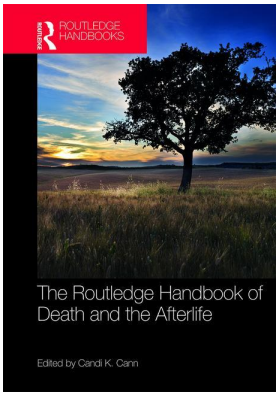

The Routledge Handbook of Death and the Afterlife

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Brain death and the politics of religion

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BRAIN DEATH AND THE POLITICS OF RELIGION

Donald Joralemon

1 When dead isn't

New Jersey Assemblyman Richard Kamin (Republican, Morris County) said in December 1990, 'Death is not a religious or moral belief. Death is a matter of scientific fact' (Schwaneberg, 1990b). There are two ways to be legally and medically declared dead in the United States. One is by the irreversible cessation of cardiac and pulmonary activity; this is the conventional definition of death that has deep roots in human history. The second is by the determination of catastrophic and permanent loss of neural functioning, at both the cortical and brain stem level (Determination of Death by Neurological Criteria, DDNC). This definition of death emerged along with, and in support of, organ transplantation, permitting the removal of still viable organs from a person whose metabolic functioning can be mechanically sustained right up to the moment of harvesting. It has been considered critical that the 'whole brain' definition be applied so as to distinguish the total loss of neural activity from vegetative states, in which the brain stem continues to function. However, despite this distinction and even with over a half-century of application, the second pathway to a death diagnosis remains contentious (Johnson, 2016).

Early in the morning of November 26, 2013, 33-year-old Texan Marlise Muñoz went to the kitchen to prepare a bottle for her infant son when she collapsed from what doctors subsequently determined was probably a blood clot in her lungs. She laid on the floor for an hour without breathing before her husband, Erick, found her and, applying his paramedic training, began cardiopulmonary resuscitation. She was transported by ambulance to Fort Worth's John Peter Smith Hospital (JPSH) where emergency staff sought in vain to save her life. That same day – Thanksgiving Day – she was declared brain dead.

Under most circumstances, Marlise's body would have been transported to the morgue or, if she declared herself an organ donor, to the operating room for the removal of organs to extend the lives of patients on the transplant waiting list. But Marlise was 14 weeks pregnant. Doctors explained to her husband that a section of the Texas Health and Safety Code (Section 166.049) prohibits the withdrawal or withholding of life-sustaining treatment from a pregnant woman and that they would, therefore, not take Marlise off the devices that were keeping her heart pumping and blood flowing. To do otherwise, they argued, would subject the physicians and the hospital to homicide charges, since the Texas Penal Code §1.07 defines murder as intentionally causing the death of an 'individual,' a legal term which in Texas explicitly includes 'an unborn

child at every stage of gestation from fertilization until birth.' Some of those who rallied against Erick's insistence that his wife was dead and should be removed from the medical technology, most notably members of pro-life organizations, directly rejected the validity of brain death and insisted that two lives were on the line. State District Judge R. H. Wallace heard Erick's legal suit and decided that Mrs. Muñoz was dead. Judge Wallace ordered the removal of assist devices no later than January 27 – the hospital did not appeal.

On December 9, 2013, medical staff at the University of California San Francisco Benioff Children's Hospital (BCH) in Oakland, CA, performed a tonsillectomy and adenoidectomy on a 13-year-old girl, Jahi McMath, to resolve her sleep apnea. Profuse bleeding from her nose and mouth during recovery quickly led to a heart attack due to blood loss. A long resuscitation effort re-established a heartbeat with the assistance of a ventilator, but Jahi's brain had been deprived of oxygen for so long that, on December 12, she was declared brain dead. A week later her mother, Latasha Winkfield, filed suit to stop BCH from disconnecting Jahi from the ventilator. She did not accept that Jahi was dead and told reporters that God may 'spark her brain awake.' She said that Jahi would only be dead when her heart stopped.

What these two recent cases have in common is religiously inspired rejections of brain death protocols. For Marlise Muñoz, it was the extension of personhood to the moment of fertilization, a core tenet of Catholic and Evangelical doctrine, which interfered with the ordinary management of a brain dead person. For Jahi McMath, it was her mother's religious faith in a miraculous recovery for her daughter that resulted in legal action to stop the removal of mechanical assist devices. In both instances, there were ample legal precedents and solid physiological data supporting diagnoses of brain death.

