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Justice and Respect for Autonomy: Jehovah's Witnesses and Kidney Transplant

Paul J. Cummins and Federico Nicoli

ABSTRACT

That Jehovah's Witnesses may refuse lifesaving blood transfusions is a morally accepted feature of contemporary medical practice. The principle of respect for autonomy supports this, and there is seldom reason to interfere with this choice because it rarely harms another individual. Advances in surgical technique have made it possible for transplant surgeons to perform bloodless organ transplant, enabling Jehovah's Witnesses to benefit from this treatment. When the transplant organ is a directed donation from a family member or friend, no ethical dilemma arises. However, when a Jehovah's Witness cannot identify a living donor and wishes to be listed for organ transplant, the transplant team may face an ethical dilemma. On the one hand, it wishes to provide care to the patient that is compatible with her or his preferences. On the other hand, the team may wonder if it is fair to other patients who need an organ and will accept blood transfusion to include the Jehovah's Witness patient on a waiting list for a donated organ. If the Jehovah's Witness patient is listed and receives an organ, then a patient who also needs an organ, and who is willing to accept all care to optimize the success of the transplant, may be denied an organ.

To frame the ethical dilemma outlined above we present an anonymized case of a Jehovah's Witness woman in urgent need of a kidney, who was referred to one of the authors' institution's transplant center. We review the evolution of the Jehovah's Witness position on blood transfusion and the medical community's efforts to provide care that accommodates this religious commitment. If Witnesses are to be denied transplant in the name of justice, there must be an ethically sound reason. We identify two rationales in the literature: (1) this allocation is unacceptable because it will cost lives; (2) resources should be allocated to patients who comply with the standard of care. We argue that neither apply to this dilemma. We also emphasize the importance of examining the data on outcomes of transplant with and without transfusion. Our interpretation of the published data on transplant without transfusion is that the outcomes are similar. We conclude that, in the absence of data that resources are risked, it is not ethical to refuse to include a Jehovah's Witness patient on a waiting list for an organ. Finally, we reflect on the heterogeneity in transplant institutes' polices for accepting Jehovah's Witness patients.

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INTRODUCTION

The medical community in the United States has a long record of adapting to the constraints

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that the Jehovah's Witness faith imposes on medical care. For example, Denton Cooley, MD pioneered bloodless open-heart surgery.[1] In other countries, Jehovah's Witnesses comprise an emerging religious minority, but one which is rapidly growing, as in Italy, where one author is a clinical ethicist.[2] In countries where the medical community is less accustomed to interacting with Jehovah's Witnesses, medical professionals might judge that providing care that is consistent with a Witness's faith, which could result in the patient dying when, otherwise, he or she would heal, is incompatible with medical ethics. Their judgment might be reinforced if the Jehovah's Witness patient's choice negatively affects another patient's health. That this patient's death may also profoundly affect her family and friends is another consideration that could influence medical professional's judgment.

Jehovah's Witnesses' refusal of blood transfusion is, probably, the most well-known example of a religious-based refusal of medical intervention. The Jehovah's Witness religion, founded in 1872 in Pittsburgh, Pennsylvania, is administered by the Watchtower Bible and Tract Society of Pennsylvania (the Watchtower Society). In 1945, the Watchtower Society promulgated a doctrine that "Blood transfusions and blood products are officially banned as 'pagan and God-dishonoring,' " effectively forbidding Witnesses to accept them.[3] And in 1967, the Watchtower Society also imposed a ban on organ transplant.[4]

Between 1980 and 2000, the Watchtower Society revised its guidance to Jehovah's Witnesses on blood transfusion and organ transplant. In 1980, the Watchtower Society rejected the use of stored autologous blood for transfusion, but it did endorse a policy that Witnesses should consult their personal consciences to decide whether to accept acute normovolemic hemodilution (ANH), intraoperative blood salvage, and blood fractions like albumin, immune globulins, or clotting factors.[5] Jehovah's Witnesses continue to be directed to reject transfusion of whole blood, red blood cells, platelets, plasma, hemoglobin solution, stored autologous blood, and blood donation. The Watchtower Society also revised the choice to undergo organ transplant into a matter of personal conscience, reversing its previous guidance.[6]

In this article, we consider a case in which a Jehovah's Witness patient requested to be listed for organ transplant but requested a procedure compatible with the guidance from the Watchtower Society. For the sake of brevity, we will refer to an organ transplant that adheres to these constraints as "transfusion-free transplant." We address the ethical question of whether transplant teams are justified in refusing to list a Jehovah's Witness patient who requests transfusion-free transplant to ensure that organs are allocated to a patient who will accept all protocols for optimizing graft survival. While our focus is on kidney transplant, our argument could be relevant to heart, liver, lung, pancreas, and stem-cell transplant.

