight of both. Must both die or can the one whose chute opened kick away the second man to save himself? The rabbis replied that it was acceptable for the first man to free himself since the second man was in their judgment already “designated for death”.

The rabbis used a similar argument in their second analogy. It involved a caravan surrounded by bandits who demanded a specified individual be turned over for execution as the condition for letting the others go. As in the first example, the rabbis determined that since the targeted individual was already “destined for death” there was no moral impropriety in revealing his identity to save the others.

The Catholic authorities in Philadelphia also approved the operation even though it could be foreseen that it would result in the death of one of the infants. They based their position on the

doctrine of double effect. That theory, first formulated by Thomas Aquinas in the 13th century as a justification for self defence,⁵ holds that while one may never directly intend an evil act (such as killing an innocent person), the evil effect (the death) may be permitted if the effect is not intended in itself but is indirect and justified by a commensurate reason.⁶ The most common application of that principle in bioethics is the justification of the use of analgesics to relieve pain in the terminally ill patient even though it can be foreseen that such use might unintentionally shorten the patient’s life.⁷

When Dr Koop sought judicial approbation for the procedure, a single sitting judge in the Philadelphia Family Court insisted that a three judge group be empanelled to hear the petition. That panel rejected the argument of the hospital lawyers that because the twins had only one heart there was only one person and thus no “killing” would occur if the twins were separated. The lawyers’ second argument was similar to one of the rabbinical analogies. Two mountain climbers were attached to each other by a rope. One slipped, but was caught dangling at the end of the rope. The partner, despite great efforts, was unable to pull the dangling climber to safety. If the rope was left uncut, the secure climber would soon tire and both would plunge to their death. The lawyers argued it was legitimate for the secure climber to cut the rope (with the foreseen death of his companion) to save himself. (This situation occurred at 19 000 feet in the Andes when Simon Yates cut his dangling fellow climber, Joe Simpson, from the rope. Simpson survived and supported the decision of Yates to save himself at the probable expense of his own life.⁸) The judges, who deliberated only a few minutes before authorising the surgery, issued no opinion in support of their decision. The surgery was successfully performed, but the surviving twin died within three months.

In a 1987 essay in the *Hastings Center Report* on the Philadelphia case George Annas noted that though both law and ethics supported reasonable medical attempts to separate Siamese twins with conjoined hearts, the rationale or justification for killing one to save the other remains perplexing. Further, he observed, “Since the separation procedure remains experimental and survival is unprecedented, the parents unquestionably have the right to refuse the surgery”.⁹ In 1996 Thomasma began his commentary on the ethical concerns in the care of the conjoined Lakeberg twins with a similar observation on the “perplexing and complicated” nature of the issues. In addition to the medical and clinical uncertainty, Thomasma raised questions on the family’s decision to go ahead with the surgery against the unanimous medical advice of the treating physicians. He was also concerned about the implication of committing vast amounts of medical resources for what from the outset seemed a doomed adventure.

Four years later the Manchester conjoined twins case once again plunged us into a similar quandary. Though separating Mary and Jodie

was a less risky surgical undertaking than attempting to separate twins conjoined with a common heart, their case presented a new and unprecedented issue: the parents opposed the surgery.

Parents' view

The parents could not accept that one of their children should die to enable the other to survive. If Jodie survived, she would be left with a serious disability. As the parents noted, there are few, if any, facilities on their remote island to care for a disabled child or for the child "to have any sort of life at all". Further, the parents made it clear that there were virtually no financial resources to provide Jodie's medical treatment at home. This meant she would have to be left in England with no assurance of who would take care of her. Leaving their daughter in England was not a choice the parents wanted to consider. Given these circumstances the parents had strong feelings that "neither of our children should receive any medical treatment". They were "quite happy for God to decide what happened to [their] two young daughters."

Ruling of the trial court

At the High Court hearing Judge Johnson found, "the evidence is that in medical terms Jodie's life would be virtually as long as and would have the quality of that of an ordinary child..... For Jodie separation means the expectation of a normal life, for Mary it means death". If not separated, Johnson found that Mary would remain in a pitiable state. Further he found that the few remaining months of her life "would not simply be worth nothing to her. They would be hurtful". He authorised the surgery, as he put it, to spare Mary.