These are the well-publicized cases in which brain death determinations have run afoul of religious faith, but it is likely that there are many other such disputes. For example, in New York a young adult Jewish male with a diagnosis of a particularly aggressive form of brain cancer (Glioblastoma Multforme) had spiraled downhill as the tumorous growth spread. His parents and younger siblings demanded aggressive care even after physicians explained that a prolonged period of unresponsiveness indicated he was likely brain dead. The family stood sentry at the patient's room to stop the mandatory confirmatory tests for brain death from being performed and demanded that their son/brother be transported to Israel for 'alternative therapy.' Some Orthodox Jews reject the idea of brain death. In this case, the patient was transferred to an acute long-term facility in neighboring New Jersey. To the best of my knowledge, this drama never generated headlines.[1] I suspect that there are many similar cases that go unreported.[2]

What are we to make of these contests over the legitimacy of brain death determinations? I argue that they reflect a growing movement in the United States that pits religious belief against medical knowledge, with increasing legislative might supporting the claim that, as a matter of civil law, religiously grounded beliefs must be rigorously protected. To make my case, I turn to the concept of 'religious exemptions' as it has been applied to public policies related to brain death in the states of New York, California, and New Jersey; as well as to the proliferation of so-called Religious Freedom Restoration Acts (RFRA) across the country. I conclude with thoughts about the relationship between these religiously inspired objections to medical practice and the First Amendment of the U. S. Bill of Rights, which both protects religious expression and prohibits government sponsorship of specific religions.

2 Accommodating religious views

The United States is not alone in having seen objections raised to the application of brain death definitions. There is well-documented resistance to the concept in countries around the world

such as Mexico (Crowley-Matoka, 2016), Egypt (Hamdy, 2012), Iran (Yousefi, Roshani and Nazari, 2014), Nigeria (Rabiu, Oshol and Adebayo, 2016), Japan (Lock, 2002), England (Kierans and Cooper, 2011), Germany (Hogle, 1996), Norway (Hadders and Alnæs, 2012), and others. In some cases, it is the uncertainty of medical staff and the language used to convey the death determination that contributes to resistance on the part of surviving family. In other instances, it is suspicions among minority populations about the medical profession and its vested interest in securing organs for transplantation. Significant variations in the diagnostic procedures used to determine brain death also lead to reservations about the brain death concept. Perhaps the most frequent source of family resistance is the common-sense disconnect between the meaning of 'dead' and the appearance of a person still connected to medical support technologies and manifesting signs of continued life. Each of these sources of resistance can be based on fully secular objections and they are often resolved by better and more sensitive communication procedures, although not necessarily ending with consent for organ donation.

It should come as no particular surprise that the determination of death by brain criteria would generate objections based on religious beliefs in the United States. Think of all the points of contention that have emerged in just the past decades over medical practices in America because of conflicts with faith positions: abortion, contraception, embryonic stem cells, cloning, physician-assisted death, withdrawal of hydration and nutrition for persons in vegetative states, vaccinations, artificial reproduction – the list goes on. However, this particular religious objection is unusual in that it opposes a medical category that is firmly established in both federal and state law – not to mention international conventions – and is intricately tied to a medical procedure (organ transplantation) that enjoys widespread approval. Even so, three states (New York, California, and New Jersey) have judged objections to brain death diagnoses on religious or moral grounds worthy of accommodation.

For nine years, beginning in the late 1970s, the New York State Medical Society urged the Legislature to adopt a law acknowledging the legal status of brain death diagnoses. At the time the only protection physicians had from accusations of homicide when they terminated treatment for a brain dead person was an Appeals Court decision (*People of New York v. John Eulo v. Robert Bonilla*, 1984) blocking the claim of two convicted murderers that the removal of life support, not the injuries they caused, was responsible for their victims' deaths. That decision concluded,

> The term "death" . . . may be construed to embrace a determination, made according to accepted medical standards, that a person has suffered an irreversible cessation of breathing and heartbeat or, when these functions are artificially maintained, an irreversible cessation of the functioning of the entire brain, including the brain stem.'

