The decision (Baek 2016) to discharge an incapacitated patient who had endured severe diffuse axonal injury, so that he could die at home, raises two critical questions for critical care: Which principles should inform the resolution of such cases, and by which processes should decisions be reached? I reflect on how this case might have been viewed in the United Kingdom (and under English law specifically). I query whether the likely response would have been one of principled pluralism or indefensible inconsistency, and consider which principles and processes might guide the resolution of such cases.

PRINCIPLES, PROCESSES, PROBLEMS?

Had this patient’s fate been subject to the principles and processes of English law (essentially, the law of England and Wales), his family and clinicians would have been bound by the terms of the Mental Capacity Act 2005. The Mental Capacity Act, which came into force in 2007, allows those currently possessing capacity to make provision for a future in which they lack the capacity to decide (non)treatment matters for themselves. First, an individual can make an “advance decision to refuse treatment,” which, if it is to bind the clinicians, must be valid and applicable to current circumstances and, if it is to decline lifesaving treatment specifically, must say so explicitly in writing and be signed and witnessed. Second, and perhaps additionally, the individual can appoint a “welfare attorney” to decide on his or her behalf—although, again, the appointment of this “lasting power of attorney” must explicitly confer the power to decide on matters of life or death. Notably, however, the welfare attorney is legally bound by the overarching obligation to serve the patient’s best interests. It is this test, familiar across the world, that also determines the fate of those (many?) who have not made an advance decision to refuse treatment. Section 4 of the 2005 Mental Capacity Act provides some indications as to how an individual’s best interests are to be interpreted: “So far as is reasonably ascertainable,” reference should be made to the individual’s “past and present wishes and feelings,” the “beliefs and values” that would be likely to influence their decision, plus “any other factors” they would be likely to consider if able.

The best interests standard had long occupied English law and thus guided clinicians and, indeed, judges in their decisions (not) to treat. For their part, the judges continue to undertake a balancing exercise, identifying factors for and against the proposed course, in order to reach their decisions. There may be something positive in the availability of an independent and authoritative forum to decide contested or complex cases. Yet whether the judges are reaching the right decisions in such cases remains an enduring question. Certainly, the English judges are familiar with patients, like this one, who are afflicted with a disorder of consciousness. Indeed, if clinically assisted nutrition and hydration (CANH) is to be withdrawn from a patient in a permanent vegetative state or in a minimally conscious state, then the court’s view must be sought (Huxtable 2012). The former category of cases nowadays routinely receive the same answer (which understandably leads commentators to query why the requirement for judicial sanction persists; Halliday, Formby, and Cookson 2015): Treatment can be withdrawn, in the patient’s best interests (Huxtable 2012). In such cases, the judges tend to favor quality over quantity of life.

Elsewhere, however, the judges appear less certain about which value(s) should be their guide when determining the best interests of an incapacitated patient. This theme is most vividly exemplified in recent rulings related to the (non)treatment of minimally conscious patients. CANH continues for one such patient, contrary to the wishes of her family and their evidence that she would...
want treatment to stop; according to the judge, “The importance of preserving life is the decisive factor in this case” (W v M 2012). But CANH is withdrawn from another such patient because “respect for [her] dignity and human freedom overwhelms further prolongation of life” (M and Mrs N 2015).

Perhaps there is also something positive to be said about the judges’ openness to value pluralism in their dealings with the best interests standard (Huxtable 2013). But their pluralism might be our inconsistency: Perhaps, on a more critical reading, the judges are sacrificing a principled stand in favor of capricious subjectivity. Since Baek’s patient fell short of a persistent vegetative state (PVS) diagnosis, we are left uncertain as to his likely fate, had he been subject to English law. Such indeterminacy can only undermine the law’s action-guiding function (Huxtable 2012). It appears, then, that we must look beyond law, to the values at stake, to determine how this patient’s case should have been resolved.

CONQUEST, CONSENSUS, COMPROMISE?

Guided by the patient’s family, the clinicians in Baek’s case chose to favor (precedent) autonomy, which inclined them toward non-treatment and palliative care. An advance decision tends to be viewed as the gold standard expression of precedent autonomy, but few people formally set down their wishes in such ways, and their creation, interpretation, and application are beset with difficulties (Huxtable 2015). In the absence of such a binding directive, the patient’s views and values form only part of the broad assessment of their best interests. Allowing the patient’s assumed views and values to determine the final course in such circumstances might therefore require some bravery on the part of theclinicians and family, as was arguably the case here.