Court of appeal

The judges at the Court of Appeal agonised over the case and confessed to long and sleepless nights as to how they should rule. Repeating the parents' question Lord Justice Alan Ward asked in open court, "Do we murder Mary to save Jodie?" On the other side the judges mused that one could argue that Mary is assaulting Jodie, slowly killing her by relying on and weakening her organs. Still, as Lord Justice Ward noted, "The moment the knife goes into that united body, it touches the body of unhappy little Mary. It is in that second an assault.....For what justification? None of hers".¹⁰

On 22 September 2000 the Court of Appeal issued its opinion authorising the surgery.¹¹ The opinions covered a wide spectrum of issues from medical, family, and criminal law. Lord Justice Ward began his opinion with the caveat that in this case the right answer is "not all that easy to find". The conflicting moral and ethical values and the unsettled state of the law on this area made a decision especially arduous. Lord Justice Ward himself predicted that half the population would approve of their decision and the other half think it "potty". It was, however, not ethics or morals, he stated,

but the law which must determine the outcome.

That response, though not unexpected from a court, was somewhat strange in light of Justice Ward's own prefatory comments that, "It would have been a perfectly acceptable response for the hospital to bow to the weight of the parental wishes however fundamentally the medical team disagreed with it". Further, he observed, "Other medical teams may well have accepted the parents' decision". Had the medical team at St Mary's done so, Lord Justice Ward noted, "there could not have been the slightest criticism of them for letting nature take its course in accordance with the parents' wishes". This comment seemed to find the parents' request to be both reasonable and lawful. In fact in his summary of the case Justice Ward stated, "I would have no hesitation in saying that the parents' position taken after prayerful consideration is pre-eminently reasonable". But he quickly countered that once an issue was raised in court, "The court's duty.....is to give effect to its own judgment of where the best interests of the child lie".

Had the physicians concurred with Justice Ward's private assessment of the reasonableness of the parents' decision or had the Manchester Hospital Trust—in spite of the medical team's views—acceded the parents' request, no one could fault either party. Yet, because the medical team were keen on the surgery, and the hospital supported that course, the hospital had the right to challenge the parental decision. How, one might ask, does the "right" of the parents to opt for a fully lawful and reasonable choice cease when a particular medical team, or more specifically a healthcare trust administrator, fails to share the parents' values?

The ruling in this case is particularly striking in light of the fact that there are no more than a half dozen or so medical teams in the world qualified to undertake the surgical procedure. Does the happenstance of the family coming from Gozo to seek medical advice from one of two facilities in the UK with experience separating conjoined twins transform the legitimacy of parental choice to accept or reject the surgical separation into a legal obligation to submit to what they and the court perceive to be the murder of one of their children to save the other? With what justification is the choice shifted from parents to physicians? Does it come about because the Manchester team has performed two surgical separations in the past neither of which was similar to the proposed surgery and in neither case were there any survivors? With that field experience has the surgical intervention been transformed from what Annas described as an "experimental" procedure which the parents "unquestionably have a right to refuse" into an obligatory submission to the surgeon's knife?

These questions are particularly poignant in light of the report in the *BMJ* that Professor Lewis Spitz, the paediatric surgeon at Great Ormond Street who had been consulted by the Court of Appeal, had written to the Department of Health asking for that hospital, which

had carried out “12 operations in which half the children had survived” be recognised as the lead centre of excellence for the separation of conjoined twins.¹² That request was made after it had become clear in Spitz’s words, “that St Mary’s has never carried out the sort of operation” required in this case. If that is so, is not the procedure by definition “experimental” and thus one that requires patient or proxy consent?