In the case we describe below, the transplant team at the Mount Sinai Hospital (MSH) Recanati/Miller Transplant Institute (RMTI) was unsure if listing a Jehovah's Witness for kidney transplant was ethical. It is important to address this issue because there is actually very little guidance within the bioethics literature for transplant surgeons to consult.

Our review of the bioethics literature reveals that there are only two articles that address the issue, and both argue that it is ethically acceptable for surgeons to make transfusion of whole blood a condition for transplant. This guidance, we believe, is wrong: transplant surgeons should not force a Jehovah's Witness patient to choose between her or his religious convictions and medical care.

We offer two reasons why the guidance is wrong. First, without empirical evidence that transfusion-free transplant compromises the survival of a graft, refusal to list a Jehovah's Witness is unfair discrimination. Second, we reject the argument that requiring blood transfusion as a condition for inclusion on the transplant list is ethical because Jehovah's Witnesses are not making autonomous decisions to refuse transfusion.

First, we present our case, and then we describe each article's distinct rationale for not listing Jehovah's Witnesses for organ transplant, and we offer conceptual rebuttals for them. We then review the medical literature on transfusion-free transplant to offer an empirical rebuttal of these rationales. Next, we consider and reject an argument that a Jehovah's Witness's refusal of blood transfusion is not an autonomous choice. Finally, we anticipate a potential criticism that the evidence about transfusion-free transplant in the medical literature fails to capture the risk in individual cases.

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CASE

Our case is about a 61-year-old woman with kidney failure due to hypertension and diabetes mellitus, complicated by coronary artery disease and hepatitis C chronic infection, which she acquired from a blood transfusion following childbirth. In late 2013, she was referred to the RMTI because it has a program for kidney transplants from donors with hepatitis C infection to patients with hepatitis C.

The patient was receiving dialysis, but she did not tolerate it well because she experienced persistent chest/back pain, nausea, and mild hypotension within 15 to 30 minutes of the beginning of dialysis. In addition, her only dialysis access was through a thigh graft. The medical team was unsure how long it could maintain access for the patient's dialysis treatment. Because the patient was not able to find a living kidney donor and she faced the prospect of not being able to continue dialysis, she was in extreme need of a kidney transplant.

The transplant team had to decide if the patient was a candidate for registration for a kidney transplant with the Organ Procurement and Transplantation Network (OPTN). The decision to register the patient on OPTN became more complex when she informed the team that she would not accept blood transfusion or blood products because she was a Jehovah's Witness. The patient expressed a strong desire to undergo kidney transplant, but she was insistent that she would not accept blood transfusion or blood products. She expressed frustration with prior "ugly experiences" at other institutions, in which her commitment was "ridiculed," and physicians told her that they would transfuse her when she was unconscious. The patient understood that her health was precarious, but "it would be silly to make a decision that would displease Jehovah, when my life is at risk, especially if there are alternatives to transfusion."

The transplant team wanted to help the patient, but it also worried that it would harm another patient who would be willing to accept transfusion, if that patient was passed over for a kidney. The transplant team's ambivalence about whether or not to list the patient for transplant reflects uncertainty about how the principle of justice applied in this case, and the dilemma the team faced can be put as follows: is it just to allocate an organ to a patient whose autonomous request for transfusion-free transplant will be honored? To begin to answer that question, it is important to consider the validity of rationales for excluding a Jehovah's Witness patient as a transplant candidate.

ETHICAL GUIDANCE IN THE LITERATURE

Transplant teams who consult the medical ethics literature on this issue will find very few articles. We identified two articles that provided guidance on allocating organs for transplant to patients who requested transfusion-free transplant: Boggi and colleagues' "Kidney and pancreas transplants in Jehovah's Witnesses: ethical and practical implications," and Bramstedt's "Transfusion contracts for Jehovah's Witnesses receiving organ transplants: ethical necessity or coercive pact?"[7] Our primary objection to the arguments made by Boggi and colleagues and Bramstedt is that they fail to account for empirical evidence on transfusion-free transplant. We also find their arguments to be flawed. We will present and rebut the arguments in turn before discussing the evidence that refutes them.