Best interests is, after all, a broad concept, which can accommodate a plurality of potentially competing values, such as those that prioritize the patient’s preferences (as here), the patient’s quality of life, or more objective values, including the value of life itself (DeGrazia 1995). The decisive conquest of one such value or cluster of values looks like a false hope—questions will rightly continue to be asked about whether it should be this or that value, how the value is to be understood and applied, and so on (Huxtable 2012). It would also be foolish to hope for consensus, at least in every case; the key stakeholders may have agreed in Baek’s case (although one is left to ponder the views of the nurse who feared that non-treatment might amount to physician-assisted dying), but this will not always be an option, and maybe understandably so, given the enduring rivalry of different ethical opinions.

Perhaps, then, the judges are onto something: There is merit in value pluralism. Some scrutiny of the values is nevertheless itself merited, but the judges—in England, at least—have proven less willing (or able?) to apply such scrutiny, with English law appearing increasingly “de-moralized” (and clinicians becoming correspondingly de-moralized) (Montgomery 2006).

Here, then, a plea arises for a different process, one in which the values questions are confronted head on. The stakeholders in Baek’s case availed themselves of just such a mechanism, in the form of a bioethics consultation. Given their remit, clinical ethics support services seem capable of providing the necessary ethics injection, but they too invite scrutiny. In light of the enduring values conflicts, it seems advisable that such a process be pluralistic in outlook. However, as Baek implies, it should also be critical in orientation—rigorously sifting through the values at stake, and seeking to navigate a way through ethically choppy waters. Such a process might occasionally create consensus, and it might sometimes lead the participants to converge on a conquering value, both of which appeared to occur in Baek’s case. But a third option might also present itself in such processes: Compromises might be crafted, which manage to attend appropriately to the different voices and values. Compromise can be a dirty word, particularly where morality is concerned, but sometimes compromise will be indicated by enduring ethical or medical uncertainty (which was present, to some extent, in Baek’s case) (Huxtable 2012).

CONCLUSION

Of course, compromise was not needed in Baek’s case, and it is notable too that the process there (commendably) involved hearing from all of the affected parties. This is not always the case, including in the United Kingdom, where clinical ethics committees apparently seldom hear directly from family members (Newson 2009). Moreover, and certainly in the United Kingdom, there has been criticism of some clinical ethics support services for their alleged lack of robust “due process” and for their variability in training, competencies, and standards (McLean 2008). Perhaps, in such matters, the courts still have the edge. But, as we have seen, the judges seem reluctant to peer too closely at the values at stake.

Maybe, for now, we need these distinct bodies to coexist, each filling the gaps of the other. Of course, in an ideal world, we would need neither courts nor clinical ethics support services—clinicians and families, plus patients where they are able, would navigate the aforementioned ethically choppy waters together, to arrive at a safe destination. In our world, however, some degree of oversight and independent input seems likely to be warranted in complex or contentious cases, so we should continue to ponder not only the principles, but also the processes, available for resolving such cases.

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Actions Can Speak Louder Than [Written] Words: Surrogate Decision Making Based on Stated Preferences

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Baek (2016) eloquently recounts the case of an unfortunate gentleman who sustained a severe neurologic insult and had a poor likelihood of meaningful neurological recovery. This report is illustrative of heart-wrenching cases encountered daily across the health care spectrum—where the surrogate’s beliefs, patient’s wishes, and lack of advance care preference documentation make clinical decisions challenging. While we support Baek’s overall conclusions and believe this case highlights many important points, we believe some issues require further clarification and exploration prior to drawing conclusions. In particular, we begin with the notion that the decision to focus on comfort care was supported despite the fact that “the patient did not have a progressive condition.” Prioritization of a comfort-directed strategy comports with the law and medical practice, whereby patients (or their surrogates) maintain not the right to die, but “the right to be left alone” and have unwanted interventions discontinued when not consistent with their goals, values or preferences. As such, the lack of a progressive condition becomes secondary in this case and many other cases like it.

This case highlights the importance of both advance care planning, and how to go about shared decision making when such plans are absent. The patient was noted to have undergone tracheostomy and gastrostomy tube placement at the referring hospital prior to transfer, and Baek reports that conversations about the patient’s previously expressed preferences and values “did not occur . . . because of the haste in managing his acute state and the uncertainty of his long-term prognosis” (Baek 2016, 65) We would argue that a decision to perform these nonemergent procedures without the informed consent of the patient and/or surrogate violates a patient’s autonomy and in many situations could violate the law (Swetz, Hook, and Mueller 2013).

It appears that the initial lack of shared decision making allowed for the patient to receive treatments that may have been against his previously expressed wishes,