Notwithstanding this judicial protection, New York physicians demonstrated a reluctance to act on brain diagnoses, resulting in unnecessary and expensive medical care performed on what were, from a medical perspective, cadavers, as well as long delays for families anxious to put an end to their own uncertainty. The Medical Society insisted that this terrible situation could only be remedied by legislative action; instead, Governor Mario Cuomo appointed a thirty-one-member 'State Task Force on Life and the Law' to develop guidelines for the determination of death. The resulting *Guidelines for Determining Brain Death* (2011) required all New York State Hospitals to develop written policies that identify the procedures and tests for a brain death diagnosis, that provide standards for notifying next of kin that such tests and procedures are in progress, and that offer 'reasonable accommodation of an individual's or Surrogate Decision-maker's religious or moral objection to the use of the brain death standard to determine death' (p. 3).

The *Guidelines* offer little direction as to what 'accommodations' should include, beyond a vague reference to 'the continuation of artificial respiration under certain circumstances.' They do require that the duration of the accommodations be specified, and that persons and groups to whom objections might be addressed – 'clergy members, ethics committees, palliative care clinicians, bereavement counselors and conflict mediators' – should be identified. Perhaps most interestingly, the *Guidelines* stipulate that objections that are based solely upon 'psychological denial that death has occurred or on an alleged inadequacy of the brain death determination' and not on moral or religious beliefs, are not due reasonable accommodation (p. 4). The document is silent on the question of how physicians are to distinguish denial from religious or moral beliefs.

California's 'Accommodations and Brain Death Act' (Cal. HSC. Code §1254.4, enacted in 2009) adopts a position similar to New York's *Guidelines*. It requires 'reasonable efforts' to accommodate objections to a brain death determination voiced by family or surrogate decision-makers on the basis of 'religious or cultural practices.' Like New York, the legislation leaves it up to the hospital to define what is reasonable, but it demands consideration of the 'needs of other patients and prospective patients in urgent need of care' (Cal. HSC. Code §1254.4).

The state of New Jersey took a different path to brain death. After extended and contentious debate in the legislature, the 'New Jersey Declaration of Death Act' (P.L. 1991, Chapter 90, Codified as Chapter 6A of Title 26 of the Revised Statutes) was passed by the senate and assembly, and signed into law by Governor Jim Florio on April 8, 1991. An amendment that was taken out and then re-inserted states:

> The death of an individual shall not be declared upon the basis of neurological criteria pursuant to sections 3 and 4 of this act when the licensed physician authorized to declare death, has reason to believe, on the basis of information in the individual's available medical records, or information provided by a member of the individual's family or any other person knowledgeable about the individual's personal religious beliefs that such a declaration would violate the personal religious beliefs of the individual. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-respiratory criteria pursuant to section 2 of this act.
>
> *26:6A-5*

This is the only statutory exemption to brain death for religious objections in the United States and it goes further than New York's *Guidelines* by specifying the remedy: requiring that only a cardio-respiratory determination be applied in such cases. Unlike New York's policy, the New Jersey law only accepts 'personal religious beliefs' – not moral objections – and makes no mention of psychological denial. The text was not without opposition from legal, medical, and organ transplant groups. For example, Tony Pizzutillo, a lobbyist for a coalition of legal and medical groups (e.g. the New Jersey Hospital Association, the State Bar Association, the New Jersey Organ and Tissue Sharing Network, the New Jersey Medical Society, and the State Nurses Association) said that his clients are 'highly uncomfortable with allowing medical science to be meddled with by religious beliefs' (Schwaneberg, 1990b). Dr. Abbott Krieger, chief of neurological surgery at the University of Medicine and Dentistry of New Jersey, insisted that 'this is a medical decision. Once a person is brain-dead, they're dead' (ibid.).

On the other side, Rabbi Shmuel Blech, a member of the state Bioethics Commission that drafted the law, argued that, '[w]e ought not to deny those who have religious reason for interpreting death as their forebears did their rights under the law' (Schwaneberg, 1990a). Others testified that the exemption would be 'an expression of the state's commitment to religious liberty' (ibid.). State Senator Gabriel Ambrosio (Democrat, Bergen) made the odd claim, given

the medical reality of brain death, that a 'patient does not lose his or her rights just because of a debilitating illness' (Schwaneberg, 1991).

