"I would rather die than have a blood transfusion:" A dialogue about life, death, and freedom of conscience

DARREN E. LUND
University of Calgary

ABSTRACT: This article documents and analyzes the case of a physician encountering an ethical dilemma that pitted his wishes and professional oath against respecting the specific religious requirements of a patient and his family around the patient's medical care. In conversation with an educator who focuses on equity and diversity issues, the physician recounts the details of the case against the backdrop of relevant medical literature. The reflective duoethnographic-style dialogue herein draws on parallel issues surrounding respecting freedom of conscience, and religious diversity in medical and educational settings, and recounts some of the personal and professional implications of professional decisions, sometimes entailing life and death consequences.

Keywords: religious freedom, blood transfusion, faith, medical ethics, law, diversity, education

RESUMÉ: Dans cet article, nous racontons et analysons le cas d'un médecin qui a fait face à un dilemme éthique où il a dû choisir entre ses désirs ainsi que son serment professionnel et les exigences religieuses d'un patient et de sa famille en ce qui concerne les soins médicaux de ce patient. Pendant une conversation avec un éducateur qui étudie des questions d'équité et de diversité, le médecin raconte les détails du cas dans le contexte de la littérature médicale pertinente. Le dialogue réflexif duo-ethnographique prend inspiration de questions parallèles sur le respect de la liberté de conscience et sur la diversité religieuse dans des contextes médicaux et éducationnels. Nous discutons également les implications personnelles et professionnelles des décisions professionnelles qui comprennent parfois des conséquences de vie ou de mort.

Mots clés : la liberté religieuse, la transfusion de sang, la foi, l'éthique médicale, le droit, la diversité, éducation

Introduction

Brian[1]: This article has been revised and rewritten a number of times. The first time it was written with a focus on the medical ethics developed in the 1970s in the United States, including autonomy, beneficence, non-maleficence, and justice. After it was not accepted for a surgical education journal, I rewrote it with a focus on the seven Canadian CanMEDS roles of medical expert, scholar, professional, manager, health advocate, collaborator, and communicator. However, an earlier version was assessed as being inappropriate for publication in another education-related medical journal.

The subject of this piece was a patient whom I was treating while I was a second-year general surgery resident about a decade ago on my intensive care unit (ICU) rotation at a Canadian hospital. I developed a profound relationship with the family and hence I decided to write a case report with my staff attending at that time. In the initial version of the articles there was quite a bit of medical jargon. Here, I am seeking to share my thoughts on this case with a non-medical audience with a greater focus on the relationships of the persons involved in this patient's care as a case study to serve as a basis for our dialogue here. That is why I sought to involve you in this writing/research project.

Darren: Frankly, I am honoured and excited by this case, as I have had a chance to read some early drafts and the issues that emerge are quite profound and emotionally heavy. It was my good fortune, I think, that you "accidentally" enrolled in a qualitative research methods course a few years ago, rather than in a medical education course as you probably intended! I have had some really rewarding opportunities to learn and practice the emergent method of duoethnography in the past few years since first learning about it from some education colleagues, Joe Norris and Rick Sawyer, who pioneered and continue to shape its direction in a collaborative manner (Norris, 2008; Norris & Sawyer, 2017; Norris, Sawyer, & Lund, 2012; Sawyer & Norris, 2013). The dialogic method emerges from autoethnography and features in-depth collaborative conversations between two people focused around a topic of mutual interest. Rather than "bracket out" personal views and biographies, these become part of the text. I believe that drawing on elements of this approach will be a good way to "dig a bit deeper" about some of the issues that arise surrounding this interesting case.

Brian: I will begin by sharing that the patient's family was aware in 2006 that I was attempting to publish this article. Through my literature searches, I found most of the relevant ethical, medical, and legal articles were still published in medical journals, but I understand how the issues that arise here may have relevance beyond this field. Because this is an early attempt for me at writing a qualitative research article, as a researcher who has always been quantitative, I am quite hesitant to "soften" my writing style in this way. Let me begin by outlining the circumstances of the case, beginning with the core conflict that emerged for a particular patient.

