

# The challenge of Terri Schiavo: lessons for bioethics

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Time to redefine the ethical principles of care for restricted people

The extremely emotional, extraordinarily public battle in the USA over the fate of Florida woman Terri Schiavo presents a fundamental challenge to what most medical and legal ethicists have long assumed to be long settled issues of care for restricted persons. It is not that currently accepted procedures, and the ethical framework on which they are based, are wrong, just that they are again up for grabs.

Professionally accepted definitions of medicolegal states—"terminal condition", "persistent vegetative state", "quality of life", and "best interests" in "end-of-life" cases, for example—have been challenged by those who sought Mrs Schiavo's continuance rather than her death by dehydration and starvation following removal of a feeding tube in place since 1990. These definitions are at the operational heart of operative principles that are similarly critiqued by those arguing, on Mrs Schiavo's behalf, the ethical primacy of a "sanctity of life" principle and a definition of protected personhood based on more than the discrete physical self.

What results is a fundamental challenge to broadly accepted bioethical constructs rather than, as others have assumed, either uninformed, biased reportage by a rampant press<sup>1</sup> or the "hijacking" of a relatively simple case by "disability activists".<sup>2</sup> A more recent if similarly dismissive explanation, that religious and political conservatives have inappropriately politicised the case, similarly fails as a vehicle for understanding the issues engaged in the debate over Mrs Schiavo's continuance or termination.

Reportage in major newspapers has been exhaustive but generally even handed, attempting to present the arguments of all in a case where language and definitions change from speaker to speaker.<sup>3</sup> And while some advance a "disability perspective" in this case their argument both precedes the current controversy and extends well beyond it to other areas of bioethical debate.<sup>3</sup> The Schiavo case may better be understood as the broadly public embrace of a more general disability critique of bioethics that has been extensively argued both publicly<sup>4</sup> and in the literature.<sup>5</sup> The challenge for bioethicists is to first

## Abstract

This essay reviews a range of issues arising from the complex case of Terri Schiavo and the lessons the case raises for bioethicists. It argues that embedded in the case is a broader controversy than is immediately evident, one involving the definitions by which bioethics judge cases of extreme physical and psychological limits, in its principled form of address. Further, it argues that bioethicists who assume the issues involved in the case are settled miss the point of the emotional responses it has brought forth.

accept that a challenge exists and then to identify the specific, relevant issues they might wish to engage.

## DEFINITIONS

Since her collapse in 1990, Mrs Schiavo had been assumed to be in a "persistent vegetative state", legally defined in a Florida statute as a "permanent and irreversible condition of unconsciousness" from which no recovery is possible.<sup>6</sup> Withdrawal of nutrition and hydration permitting a "natural" death was therefore appropriate in a "terminal condition" like Mrs Schiavo's where end-of-life protocols are legally permitted in Florida statutes for "end-stage" cases.<sup>7</sup>

Those seeking Mrs Schiavo's continuance argued, however, her condition was only "end-stage" and "terminal" when hydration and nutrition were removed. Her life might have continued for years had her care continued. In this construction withdrawal of hydration and nutrition is active euthanasia neither warranted clinically nor to be accepted ethically. Simply, advocates of her continued care reject the argument that cessation of life support, prohibited in all other situations, is acceptable when physical or cognitive limits are defined as extreme.

More concretely, some challenge the diagnosis of persistent vegetative state itself as uncertain and open to challenge. This argument is given weight in a series of clinical studies published in recent years. Shewmon,<sup>8</sup> for example, argues that contrary to standard definitions we cannot state categorically that the vegetative state is defined by a total loss of cortical function. Others studying patients diagnosed as vegetative—a term many critiques reject as demeaning<sup>9</sup> have found that between 12% and 34% of patients diagnosed as

persistently vegetative are at least minimally conscious and may respond to therapy.<sup>10</sup>

## Suffering and "quality of life"

For some bioethicists the niceties of these distinctions are largely irrelevant. A person in Mrs Schiavo's obviously limited state is "suffering" from an unacceptably minimal "quality of life" that may be "naturally" ended by the withdrawal of hydration and nutrition. In such situations euthanasia is permissible, and in Helga Kuhse's words, "doctors should be permitted to give death a helping hand".<sup>11</sup>

If all cerebral function had ceased Mrs Schiavo could not have been suffering, however. And if she had been even minimally conscious then death by starvation and thirst would themselves have caused suffering that cannot, critics say, be supported. The doctor's "helping hand", encouraged by some bioethicists, seen from this perspective is malicious. To assume there is no "benefit" to continuation because treatment will be "futile",—with no curative value<sup>12</sup>—imposes upon the patient a doctor's frustration at being unable to do anything but maintain his or her patient in a limited state.

Further, arguing that Mrs Schiavo's quality of life was insupportable, and death therefore preferable to continuation, conjures for some the eugenic arguments famously argued by Binding and Hoche in 1920s Germany,<sup>13</sup> and more generally by US eugenicists from Haiselden to Mr Justice Oliver Wendell Holmes in the famous US Supreme Court decision *Buck v Bell* (for a comprehensive review of this history see Pernick, 1996<sup>14</sup>).