The Court of Appeal, in explaining how and why it ruled as it did, noted that “sincere professionals could not allay a collective medical conscience and see children in their care die when they know one was capable of being saved”. But if, as this court itself has ruled, the parents’ choice is a legitimate one, beyond criticism, why proceed further? The court’s answer was unambiguous. Once a case is brought to the court, the court itself, must, under the welfare principle, independently determine what is in the best interest of the child. That, said the court, “is what courts are for”.

The Court of Appeal took the extraordinary step of asking Cormac Murphy-O’Connor, the Catholic Archbishop of Westminster, to submit an *amicus brief* outlining the moral issues in the case. The Archbishop’s statement emphasised the traditional Catholic teaching that all human life as a gift from God is sacred.¹³ Consequently no one should cause an innocent person’s death. Further, he stated that there is no duty to preserve life if doing so requires extraordinary measures or procedures that result in a grave injustice. The deliberate “killing” of Mary, he argued would constitute such an injustice. In support of the parents’ position the Archbishop concluded that “out of respect for the rights of both children any choice but the refusal of the surgery would be morally impossible”.

Opinion of the Court of Appeal

The opinion of the Court of Appeal was a long, nuanced and complex analysis of the application of English law to this case. Lord Justice Ward began his opinion for the court, which was joined by Lord Justice Brooke and Lord Justice Walker, with the well established principle that every persons’ body is inviolate. He then found that Mary was a live person separate from Jodie. The Court of Appeal rejected Justice Johnson’s finding that the remaining few months of Mary’s life if not separated would “not be simply worth nothing to her. They would be hurtful”. This was because she would be unable to indicate that she had been hurt by Jodie’s movements or her own. Rather the Court of Appeal reaffirmed that the sanctity of life principle that every life is of inherent value and ruled that Mary’s life was of “inestimable value and dignity”.

The issue then is of what benefit would the surgery be for each of the twins. In Lord Justice Ward’s view it simply could not be in Mary’s best interest to undergo an intervention that would end her life. On the contrary it would be very much in Jodie’s best interest to be separated: she could then anticipate a full and

“normal-fairly normal life.” Faced with this dilemma Ward inquired, “What does the court do now?” To decline to decide, he opined, would be an abdication of the court’s responsibility. His solution is “choosing the lesser of the two evils”. So the court must determine what would be “the least detrimental alternative”.

In this search Ward ruled that under English law the parental right to determine the outcome must yield to the judge’s independent assessment of the welfare of each child. This overruling is not to be a lightly undertaken task nor is it to be a substitution of the judge’s values for those of the parents. It is, he insisted, to be imposed only when the court is “judicially satisfied that the welfare of the child requires that the parental right should be suspended or superseded”.

Unlike the Archbishop of Westminster who, following the 400 year old tradition in Western moral analysis that no one need undergo “extraordinary” interventions to preserve life, concluded that the parents retained the right to reject the surgery,¹⁴ Lord Justice Ward insisted that those placed in the dilemmas presented by this case “simply have to choose the lesser of their inevitable loss”. The court gave no rationale for this conclusion other than its belief that this is what caring parents would do. Nor did it offer any justification for the substitution of its way of resolving this issue for that of the parents, other than that the physicians must be free to choose what they are to do in a situation where forced to choose between the conflicting interests of two patients.

In trying to ascertain what is the lesser evil, the court stated its task is to assess the worthwhileness of the proposed surgery for each of the parties. The operation Ward found “will give Jodie the prospect of a relatively normal life”. It would, on the other hand, necessarily shorten Mary’s life. But citing the examples of rabbinical scholars in the 1977 Philadelphia case, Lord Justice Ward declared that Mary is already “destined for death”. She is alive he stated:

Only because.....she sucks the life blood out of Jodie.....Mary’s parasitic living will be the cause of Jodie’s ceasing to live. If Jodie could speak, she would surely protest, “Stop it, Mary, you’re killing me”. Mary would have no answer to that. Into my scale of fairness and justice between the children goes the fact that nobody but the doctors can help Jodie. Mary is beyond help.