Religious Freedoms and Medical Ethics

> *And whatsoever man there be among you, that eateth any manner of blood: I will even set my face against that soul that eateth blood, and will cut him off from among his people.*
> (Leviticus 17: 10-14, *Holy Bible, King James Version*)

Brian: This excerpt from the Old Testament passages of the *Holy Bible* has led Jehovah's Witnesses to construe intravenous blood transfusion as an instance of eating blood. They insist that the intravenous route is no different than consuming it orally, as the blood enters the body regardless; "blood transfusions are nothing more than a source of nutrition [entering the body] by a shorter route than ordinary" (Thomas, Edmark, & Jones, 1968).

In 1993, the Supreme Court of Canada held that "every patient has a right to bodily integrity… This includes the right to be free from medical treatment to which the individual does not consent" (Supreme Court of Canada, 1993a). However, in medical practice, the care of Witnesses is controversial, especially when pregnant women and children are involved and also in the trauma setting. Jehovah's Witness is a Christian faith with more than six million active Jehovah's witnesses worldwide in 2002 (Bodnaruk, Wong, & Thomas, 2004). Some aspects of blood transfusion refusals are clearly prescribed in the beliefs of Jehovah's Witnesses, while other aspects have no clear Biblical directives (Thurkauf, 1989). For example, transfusions of whole blood and packed red blood cells are forbidden. But the decision to use other parts of whole blood and even hemodialysis for kidney failure is left up to the individual and their Church sector.

It was only in the last twenty years that the courts have subordinated the physician's interest in preserving life over the constitutional rights of the patient (DiPietro, 1987; Macklin, 1977).

The case of *Malette* v. *Shulman* (Ontario Court of Appeal, 1990) exemplifies this when an Ontario physician was successfully sued for battery. The physician knew that his patient had a signed card asking that no blood products be given because of her religious beliefs, but he felt that she required a blood transfusion to save her life and ordered a blood transfusion. This Ontario physician was successfully sued for battery.

Darren: Instances of religious diversity and conflicts between cultural and familial practices and institutional rituals and requirements are also a common theme in the field of diversity in educational settings (Joshi, 2012). More often than not, however, they are relatively non-dramatic moments within the lives of schools and classrooms where children of Jehovah's Witnesses are disallowed from participating in particular practices that their faith community deems inappropriate. For example, these children are typically requested by their parents to exclude themselves from birthday parties, from general assemblies or other school gatherings, and from any activities such as singing the national anthem or saluting the flag. Following a series of court rulings, school districts across North America have implemented a wide range of diversity-themed policies and directives to guide their responses to these and other religious conflicts. As Watkinson (1999) notes, court rulings in Canada have upheld, with some specific exceptions, the freedom of conscience and religion clauses of the *Canadian Charter of Rights and Freedoms*, to support students' rights to be free from state-imposed religious practices. She observes that courts have determined that "religious practices, which are distinct from religious studies, do not belong in public schools" (p. 73). In virtually no cases, however, do these issues become life-and-death circumstances in school settings.

How prevalent are religious issues and conflicts in the medical field, and do you think the specific religious sect, Jehovah's Witnesses, draws an undue amount of attention and concern regarding their particular beliefs?

Brian: This religious sect certainly garners a significant amount of attention since physicians tend to take extra special precautions in the care of these patients. This includes confirmation of the belief and the extent of the belief in receiving other blood products or variations thereof. I do not think this attention is undue, since it is the hasty physician who merely acknowledges this belief system without affirmation of its details who will run a disservice to his/her patient.

Although Jehovah's Witnesses come to medical attention no more frequently than any other populations, their care is always more complicated because of their refusal of blood. Physicians are well aware of their beliefs and, based on ethical and legal obligations, always make special arrangements for the care of these patients. In the trauma setting, it has been suggested that despite having similar severity of illness scores, their prognosis is poorer when compared to the general ICU population (MacLaren & Anderson, 2004). Although there is a wide range of literature published on the caring of Jehovah's Witnesses, from the medical science (Bodnaruk, Wong, & Thomas, 2004; Kleinman, 1994; Kulvatunyou & Heard, 2004) of maximizing the body's functions to produce their own blood cells, to the legal aspects (Kleinman, 1994) of treating Jehovah's Witnesses, there is a paucity of literature examining the relationship between the family, the patient, and the medical team.