New Jersey's solitary status as a legal refuge for brain death objectors has resulted in it being the destination for families battling to avoid, or void, death determinations in other states. The young Jewish man transferred to a New Jersey care facility is not alone. Jahi McMath was also moved to the Garden State when a California court opened the door to her family to take charge of her care. Although I have not found any record of the number of such transfers, I strongly suspect that these are not the only cases. At the same time, it would be a mistake to treat New Jersey as a singular supporter of religious exemptions. We need to put these three states' protections in the wider context of national efforts to grant religious beliefs special consideration under a variety of healthcare mandates. The proliferation of so-called Religious Freedom Restoration Acts suggests a broader movement in the contest between medicine and politics in the United States.

3 The scope of the religious exemption

It is beyond the focus of this writing to rehearse the U. S. legal history of religious protections, beginning with the First Amendment of the Bill of Rights and its guarantee of free exercise of religion and proceeding to the highly contentious Hobby Lobby decision (*Burwell v. Hobby Lobby Stores, Inc.*, 2014), which granted for-profit corporations operated by Christians an exemption from the 'Contraception Mandate' in the Affordable Care Act. Suffice it to say that over the last twenty-five years there has been what Professor John Witte Jr., director of the Center for the Study of Law and Religion at Emory University, calls 'a sort of religious affirmative action program' that has carved out 'more than 200 special arrangements, protections or exemptions for religious groups or their adherents' (Henriques, 2006). These range from regulatory exceptions for day-care centers associated with religious institutions to special treatment in zoning and taxation decisions for the construction of faith-related facilities.

When weighing the responsibility of state and federal authorities to avoid or mitigate burdens on religious freedom resulting from laws or policies two different standards have been applied. The first demands that any law or policy that imposes a burden on religious liberty has to be justified by proving a compelling governmental interest and by demonstrating that the least restrictive means possible has been adopted – this is the so-called strict scrutiny model. The second approach, applied in the important Supreme Court decision in *Employment Division v. Smith* (1990),[3] permits the burden of religious liberty in the application of laws if those laws do not single out religious institutions or practitioners (neutrality) and are generally applied. Under this standard, claimants would have to prove that a law disproportionately harms them and their free exercise of religious belief. The reasonableness of the law itself would not be at issue, only whether it is equitably applied.

In the wake of the Smith decision, Congress debated and passed the 'Religious Freedom Restoration Act' (RFRA) that President Clinton signed into law (Pub. L. No. 103–141, 107 Stat. 1488, November 16, 1993) requiring that the courts return to the 'strict scrutiny' standard. The relevant passage of the Act reads:

> Government shall not substantially burden a person's exercise of religion even if the burden results from a rule of general applicability, except . . . if it demonstrates that the application of the burden to the person: 1) is in furtherance of a compelling governmental interest; and 2) is the least restrictive means of furthering that compelling governmental interest.

Soon after passage of the Act, the Supreme Court ruled that it was unconstitutional as applied to state laws. A claim could be made against a federal law considered burdensome, but the federal government would exceed its constitutional mandate were it to step in to arbitrate disputes over state laws. This decision, in turn, stimulated a proliferation of state RFRAs, designed to make sure that the strict scrutiny required by the federal law would apply as well in local jurisdictions. As of 2015, twenty states had adopted their own versions of the federal RFRA and an additional six states had such laws pending approval (Johnson and Steinmetz, 2015). It should be added that the laws show significant variation (Lund, 2010).

I can't draw a direct line between RFRAs, at either the state or federal level, and the attempts by New York and New Jersey to offer accommodation to religious objections to brain death determinations since neither state has adopted such legislation.[4] However, I consider it likely that the general climate favoring an expanding list of religious exemptions, of which RFRAs are symptomatic, is implicated in the approach taken by the two states, as well as by the lenient response of the California court in the McMath case. It has simply become conventional in the United States for politicians and some judges – as well as the legal advisors for hospitals – to assume it is best to err on the side of tolerance when belief challenges medical science.