This critique empowers a radically different reading of not simply appropriate behaviour in the Schiavo case but in

a range of situations—genetic, neurological, and post-traumatic injury—involving those with physical and cognitive limits. From this perspective the battle over Terri Schiavo's continuance was a special case within a far broader field of dispute over the legitimate rights of restricted persons and the broader duty for their continuing care. The importance of this challenge, and the strength of its argument, is signalled by US Congressional and state legislative involvement in this case. To the extent law reflects the ethics of a population, arguments in this case signal the rise of an ethical and moral construct strongly opposed to accepted standards of practice currently codified in law and the bioethics literature. For those who argue Mrs Schiavo's continuance, and by extension that of others in physically or cognitively limited states, legislatures are the appropriate place to seek longer term relief, replacing codes informed by one ethical perspective with another.

### Personhood

Perhaps the central issue in ethics and law is what we mean by personhood within the circle of protected life. Among Mrs Schiavo's supporters, and more generally within some disability communities, personhood is not an existential attribute based upon cognitive or physical abilities but a communal attribute whose meaning is grounded in one's relationship to others.<sup>15</sup> In this construction Mrs Schiavo was a person equal to others because her parents said she was and her continuance had been mandated by their historically anchored, unwavering commitment to that relationship's continuance.

The argument finds some support in the literature of medical ethics and bioethics. The enduring popularity of Oliver Sacks's work—from *Awakenings*<sup>16</sup> to *An Anthropologist on Mars*<sup>17</sup>—is based in large part on his insistence that even the most extreme neurological conditions deny neither personhood nor the duty to care. In this construct the sustaining relation need not be reciprocal to be respected. "I see how you love her", Sacks says to the father of an autistic artist.<sup>18</sup> "Does she love you, too?" The answer, one Sacks obviously accepts as sufficient, is: "She loves us as much as she can."

Stephen G Post implies a similar valuation when he considers a Cleveland man who lovingly maintains his persistently unconscious wife. "Even the PVS conditions does not disqualify a loved one from equal moral standing. ... It further suggests that the concept of quality of life might be replaced by the quality of lives, including family members."<sup>19</sup> The result is a duty to care

for the person the family member perceives as a person-in-relation.

The distance between this definition of the person and one of the person as a discrete, existential being lies at the heart of a now famous exchange between disability rights lawyer Harriet McBryde Johnson and Princeton University bioethicist Peter Singer<sup>5</sup> (for a detailed analysis see reference 3). She described a family's caring at home for a persistently unconscious teenager as "beautiful", an act that Singer thought somewhat "weird". The gulf between their ethical frames was sufficiently severe to prevent either from clearly arguing the primary values and resulting constructs that resulted in the apparently aesthetic judgements.<sup>20</sup>

It may be this sense of personhood as a shared rather than discrete quality that fuelled the extraordinary public demonstration of support for Terri Schiavo's survival. For those protesting the withdrawal of hydration and nutrition, the act of demonstration served in itself as affirmation of Mrs Schiavo's personhood and thus her place within the protected circle of the state's "life interest" in its citizens. The unprecedented political involvement of the Florida State Legislature and the US Congress in the Schiavo case is, from this perspective, wholly appropriate. Where else in a democracy do citizens turn when they believe current policy and law are inappropriate, prejudicial, and unethical? When courts cannot offer redress the logical next step is to seek legislation that will alter the laws in a manner that permits future judicial support.

### Sanctity of life

The central concern of Mrs Schiavo's supporters appears to be that physical continuance is lexicographically a primary value violated by the discontinuation of her nutrition and hydration. That many who so argued in the Florida case did so from a religious perspective is neither surprising nor relevant. The operative law and ethic in North America, as it is in Europe, is at heart Judeo-Christian. The "sanctity of life" argument espoused by many in this case has deep roots in that tradition as well as a long secular tradition.

Peter Singer's famous declaration that "after ruling our thoughts and our decisions about life and death for nearly two thousand years, the traditional western ethic [of life sanctity] has collapsed" was clearly premature.<sup>21</sup> The Schiavo case signals a resurgence of this collapsed ethic as a lexicographically superior, primary value, one in which the default remains life sanctity irrespective of "quality". Whether those

arguing a "culture of care", will do so uniformly and realistically—embracing the increased taxation a fully caring culture assuredly would require, for example—is a separate if important issue.

### CONCLUSION

The story of the public debate surrounding Terri Schiavo should impress upon laypersons and professionals alike the uncertainty of the context in which issues of continuation and termination are argued ethically. Nobody knows what Mrs. Schiavo would have wanted. She left no advance directive and in its absence her husband says one thing and her parents another. While the husband is the typical surrogate in this case his status has been challenged for a decade by her parents. Similarly, we do not know to an absolute certainty her cognitive status. Was she "minimally conscious" or permanently unconscious? In either case we do not know to an absolute certainty whether or not she sensed any discomfort from dehydration and starvation, or anything else. Our neurology is insufficient to make a definitive determination.

These uncertainties pale before the greater one: What is the ethical frame in which such cases should be judged? Bioethicists who assume the facts are clear and the frame for their application self-evident dismiss the concerns of those who coherently argue from a different ethical framework. The result will be to marginalise their own position, assuring their status as non-participants in the ethical, moral, legal, and political debates this case generally promotes.

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