Boggi and Colleagues' Rationale

Boggi and colleagues report that "most Jehovah's Witnesses can safely receive a kidney . . . transplant without transfusions. However, in a low, though not negligible, proportion of recipients, blood transfusions cannot be avoided without the risk of recipient death."[8] Their experience is that a risk of death is associated with post-operative complications, and they propose that making an agreement to rescue transfusion should be a condition for transplant. Boggi and colleagues acknowledge that, in medical care, patients are usually free to choose the medical interventions they will undergo. However, they claim that organ transplant is a unique form of medical care because patients' choices can "decrease the chance of other patients to timely obtain appropriate medical treatment."[9] Their concern is that permitting transfusion-free transplant puts more lives at risk than transplant with transfusion, as the patient who receives the organ but refuses transfusion will die, and a patient who may have received the organ instead will be at increased risk of dying. The authors' proposal to require rescue transfusion aims to optimize the possibility that a patient will benefit from the organ allocated to the patient. This

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is a form of triage. If this triage rationale is applied to our case, the Jehovah's Witness patient would be deprioritized for organ allocation because other patients who are willing to accept transfusion would be seen as more likely to benefit from receiving the organ.

Rebuttal to Boggi and Colleagues

Boggi and colleagues' triage rationale for excluding a Jehovah's Witness patient for transplant listing should be rejected. While it is true that triaging a patient may incorporate a survival benefit as a factor governing allocation of resources, it would be unfair to apply it to our patient. In 2013, the Board of Directors of OPTN/UNOS approved changes to its kidney allocation criteria, which take survival benefit into account.[10] This policy was implemented after the patient in our case presented to the RMTI, and it would not have affected her eligibility to be listed. The aim of this new policy is to match kidneys that are expected to function the longest with patients whose life expectancy is longer, which would reduce the need for retransplant. This survival benefit criterion is ethically acceptable because it aims to optimize the distribution of kidneys based on sound evidence. Unlike this fine-grained policy, Boggi and colleagues' principle is a coarse calculation of whether a patient is more likely to die following transfusion-free transplant than another patient. It would not survive public vetting because its incompatibility with the empirical evidence on transfusion-free transplant makes it unacceptable.

Bramstedt's Rationale

Bramstedt's position is that organ loss must be prevented, when possible, because justice requires good stewardship of donated organs. As part of this stewardship, transplant teams must pro-actively address factors that contribute to organ loss. Bramstedt identifies noncompliance—when a patient fails to adhere to a prescribed treatment or medication—as one of the main culprits.[11] Within organ transplant practice, it is generally accepted that it is ethical for a transplant team to decide not to list a patient for transplant when the team does not believe the patient will comply with the lifelong antirejection medication regimen needed to ensure graft survival. Bramstedt claims that considerations of noncompliance can justify refusal of transplant to Jehovah's Witnesses because "if a patient refuses [peri]operative rescue transfusion, this puts the survival of the graft at risk."[12]

Bramstedt recommends that Jehovah's Witnesses be required to sign a rescue transfusion contract as a condition for receiving a cadaveric organ. She explicitly compares the case of an alcohol abuser and a Jehovah's Witness to support acceptance of blood transfusion as a condition for transplant. Many transplant centers require patients whose liver disease is caused by alcohol abuse to demonstrate six months of sobriety before listing them for transplant. Bramstedt's analogy appears to be that alcohol use by patients with alcohol-related liver disease and refusal of blood transfusion by Jehovah's Witnesses are alike because both are examples of noncompliance, and if a sobriety contract is a fair response, then a transfusion contract is also a fair response. If Bramstedt's analogy holds, then a transplant team would be justified in refusing to list our patient because she is noncompliant, which would allow the organ to be allocated to a patient who would be "compliant."

Rebuttal to Bramstedt

We agree with Bramstedt that noncompliance can be an ethical disqualification for receiving medical treatment, but we deny the grounds of her analogy: refusal to abstain from alcohol or refusal of blood transfusion are not similar to a refusal to comply with an antirejection medication regimen. Refusal to comply with an antirejection medication regimen is an example of noncompliance that sabotages the treatment, and compliance with antirejection medication regimen is a necessary condition for a successful organ transplant. Noncompliance is a more compelling reason to deny a patient a treatment when resources are scarce and a compliant patient will not be treated. Bramstedt's argument depends on a comparison to noncompliance, but the comparison is false.

Even if we accept that not remaining sober is an example of noncompliance, and an ethical basis for disqualification from transplant listing, refusal of blood transfusion is not enough like nonsobriety to disqualify a transplant candidate. This emphasis aims to prevent disease recurrence from renewed alcohol abuse, and the need for a subsequent retransplant. Our Jehovah's

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Witness patient who requested a transfusion-free transplant poses no risk of future retransplant.