4 Is accommodation required?

Those who object to brain death determinations on religious grounds typically base their claim on an expansive and unqualified notion of the sanctity of human life, derived from the religious belief that only God gives life and only God can take it. They insist that only the cessation of the heart beat is consistent with a God-ordained death, both because this is the traditional definition of death and because a person who has suffered the loss of all neural capacity is still 'alive' according to their essentialist definition of life (and thanks to the supportive technology that maintains coronary and respiratory functions). The 'burden' these persons suffer is, in their view, that their loved one is being prematurely declared dead against God's will. The most radical position is that acting on a brain death declaration is equivalent to killing the person.

Does this burden rise to the 'substantial' level required under the U.S. judicial standard of strict scrutiny? Is there a compelling governmental interest in the application of brain death criteria and is there a less impactful alternative by which that interest could be met? We do not get very far by simply asserting, as in the quote with which I began this chapter, the ontological superiority of 'medical facts.' When it comes to determining death, choosing any single indicator of the end of life is really rather arbitrary. Sherwin Nuland (1995), along with many other physicians and ethicists, reminded us that death is a process, not a moment, and that any number of physical measures might just as well be used to pinpoint the difference between alive and dead (Truog and Miller, 2014). It is only a culturally specific theory of personhood that leads us to apply either brain or heart criteria in defining death.[5]

The burden on religious beliefs imposed by brain death determinations should be assessed in comparison to the cardiac alternative that believers claim to prefer. Unfortunately for their argument, there is a strong equivalence between the two so long as we remove from the discussion the association between brain death declarations and requests for organ donation (these are separable because accepting one does not require accepting the other). In hospital settings, for both brain death and terminal cardiac failure, the person's biological functions are perpetuated only as a result of assist technologies (e.g. blood pressure boosting medications, mechanical ventilators, and endo-tracheal breathing tubes) and the removal of those technologies will cause the progressive collapse of all metabolic systems, i.e. death. Thus, if there is a 'burden' it is the removal of assist technologies, not the declaration of brain death. This recognition would shift

the question from the legitimacy of brain death criteria to a more familiar discussion of medical futility. It wouldn't eliminate conflict, but it would remove any religious-based differentiation between brain and cardiac definitions of death and diminish the claim that the application of the former constitutes a 'substantial' burden.

The case in favor of a compelling state interest in accepting brain death rests on the importance of consistency in the legal and medical management of death. It should be obvious that a variation in death determinations that would mean a person is 'dead' in one state but 'alive' in another would result in profound legal and moral complications. In the McMath case, for example, the family's medical malpractice suit will be profoundly affected by a court's decision about whether she died in California in the immediate aftermath of her surgery. Likewise, inheritance laws could be thrown into chaos if a person were declared dead in one state but then considered alive in another. In addition to these legal matters, there is also an emotional price to be paid for family members who are, like their loved one, left in a liminal state for a potentially long period of time.

I conclude that there is a compelling public interest in a fair and even-handed determination of death by medical professionals to follow national standards. I also think we must consider the precedent that would be set if medical decisions based on scientific evidence could be overridden by assertions of burdens on religious beliefs. The dangers are real. In California, religious objections to childhood vaccinations put the public health at risk by rising numbers of parents claiming the exemption when they actually had just accepted the scientifically refuted claim of a link between vaccinations and autism. The application of the Supreme Court's decision in the Hobby Lobby case will likely result in the denial of critical reproductive services for employees who may not share their employers' Christian faith. Pharmacies will be granted conscience exemptions from providing important drugs based on even the slimmest of burden claims. There are simply no limits to the claims that could be brought to the courts under either state or federal RFRAs.

The second of the RFRA requirements, that applying brain death criteria must be less harmful to religious freedom than any alternative, requires that we ask, 'less harmful for whom?' It may be that the McMath family's religious beliefs or, in the Muñoz case, the unrelated objectors' convictions would be harmed less by waiting for cardiac failure for the pronouncement of death, but that alternative is itself harmful to other stakeholders, including the care givers who would have to preserve the metabolism of a person whom medicine considers dead (Miller, 2016). There is also the question of the financial burden of continued interventions, which would be at issue unless the objectors pay all medical bills.[6]