Darren: It seems like a traditional focus on determining concrete outcomes and measuring discrete variables can mean downplaying or losing some of the complex human perspectives and emotional elements involved in any such professional relationships. I am very interested to learn more about this case, and just as compelled to analyze the inner workings of a medical practitioner in specific circumstances. For most of us non-medical lay people, the world of the physician is pretty mysterious. We are not often invited into understanding and appreciating the subjective side of medical decision-making, nor into learning about the vulnerability of these esteemed members of our community. I am interested in how you came to want to capture your feelings about this case in writing. So can you lead me through how this case began?

Brian: In order to provide the best medical care to this marginalized population who already have poorer prognoses, I believe the personal relationships involved must be examined in more detail to provide an understanding of this unique patient population. I think of my descriptions here as reflecting a qualitative case study (see MacLaren & Anderson, 2004) analysis that methodically describes and interprets the management of the patient, family dynamics, and the relationships developed between the different allied health care professionals. As doctors, we asked the following exploratory research questions: What happened? What kind of relationship developed between the treating medical professionals and the family? How did the family dynamics affect the patient care? Is there anything additional that could have been

done to save the patient's life? Is there anything we can do differently for Jehovah's Witness who present in a similar clinical situation?

Darren: This seems like a very reasonable and organized list of questions to begin, although I can see how the answers to some of these guiding questions could potentially unleash a wide range of complex and interwoven aspects of patient care and personal feelings. I often see this functional approach that attempts to isolate variables within my own field of education, as researchers seek a linear progression between intended educational outcomes, and the list of practices put in place to bring them about. However, in my view it is never that straightforward, despite our best efforts to frame everything within clean lines. Perhaps you could outline the factual details of how the case began, and where this took your team.

Brian: Sure. A 28-year old male Jehovah's Witness, David[2], was admitted to our academic ICU after a motor vehicle accident in which his car was struck by a semi-trailer truck. Despite multiple injuries, he refused blood on two separate occasions while he was alert and conscious. David repeated this even when the two physicians, an anesthetist and an emergency physician, stated that he was "very sick" and that he "would most likely die if he did not receive blood products." As the patient subsequently became vitally unstable, he was transferred to the operating room where he underwent an operation to remove the bleeding spleen. In addition, he required surgical stabilization of his left leg fracture. A left chest tube was also inserted to manage the lung that was ruptured and also bleeding.

Throughout his postoperative course in the ICU, David's blood counts remained low with his peak being 39 gram per liter (g/L). The norm for males is 140 g/L to 180 g/L. His course was complicated by progressive multi-organ failure. Many allied health professionals were involved in his care from dieticians, pharmacists, nurses, surgeons, and intensivists, along with their trainees. I was involved as a surgeon-in-training. David died after eleven days in the ICU.

Darren: Just reading these words now, I am struck by your almost cold and factual accounting of the end of a person's life. I am not meaning to criticize, but to note the discrepancy between the "normal" medical way of listing facts, and the more commonly used ways we see around us in the social world. Our Western

society has so much emotional "baggage" around death and dying, and there is a stigma around even *talking* much about the end of life, even though it is inevitable for each of us. When I lost my father some years ago I noticed that even that wording is a way of softening the finality of it; I didn't really *lose* him. He is not just lost somewhere, waiting to find his way back. He died, but saying it in that way about my own father sounds a bit cold to me. I have often been awed by how medical doctors can express emotionally devastating news and horrifying diagnoses in an almost impassive manner. Just "stating the facts" seems to be the industry standard. What can you tell me about this patient's personal circumstances?

Brian: You will have to excuse me. This is a factual account of case presentation written from my initial versions of the manuscript for presentation to other health professionals. This is also similar to how we talk about patients with other physicians when we are handing over care. Of course, when we talk to the patient's family, especially with issues surrounding death, we soften it a lot more. I am receiving further training in surgical oncology, or *cancer surgery* in more lay terms. And as you can imagine, my line of work brings along with it many moments where I need to deliver devastating news. One of the reasons I chose this speciality is because I like the patient interaction.

David was survived by a common-law wife of six months who was not a Jehovah's Witness and his parents and sister who were Jehovah's Witnesses. Multiple family meetings were held, and the friction between the common-law wife and the rest of the family became more and more apparent when she wanted to authorize a blood transfusion despite his initial expressed wishes and the rest of the family's objections. Individual interviews were also held throughout the patient's care. Towards the end, the common-law wife wanted to shave his hair, stating that he had always kept it short despite his parents' protesting. To this end, the medical team decided not to shave his head, stating that they did not want further blood loss. The family also requested consultation from *The Hospital Committee Network of Jehovah's Witness* who were not healthcare professionals but were international members of the Church who offered assistance to other Church members.