TRANSFUSION-FREE TRANSPLANT IN THE MEDICAL LITERATURE

Good medical ethics should reflect sound medical science. Physicians are trusted to be fair stewards of scarce medical resources, and their allocation decisions should incorporate principles of distributive justice and medical facts. Policy that excludes Jehovah's Witnesses who seek transfusion-free transplant from a transplant listing should have support in the medical literature. To determine whether the arguments made by Boggi and colleagues and by Bramstedt are supported by the literature, we searched PubMed for studies and reports on transfusion-free transplant. We discuss our findings below.

TABLE 1. Survival rates of Jehovah's Witnesses and matched cohort for transfusion-free organ transplant

	Jehovah's Witnesses (*N* = 13) %	Matched cohort (*N* = 25) %
Overall actuarial 3-year patient survival	83	80
Overall actuarial 3-year graft survival	66	77

Source: D.B. Kaufman et al., "A single-center experience of renal transplantation in thirteen Jehovah's Witnesses," *Transplantation* 45, no. 6 (1988): 1045-9.

TABLE 2. Survival rates for Jehovah's Witnesses and non-Jehovah's Witnesses for kidney transplant

	Jehovah's Witnesses %	Matched cohort %
1-year patient survival	87	97
5-year patient survival	72	81
10-year patient survival	51	60
1-year graft survival	82	87
15-year graft survival	67	61
10-year graft survival	43	18

Source: R. Kandaswamy et al., "Kidney and kidney/pancreas transplants in Jehovah's Witnesses—A single center experience with 50 transplants," *Acta Chirurgica Austriaca* 33, supp. 174 (2001): 3 (abstract 01), *http://doi.org/10.1007/BF02953431;*

Controlled Studies

There are two studies with controls about kidney and kidney-pancreas transplant in the literature. In 1988, Kaufman and colleagues published the results of their positive experience with kidney transplant for Jehovah's Witnesses, finding comparable success rates from Jehovah's Witnesses and non-Jehovah's Witnesses.[13] Kaufman and colleagues compared 13 Jehovah's Witnesses who underwent transfusion-free kidney transplant with a matched cohort of patients (n = 25) from the University of Minnesota (see table 1).

They found that the difference in actuarial and graft survival rates of the Jehovah's Witnesses and their counterparts were not statistically significant. And Kandaswamy and colleagues found no statistically significant difference in the one-to-10-year survival rates in this comparison of kidney transplant cases of Jehovah's Witnesses and non-Jehovah's Witnesses (see table 2).[14]

Case Reports

Alongside these studies, other transplant specialists have reported their experiences in kidney, kidney-pancreas, and liver transplant with their Jehovah's Witness patients. Our search of PubMed identified 14 case reports of transfusion-free transplant.[15]

The tentative conclusion that we draw from the two studies and the case reports is that there is no consensus in the literature that transfusion-free transplant poses a significantly greater risk of organ loss than transplant with transfusion. These studies and case reports reflect that medicine has embraced the challenge to develop surgical techniques that make transfusion-free transplant possible, and emphasize the importance of peri-operative care to successful transplants.

The Relevance of the Medical Literature

Review of the medical literature indicates that Boggi and colleagues' and Bramstedt's rec-

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ommendations are not based on evidence. Given the two studies and positive case reports on transfusion-free transplant, Boggi and colleagues' proposal does not reflect an accurate assessment of the prospects for successful organ transplant. At worst, it presumes a difference where there is none. If the medical reasons that justify different allocations of resources for Jehovah's Witnesses are merely theoretical, the factor that disqualifies them from transplant listing requires vigorous scrutiny to determine whether the distinction is warranted and just. The medical profession must ensure it does not violate the principle of nonjudgmental regard when it limits patients' treatment options because of their religion.

Noncompliance may be an ethical disqualification from treatment when others are denied treatment. Bramstedt argues that the refusal of blood transfusion in organ transplant is such a case. The medical literature does not support this inference. It appears to indicate that Jehovah's Witness transplant recipients do as well as non-Jehovah's Witnesses. Bramstedt argues that failure to maintain sobriety and noncompliance with transfusion have similar effects on outcomes of graft survival. Multiple studies suggest that duration of sobriety prior to liver transplant is not a reliable predictor of abstinence following transplant.[16] A study by Rustad and colleagues suggests that it is possible to screen transplant candidates for potential alcohol relapse and aid the patients with targeted interventions.[17] Some transplant centers have revised their sobriety requirements to list patients with alcohol related liver disease for transplant.[18]

Having rebutted Boggi and colleagues' and Bramstedt's rationales for denying requests for transfusion-free transplant, we now consider an autonomy-based argument.