5 Conclusion

Many countries have experienced objections to the application of brain death criteria on religious grounds. For example, a recent article in the *British Journal of Anaesthesia* (Randhawa, 2012) notes that in the UK brain death has 'in some faith groups, led to considerable debate and remains contested by faith leaders' (p. 89). By contrast, another UK-based study (Cooper and Kierans, 2016) sees religion as a potential mediating or 'brokering' tool to encourage acceptance of a brain death determination and the donation of organs. In other countries – Egypt, for example (Hamdy, 2012) – the conflict between some religious commentaries and brain death has led physicians to avoid the problem altogether by relying only on cardiac death (Hamdy, 2012), with a resulting limitation on the types and numbers of organ transplants that are performed (e.g. kidney transplants with living donors).

What sets the United States apart from other countries is the evolving application of constitutional arguments based on religious freedom for the rejection of brain death. As noted above,

this is just a part of a wider set of initiatives that pit religion against medicine. The underlying problem with these efforts is that they are based on a partial understanding of the United States Constitution's guarantee of religious liberty. The First Amendment to the Constitution's Bill of Rights combines a prohibition against laws that *inhibit* the free exercise of religion with an equally strong rejection of governmental sponsorship or *promotion* of any particular religion – the 'establishment clause.' The application of RFRA statutes, especially in the context of medicine, threatens to violate this second component of the First Amendment.

The Texas statute that caused Eric Muñoz so much needless suffering is clearly an example of the state imposing a particular religious view on a public that may not share that belief. The sidestepping of legitimate brain death determinations, with significant public consequences, can also be seen as a violation of the establishment clause to the degree that it favors one religious view over others, with no consideration for the impact on non-believers. America threatens to lose the critical balance between protecting religious liberty and avoiding state-sponsorship of specific faiths. Physicians are often on the frontlines of conflicting religious views; the institutions that employ them are the final guardians of a reasonable balance between the equitable application of medical knowledge and resources on the one hand, and a concern for justice on the other. Going forward, demands for exemptions to the application of brain death determinations should be met with a mixture of kindness, understanding, and a solid commitment to the equal application of medicine. The United States' courts and legislative bodies should also pull back from an overly zealous approach to the protection of religious beliefs and recognize that addressing one 'burden' can cause more burdens for others.

Key words: brain death, Bill of Rights, permanent/persistent vegetative state, organ transplantation

Notes

1 This case was described to me by one of the physicians responsible for the patient's care.
2 Interviews with members of hospital ethics committees in New England and in the Southwest indicate that such disputes do arise with some regularity, but that they are typically resolved by allowing the family time to adjust to the news. In one case, a Native American healer was called to the bedside to certify that the person had died.
3 Smith, a member of the Native American Church, had sued Oregon's Employment Division for unemployment benefits after being fired as a drug counselor on the grounds that he had used peyote, a scheduled drug. Smith's use was in the context of rituals in the church.
4 Both states have legislatures currently working on RFRA legislation at the time of this writing.
5 Brain death determinations are, however, further complicated by their connections to the pragmatics of organ transplantation.
6 Johnson (2016), in an argument favoring accommodation, argues that prohibiting insurance companies from denying continuing coverage when a family objects to a brain death determination would eliminate the financial burden that the hospital would otherwise shoulder. There would, however, be a cost to all insurance premium payers for the additional expenses and a commitment of medical resources that other patients may need. Johnson understates the degree and cost of care required to maintain biological functions in a brain dead patient.

Further reading

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A very useful review of current bioethical debates, including those related to the end of life, with concise bibliographies.

Institute of Medicine (2015) *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press.
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Joralemon, D. (2016) *Mortal Dilemmas: The Troubled Landscape of Death in America*. Walnut Creek, CA: Left Coast Press.
This volume contains helpful chapters on physician-assisted death, persistent vegetative states, and the cultural context of death determinations.

Tebbe, N. (2017) *Religious Freedom in an Egalitarian Age*. Cambridge: Harvard University Press.
This volume provides context for current disputes over religious freedom and offers strategies for mediation.

Veatch, R. M. and Ross, L. F. (2016) *Defining Death: The Case for Choice*. Washington, DC: Georgetown University Press.
This volume provides historical context for the brain death debates and argues for choice as a way to protect basic religious and philosophical beliefs about human existence.

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