Darren: It sounds to me like the family dynamics here were a core part of the complexity of this particular case, and that there were some clear divisions between the wishes of the different parties. In this case, it seems apparent that the doctors were forced to "pick sides" in the dispute, no doubt guided by precedent, the law, and a

myriad of other considerations. What is your goal in analyzing the case a bit more in this written account?

Brian: My hope here is to illustrate the relationship that developed from the care of this patient. We were bounded by the short period of time that the patient was in ICU. Interviews were done in a group in the format of family meetings and patient rounds, and in an individual basis when consultations were made from the physicians to the dieticians and the pharmacists and also with individual family members. I carried out the interviews as a second-year general surgery resident during my rotation in ICU. As part of the health care team, I was also responsible for liaising between the health care team and the family members and also *The Hospital Committee Network of Jehovah's Witness* when they showed up on the request of the family later in the care of the patient. And in my quantitative methods mindset, I think there were four key relationships that developed that we can now talk about in more depth, namely, 1) the relationship between medical professionals, 2) the relationship between his common-law spouse and parents, 3) the relationship between medical professionals and the health liaison committee, and 4) the relationship between this case and society.

Relationship between Medical Professionals

Brian: Two physicians documented that the patient stated that he did not want to receive any blood transfusions. Possible consequences were clearly explained to him. Although one might argue that David was in shock and therefore incompetent of refusing standard care, the refusal was consistent with his prior known beliefs. Competence is based on his ability to make decisions, not on the decisions themselves. Even when his choice is perceived to some as irrational, paternalistic interference cannot be justified. At the time of refusal, he was alone and neither family nor friends were in the room, so familial coercion was unlikely. However, the circumstances surrounding this patient's decision to join the church of Jehovah's Witnesses were unknown. Active church members tend to live their lives and make their decision in accordance with church beliefs, which may not have corresponded with the individual church members without that influence. The Jehovah's Witness church has been known to distribute advance directives that require their members to refuse blood products in all situations. Those who did not sign the document were dismissed from the church (Supreme Court of Canada, 1993a).

Darren: I find this case very frustrating, even just learning about it second-hand some years later. It seems so apparent to me as an outsider that medical doctors typically "always know best" and have the duty to deliver the care that they believe to be right for any patient under their care!

Brian: Although medical doctors may "always know best," it is our job to help patients and their family understand why we think a certain option is the best. In the past, paternalistic care was the norm where patients are just told by their physicians what to do. In modern-day medicine, attempts are made so that patients are more involved in their own health care so that they can be involved in the decision-making process as well.

To the more junior medical staff, myself included, indeed it seemed that care was provided "with one hand tied" and that an infusion of blood would have been a simple solution. To some, his death was preventable with a transfusion. But to the devout Jehovah's Witnesses, living on our physical world is not worth the denial to eternal life in Heaven because of a blood transfusion (Kulvatunyou & Heard, 2004). In addition, with the blood specialists' recommendation, we added many other medications intended to stimulate the bone marrow to produce the body's desperately needed red blood cells despite limited scholarly evidence guiding dosing in trauma patients. Also, we added medication to maximize the body's ability to initiate and maintain hemostasis. The pharmacist and I combed the medical literature and came up with a regimen based on the best available evidence. Even though I found this process somewhat frustrating, the pharmacist with whom I worked was much more experienced than I was, and was extremely helpful in guiding me through this process. It was through her that I learned not everything in medicine is black-and-white, and there may not always be a correct answer even if it is in a life-and-death situation. With the nutritionist, we maximized the minerals and vitamins in his intravenous nutrition to maximize the availability of the building blocks for red blood cells.

Darren: Yes, this is a very chilling example of the "grey areas" that emerge in your line of work. In the less dramatic and traumatic field of teaching, where I am currently engaged in preparing student teachers to go out into the field, I regularly call upon my own set of critical incidents where a momentary decision may have had a significant impact on the people involved. I taught high

school for 16 years, and there were often powerful moments that were life-altering in retrospect. Occasionally, former students contact me, and share the meanings of these incidents in specific terms. With any job where we are constantly interacting with people, there are so many moments with complex lessons that emerge.