Having concluded that the least detrimental choice in the balancing of best interests is the operation that will “kill” Mary to save Jodie, Lord Justice Ward had to determine if the action was lawful. He considered but “fails to see” how the doctrine of double effect can apply when the side effect of the cure for Jodie is Mary’s death. Ward then spoke to the “harsh reality” of the situation—“Mary is killing Jodie”. Her use of Jodie’s oxygenated blood “will cause Jodie’s heart to fail and cause Jodie’s death as surely a slow drip of poison”. Ward then inquired, “How can it be just that Jodie should be required to tolerate that state of affairs?”

Then in language that is quite at odds with both history and his own characterisation of Mary's relationship with Jodie, Lord Justice Ward recoiled at the thought of labelling Mary "with the American terminology which would paint her to be an 'unjust aggressor'". He rejected that phrasing as "wholly inappropriate language for the sad and helpless position in which Mary finds herself". The pedigree of "unjust aggressor", however, is far older than language derived from American tradition. The concept has its origins in just war theory and can be traced back to Plato, Cicero, and Augustine.¹⁵ Further it seems rather tame terminology in the context of the description of Mary as a "bloodsucking, parasitic murderer" used by Lord Justice Ward himself just five pages before his rejection of "unjust aggressor" language.

What makes the operation lawful Ward asserted is that, in effect, it is an act of self defence. The doctors were coming to Jodie's defence and removing the threat of fatal harm to her presented by "Mary's draining her lifeblood". It was in Lord Justice Ward's view such "a plea of quasi-self defence" that makes the intervention by the doctors lawful.

Whatever the analysis of the doctors' action in performing the surgery, it was not self defence. Mary presented no threat to the surgeons. It was not for their wellbeing, but to protect Jodie from Mary's life threatening activities that the physicians would undertake the surgery. The physicians' action is not self defence, but a coming to the defence of an "innocent victim". In the post-Augustinian Christian world acting in such circumstances has consistently been justified as defence against an "unjust aggressor".

Justice Ward compounded the confusion in this area when describing the killing of a 6 year old boy who was indiscriminately shooting playmates in the schoolyard as lawful he commented: "In law killing that 6 year old boy in self defence of others would be fully justified and the killing not unlawful". An ordinary language analysis of the statement makes it obvious that though the killing might be lawful, it is lawful because it is a legitimate defence of others, not self defence.

Lord Justice Brooke discussed further the "doctrine of necessity" in English law. In *R v Dudley and Stephens* (1884) the court did not allow three members of a crew of shipwrecked sailors to kill the fourth member on their 20th day on the open sea and eat him to enable their survival.¹⁶ However, in *R v Bourne* (1939) the principle of aborting an unborn child to save the life of the mother was established.¹⁷ Similarly in the Zeebrugge disaster an army corporal ordered a young man frozen by cold and fear on a ladder to safety, to be pushed off to enable himself and others to climb to safety. This was allowed by the coroner even though it condemned the youth to death. Hence Lord Justice Brooke found four issues arising in criminal law. First, Mary was a human in the eyes of the law, and second the proposed operation amounted to a positive act of killing Mary. Third, the doctors would be held to have

the intention of killing Mary, however little they desired that outcome. Fourthly, however, it would not amount to murder because the defence of necessity would be available.

Lord Justice Brooke's concurring opinion provides a rather strange justification for the surgery. He argued that "the doctrine of the sanctity of life respects the integrity of the body". The proposed surgery, he argued, would give each of the children's bodies "the integrity which nature denied them". Lord Justice Ward gave short shrift to that argument. As he put it, "Such satisfaction [Mary] would enjoy from having a body of her own is illusory". As a result of the attempt at separation Mary would die. She would, in fact, be dead before the separation which confers the "bodily integrity" is completed.

In his separate opinion Lord Justice Walker confirmed that the parents' position, while controversial, was "not obviously contrary to any view generally accepted in our society". And, he noted that it would be even less controversial in the remote community from which they had come in search of medical advice on their children's physical condition. Walker made yet a different attempt to justify the separation. He argued that if Mary had been born with a definitive brain, heart, and lungs and was dependent not on Jodie, but machines, "it would be right to withdraw that artificial support and let her die".