Respect for Autonomy?

Muramato has argued that the practice of "disassociation" imposes coercive pressure on Jehovah's Witness patients to comply with the Watchtower Society's guidance on blood transfusion, compromising the patients' autonomy to refuse it.[19] The implied argument is that physicians are not ethically obliged to honor a Witness patient's refusal of blood transfusion because the patient's refusal does not express an autonomous choice, and that a transplant team's imposition of consent to blood transfusion as a precondition for transplant listing does not violate the principle of respect for autonomy, since the patient's refusal of transfusion is seen as coerced.

Some healthcare professionals, like Muramato, may be reluctant to accept that honoring a Jehovah's Witness patient's refusal of blood transfusion is consistent with respect for the patient's autonomy. As Ridley noted, while medical staff may acknowledge that "honoring patient values in health care decision making and respecting patient self-determination are of the utmost importance," they may worry that a Jehovah's Witness has been psychologically manipulated to refuse blood transfusion.[20]

A Jehovah's Witness who accepts a blood transfusion is disassociated from the faith by his or her actions. Disassociated Jehovah's Witnesses are subject to communal shunning. The biblical justification for this is found in the apostle Paul's claim that Christians should "quit mixing in company" with persons who unrepentantly reject certain scriptural standards.[21] This is a flawed rationalization for excluding a faithful Jehovah's Witness from transplant listing. Although physicians may be tempted to judge that a Witness's refusal of blood transfusion is coerced, this would be a mistake. The practice of shunning may occur, but this is not sufficient grounds for physicians to determine that a Jehovah's Witness patient lacks the autonomy to make this decision. Shunning may have a coercive effect, but a policy that denies transplant listing to Jehovah's Witnesses who refuse transfusion due to this concern condemns them to die.

CAVEAT

We have argued that policies that reject Jehovah's Witnesses patients' requests for a transfusion-free transplant listing are unjust because they are conceptually flawed and not sufficiently sensitive to the evidence. Some may object that it is likely that allocating an organ to a Jehovah's Witness patient will increase inefficiency, at least incrementally, because some Jehovah's Witnesses will die during transplant or post-transplant. This is a possibility, but, in the absence of an empirically verified prognostic test for increased risk, it is unfair to prospectively deny a transplant listing to an individual Jehovah's Witness. The injustice of refusing to list a Jehovah's Witness is more significant than a

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potential loss to marginal utility. Veatch has argued that justice is a moral principle that is independent of utility, that the superior ethic is one that prioritizes justice over utility, and that "no allocation formulation will be acceptable that is driven exclusively by utility."[22]

CONCLUSION

It is essential for decisions about listing Jehovah's Witnesses for transplant to take medical facts into account, if those decisions are to be ethical. As noted above, the medical consensus is that with proper peri-operative medical management and careful selection of candidates who are sufficiently healthy for transplant, the outcomes for Jehovah's Witnesses undergoing transfusion-free transplant are comparable to those of transplant patients who receive transfusions. The health of some Jehovah's Witnesses may make transplantation too risky, even with peri-operative optimization, and jeopardize the organ. In these cases it is fair not to allocate an organ, although transplant surgeons may offer it to a similar patient who consents to transfusion. Ultimately, reports of successful transfusion-free transplant in Jehovah's Witnesses are encouraging, and should expand access to treatment for these patients.

CLINICAL CASE RESOLUTION

The transplant surgeons at the RMTI believed that they could take peri-operative and operative steps to transplant the patient successfully, and because the patient was likely to die without a kidney transplant, she should be registered with OPTN for a kidney from either a hepatitis C positive or negative donor. The patient was listed for transplant in January 2014. The patient nearly received a kidney after three to four months on the OPTN registry, but another patient was a better match for the kidney. The patient also was notified of a possible match while visiting her daughter out of state, but was not able to come to the MSH due to inclement weather. Finally, a little over a year after registering with OPTN, the patient was matched to a kidney from a hepatitis C positive donor and underwent transplant. The patient continues to be monitored by the transplant team at RMTI, and she is doing well, soon to begin the new treatments for hepatitis C. When the patient reflects on her time waiting to be matched, she says that she was preparing to die, but Jehovah orchestrated the circumstances that allowed her to receive a kidney. "It would be devastating to have been denied the extra days free of dialysis to spend with my family."

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BLINDING OF THE CASE

Details of this case have been blinded to protect the privacy of the patient.

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8. Boggi et al., "Kidney and pancreas transplants," see note 7 above.

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