As an example, I recently received an email from a new teacher who shared a moment in her science classroom where a young male student suddenly left the room crying, and the teacher followed. She learned that he was having his menstrual period. The transgender male student shared his complex situation dealing with his gender identity, and a hostile home life, and found a receptive and supportive ear with this teacher. The reason she told me about this incident was that we had dealt with this issue in my class, and she thanked me for preparing her to be a better teacher for this student. She also said that the student later told her that her response to him had "saved his life" in very real terms.

As professionals we always struggle to make solid decisions, but rarely know for sure if these are the best ones. It sounds like you were doing everything possible in this case to assist this fellow under the circumstances, yet weren't there moments during all of your interventions when you wondered if you were doing the "right" thing?

Brian: Unfortunately, that is a reality of my line of work. Most everything is grey and rarely is anything absolute. When we are making recommendations for the type of surgery for a certain cancer, there are always risks for that surgery. It is just that the benefits of the surgery outweigh the risks. And that ratio may be different with different patients, which is what makes this field so exciting. We are trained to treat each patient as an individual. Just because your neighbour was recommended this course of management for her breast cancer does not mean that that course would be suitable for you. And this is why multidisciplinary care, where physicians from different specialities and professionals from allied care come together to formulate the best patient management plans they are able to, is so important.

We used sedation and paralysis to minimize David's oxygen consumption as there were very limited red blood cells carrying oxygen to vital organs like the brain and the heart already. Although the patient may not have been able to communicate with his family even without the sedation, the sedatives took away any chances for him to communicate his last dying words. In retrospect, this was not asked of the family as I, together with the

rest of the medical team, had paternalistically decided that it was best to sedate the patient to conserve his energy. We had hoped that he would be able to live through his injuries with no blood transfusions. We did not stop to think that the family and the patient himself may have just wanted to communicate. instead of his being sedated.

Darren: Brian, I really respect and appreciate your openness here, and in many ways, the emotional risks you are taking in re-telling this story in this rather public manner. It seems that most professionals want to put on a brave face and present confidence to the world under all circumstances. My friend has worked as a volleyball referee and he has told me that, even in a case where he may have made the incorrect call on a particular play, he typically feels compelled to maintain his confidence and integrity as the official and stand by the original call. I hope this sports example is not too trite, but it seems emblematic of our need to be seen as competent and self-assured in positions of authority. In the case of the medical field, there are lives in the balance, and showing your sensitivities to nuances, your uncertainty in complex cases, and your doubts about particular decisions may work against you in some ways.

Brian: It is certainly not too trite. We draw examples from our everyday life and it shapes who we are. I think it is human to show doubts about a particular decision – it keeps us humble and more open to improvements. Writing this article has helped me reflect on this patient, as this patient touched me deeply early in my career, which led me to write about this in the first place. Since this incident, I have completed another four years of additional training.

Personally, this is one of first patients who had died under my care. As junior medical staff, we tend to spend more time with the patients and their family than the staff attending. This patient and his family touched me deeply and, fortunately or unfortunately, I got too attached to the patient where I came into the ward to see the patient even when I was off duty. Even though my spouse was very understanding and supportive, I needed to learn how to balance my professional and personal life. However, these skills are not taught through our training. Physicians are humans, too, and some are better than others at separating their emotions from their professional lives for better or for worse.

Darren: You acknowledge taking his death hard and I think that is

healthy. I am pretty certain that not caring at all, or *pretending* not to care, can have negative long-term effects. My father used to come home with chilling stories of death and suffering on the streets of Calgary during his days walking the beat, and later as a detective investigating heinous crimes. But rather than talk about the emotional impact these were having on him, he typically used a light-hearted tone, even to the point of sounding shockingly insensitive. In retrospect, and considering some of the haunting stories he shared with me just in the weeks before he died, I believe he had been using dark humour as a coping strategy to survive his emotionally arduous job.