The question in this case is not the legitimacy of an operation to separate conjoined twins even if the procedure results in the death of one twin. That question was fairly well resolved over a decade ago in the Philadelphia cases, but perhaps not until this case by the English courts. The question here is the legitimacy of performing a life ending separation over the objections of the parents. Put starkly, the issue is "Whose decision is it anyway?"

The judges insisted that under English common law once a legal challenge was made to the parents' choice, it was not the reasonableness of the parents' choice, but the judge's independent assessment of the child's best interest that must prevail. This was to occur even if the parents' judgment was perceived by the judge himself to be "pre-eminently reasonable" and one well within existing societal norms. Having adopted that position, the judges on the Court of Appeal found that in the circumstances of this case "we see no other way of dealing with [the case] than by choosing the lesser of the two evils".

The judges in dismissing as the language of "unjust aggressor" or the long standing principle of double effect, had, in effect, boxed themselves into adopting the very approach they dismissed as unwarranted: a utilitarian calculation of lives saved. And though they decried substituting a judge's value for that of the parents, they proceeded to do just that when they imposed on the parents their own interpretation of the best interests of the child.

This intervention appears to have flown in the face of the judgment in *Re T* (1997) where the Court of Appeal upheld the objections of (equally) devoted parents to having their 18

month old child undergo a liver transplant recommended by the medical team.¹⁸

It also ignored the advice of Sir Thomas Bingham MR in *Re Z* that the decision of a devoted and responsible parent should be treated with the utmost respect.¹⁹ It should not be disregarded or lightly set aside. Yet in this case the values of the clearly devoted parents were overturned by the judgment of the court.

The tragedy in this case beyond the pitiful plight presented by the pregnancy is the oversimplification and over-reaching by both the Archbishop of Westminster and the Court of Appeal. The Archbishop's brief suffers from the flaw that mars most legal briefs: it provided one sided argument in favour of a desired position. To state, as did the Archbishop, that respect for the rights of both their children made any other choice on their part "morally impossible" is to ignore the consistent Catholic teaching, held from St Thomas' 13th century formulation through to the present day, that the principle of double effect would support a parental decision to authorise the surgery. It is also to ignore the even older Catholic moral tradition that it is legitimate to "repel" someone who unjustly threatens an innocent life, even to the extent of taking the life of the one whose actions endanger the innocent victim. The failure of the Archbishop to explore the full range of the rich and highly nuanced Catholic teaching in this area is a disservice to others who may someday face the awful and agonising choice confronting the parents in this case. Rather than truncate the long standing moral tradition of these issues, the Archbishop could and should have made it clear that in this situation it would have been equally acceptable within traditional moral principles to opt for the surgery in hope of saving the child whose heart is temporarily sustaining both lives or to reject it as a disproportionately burdensome medical intervention.²⁰

The Court of Appeal likewise went too far in its assertion that faced with the situation the parents confronted the decision maker must choose "the lesser evil". That is a choice these three judges made in the case. It is also, perhaps, the choice they would make if they were in the parents' position. But as Lord Justice Ward made clear, the parents' choice of letting nature take its course was "pre-eminently reasonable" and one acceptable to the community.

It is not for these writers to tell jurists how to read the demands of the English common law. But it is to be hoped that if confronted with a

similar situation judges in other jurisdictions would heed Justice Benjamin Cardozo's insight in *The Nature of the Judicial Process* where he wrote:

*The judge, even when he is free, is still not wholly free. He is not to innovate at pleasure. He is not a knight-errant, roaming at will in pursuit of his own ideal of beauty or goodness.*²¹

Commenting on that observation in a dissent in the famous *Georgetown* case, in which the DC Circuit Court of Appeals upheld a decision to force a blood transfusion on an adult Jehovah's Witness, Judge Warren Berger (later the Chief Justice of the United States Supreme Court) noted, "We should heed Cardozo's counsel of restraint and reconcile ourselves to the idea that there are myriads of problems and troubles which judges are powerless to solve; and this is as it should be".²²

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