Brian: Let me open up another theme we found in this case:

Relationship between Common-law and Parents

According to Saskatchewan's *Health Care Directives and Substitute Health Care Decision Maker Act* (Government of Saskatchewan, 1997) the next of kin in this case is the common-law spouse who "cohabits as a spouse in a relationship of some permanence." Although this act was vague in the definition of time needed for cohabitation to qualify as a common-law, we determined the patient's common-law wife as the next of kin. However, she was not a Jehovah's Witness, while patient's closest family members were. Initially, the entire family agreed to respect David's wishes for no blood products. However, near the end of his active treatment, as his prognosis worsened, his common-law wife requested transfusion of blood products. The substitute decision-maker is bound by law to act according to the patient's known wishes. The assumption is that the spouse is the individual most likely to know whether the patient is devoutly adherent to all religious tenets. In our professional judgement, the spouse's request was incongruent with the patient's prior known and previously stated wishes and hence we did not honour the request.

Darren: I am a bit confused by this. Of course, I was not a party to these circumstances, but selecting a sibling's or a parent's opinion over that of a spouse just seems inappropriate to me. Perhaps I am missing some of the particular details of this case, or the many factor influencing this choice, but I don't believe that my immediate blood relatives would make a decision about my wellbeing that would be truer to my own wishes than would my spouse. I cannot imagine how she must have felt by this choice made by her spouse's doctors.

Brian: If the patient himself had not, while he was fully competent, been able to affirm his beliefs as a Jehovah's Witness, we certainly would have had to honour his spouse's decision for the transfusion. This assumes that the spouse would know how devout a Jehovah's Witness David had been most recently.

Through my interviews with her, and explaining to her why we did not honour her request for a blood transfusion even though she was the next of kin, and would legally have been able to consent to a blood transfusion, I felt the love she had for him. She did not want to be alone and wanted to spend the rest of her life with him. Although it was clear that she did not have a positive relationship with his parents and sister, they all attended the family meetings faithfully and were respectful of each other. With this disagreement in the treatment plan for the patient, the rift was further widened. In the end, because I felt that the family's beliefs were more consistent with the patient's, I was approaching the parents instead more often for directions for the patient's medical care than the common-law wife.

Darren: It sounds so apparent that there was a deep chasm here, likely only made more apparent by these awful circumstances and the differences between their two positions on his medical treatment. Did both of his parents share the same views on their son's spouse, and on the choice for his medical treatment?

Brian: When I interviewed the parents and the sisters, they confided that they have been more estranged from their son than they would have liked. They blamed the distance in their relationship on the common-law wife. In the ICU, because there is so much equipment around the patient, only a few people can be allowed into the patient's room at one time. These three family members were always together seeing the patient; the common-law wife was never in the room with them at the same time. I did not have the chance to interview the mother and father separately, but the mother seemed to be more vocal about her feelings about the common-law wife whereas the father was somewhat more subdued. Unfortunately, I did not have a chance to explore this relationship further. The mother was always the one who was more affectionate, and who had her arms around her intubated son, talking to him. The father would usually be standing by his bed or sitting in the chair.

Darren: Clearly the internal family relationships were crucial elements of this case, and I imagine your decisions as members of

the professional team were made more complex by the balance you needed to strike in all of this. I am curious how the institutional relationships played out as another factor.

Relationships with the Health Liaison Committee

Brian: Yes, it was a key theme that emerged related to this particular case. The family and the church requested the involvement of the health liaison committee, *The Hospital Committee Network of Jehovah's Witness*. This international liaison service was "established to promote better understanding and to assist health care providers to treat patients without using blood" (Kulvatunyou & Heard, 2004). Unfortunately, when community health organizations become involved with patient care, some medical professionals find their interference obstructive. Fortunately, this was not the case with this Jehovah's Witness group. We actually found them quite helpful in providing social support for the family. They also provided extra medical literature – some more helpful than others – in our care for this patient. Most useful to me, they provided a documentary film (Watch Tower Bible and Tract Society of Pennsylvania, 2004) that is given to their Church members in regards to transfusion alternatives. Although some of the medical facts were not very accurately portrayed, it provided me with the vantage point of Jehovah's Witnesses. For example, it highlighted the fact of viral and bacterial infections quite extensively throughout the video and it appeared to me to be a scare tactic. In Canada, the risks of these infections are 1 in 913,000 units and 1 in 120,000 units for HIV[i] and hepatitis C respectively (Canadian Blood Services, 1999; Remis, Delage, & Palmer, 1997). These risks are substantially lower than the risk of death if the blood transfusion is required for life. But the risk for viral infections was highlighted throughout the video with interviews, and with emphasis by having it appear in print across the screen.

Darren: This does seem like a clear example of propaganda, or at the very least, some imbalanced persuasion that should not outweigh the integrity of the medical staff's data or experiences. I think this committee existed not to assist professionals with good decisions, but to ensure that the wishes of the religious community were followed according to their own standards rather than any outside considerations. What was the final theme you identified here?

Brian: Our experiences with this patient seemed to me to have a core of equity and justice as a key factor in this entire episode.

Relationship between This Case and Society

Erythropoietin (EPO) was used in this patient to stimulate the bone marrow to produce more red blood cells. However, the Saskatchewan government only pays for EPO in renal failure patients. Thus, the expenses fell upon the shoulders of the patient's family because of their religious choices. The team had to balance the exorbitant cost of EPO and the potential benefit to the patient. One could argue that this was unjust, as other publicly funded and expensive management techniques were already employed for this patient. But the patient chose a more complicated and expensive management course himself, and his stay in ICU was hence extended, increasing the cost of his medical care. We know of no system wherein these allocation decisions are subjected to fair adjudication.

Darren: I am not sure monetary values can ever be assigned to human life. And even though in this economic climate where health care resources are tight, I do not think there can be a correct answer to this. There seems to have been a "culture clash" between the medical profession and a faith community that echoes the experiences recounted in Anne Fadiman's book *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures* (1997). She does a thorough and thoughtful job of collecting, documenting, and analyzing the details of what went wrong in one very complex medical case. The details of the situation are different of course, but the messy conflicts and negative patient outcomes were very much along the same lines.

Brian: I recently attended a Bioethics session presented by a lawyer and PhD scholar with a university's Office of Medical Bioethics in a Faculty of Medicine. She was introducing the day's session with some case presentations that included one involving Jehovah's Witnesses. She presented concepts of autonomy, coercion, and issues surrounding the Watch Tower Society, which is the governing body for Jehovah's Witnesses. In the end, although she also presented the Supreme Court of Canada ruling (Supreme Court of Canada, 1993a), she suggested to a room full of junior physicians that we should consider transfusing a Jehovah's Witness based on the predicament that patients have been coerced to refuse blood transfusions and that a new court ruling is now due,

nearly twenty years later. This was not received well by the audience, including me. After the seminar, I asked the other physicians around me and determined that they would not transfuse either, given the ruling by the Supreme Court of Canada. We would not want to engross ourselves into a legal battle, especially when we were newly coming out to practice. We may not agree with the principals of Jehovah's Witnesses, but with the Supreme Court ruling, we feel that our hands are tied with regards to this ethical controversy.

Darren: It is interesting how many competing ideas and ideologies we sometimes have to balance in our daily work. For you and your team in this case, the results were fatal, but clearly following a particular set of guidelines. Do you think your decision to acquiesce to a court ruling should supersede your other professional imperatives to sustain life using proven procedures? I am not suggesting any lack of courage, but could there be some room for a change of heart as you gain further confidence in your field? Appreciating how impossible and unrealistic it is to be neutral under any circumstances, I am also wondering to what extent your own world views impacted your thinking about this case.

Brian: I am not a Jehovah's Witness. In addition, other than attending a Catholic private elementary school in my early school years and belonging to a protestant church for a few years in my teenage years (because of coercion by some family friends), I have not been a devout observer of any religion. Without immersion into the church social and worship circle, I may carry a bias for the primacy of preserving life as taught by many years of medical training. The exploration of this case will be influenced by my experience and my beliefs in a very complex way.

Jehovah's Witnesses present a challenge to their treating clinicians. They have poorer prognoses when compared to their counterparts who do not refuse blood products. As long as patients are aware of this, medical practitioners must respect their autonomy when they choose to uphold their religious belief – both because of ethical and legal reasons. However, clinicians must not view this as the patients forfeiting life. Jehovah's Witnesses do want to live, and their refusal of blood is by no means a suicidal attempt as has been argued in the past in court. Blood transfusion, particularly early on in therapy, may have saved this patient's life. However, the patient's autonomy was respected and the family was satisfied with his care to the end.

Darren: It seems like you have "made peace" with your course of action in this case, but I am left wondering if you are still a bit haunted by the role you were, in some senses, forced to play in this man's life under your care. Yes, David and his family held a differing world view, and a particular refusal for certain medical treatments, but I am not sure that I would support the view that refusing a transfusion, and thereby hastening his preventable death, was the correct one. Fadiman (1997) writes about the competing cultures in the case she documented:

> As powerful an influence as culture of the…patient and her family is on this case, the culture of biomedicine is equally powerful. If you can't see that your own culture has its own set of interests, emotions, and biases, how can you expect to deal successfully with someone else's culture? (p. 261)

In this case, I believe the medical community certainly found a way to honour what they felt were this patient's wishes in spite of a conflicting medical worldview.

My career has been focused on promoting the need to respect differences, including religious beliefs, but I believe there must be some line in the sand at some point. I am thinking right now of common cultural practices that involve genital mutilation, and our Canadian belief that imposing Western ideals around autonomy and the protection of individual dignity can *and should* trump harmful practices in this instance. In my view, your case falls into a similar ethical category. If you know a procedure will save a person's life, I think you have the professional and medical imperatives to do so, even overriding personal and religious freedoms if necessary, as in this case. Do we really need a court decision to affirm this? Are there not some things worth fighting for, even at the risk of an extended and expensive legal battle?

Brian: We do not need a court decision to affirm this. But unfortunately, in this medico-legal atmosphere (that is not, incidentally, as litigious as other countries like the Unites States of America), we do have to abide by previous court decisions even though I am having some ethical unrest about the decisions made in this case. For the Jehovah's Witnesses, living in our world may not be their ultimate goal, but ensuring a place in Eternal Heaven may be. Physicians who are new in their training must come to terms to this and understand that there must be a balance between religious freedom and health care. However, in the end, this may be impossible and one side will always win.

Final Reflections

Darren: Re-reading this dialogue now, a few years later, I am a bit overwhelmed again by the complex relationships embedded within this dialogue that include moral and ethical, professional and legal, individual and familial, personal and theological, and both private and public. These relationships necessarily remain unresolved in this postmodern world.

For instance, looking at the distinction between the moral and the ethical – with moral generally being able to distinguish between right and wrong, and to live according to that which is right – morality is arguably the foundation of ethics, the philosophy of how morality guides human behaviour. Morally, then, doctors accepted the individual right of a patient to refuse a particular medical treatment notwithstanding the likelihood that death would – and in fact did – ensue as a result. Thus, they respected the autonomy of the patient. This decision caused Brian distress, as death was clearly avoidable, and because doctors have a duty to deliver care. If the assumption is that life is to be preserved by the medical profession using all means and expertise to do so, then it may be decided that the doctor's inaction in this case was immoral. However, as a person with autonomy and dignity, the patient's desire deserves to be respected (Canadian Medical Association, 2004).

Professionally and legally, could the doctor be considered complicit in the patient's death? A wider emerging issue is, should a doctor be forced to be complicit? In Ontario, recent rulings suggest the answer seems to be yes (Pfeffer, 2017). Indeed, Canadian law held for many years that no one could assist in taking the life of another. Justice Sopinka in the *Rodriguez* case, Justice Sopinka stated,

> I am unable to discern anything approaching unanimity with respect to the issue before us… To the extent that there is a consensus, it is that human life must be respected and we must be careful not to undermine the institutions that protect it…. To permit a physician to lawfully participate in taking a life would send a signal that there are circumstances in which the state approves of suicide…. I am thus unable to find any principle of fundamental justice is violated by s. 241(b). (Supreme Court of Canada, 1993b)

Years later the same court found that a person could legally assist someone who wished to commit suicide, and directed Parliament to change the law to accommodate such cases (Supreme Court of Canada, 2015). The point is that if a citizen can commit suicide – which has never been a criminal offence – with

the help of certain people, then it is now very clear that someone may refuse certain medical treatment for whatever reason they wish – religious or not. The issue of life or death is not, therefore, bound to religious decision-making as far as the institution and the medical profession are concerned, or it ought not to be so.

Regarding the individual and familial relationships, then, what is the nature of the obligation between a patient and family members insofar as the health of the patient is concerned? In the above case, there was unanimity between some of them for religious reasons. The nature of every Canadian's right to freedom of religion is based as an individual right, but given more recent case law from the Supreme Court of Canada, this right also has collective implications and as such, the right may be held by a collective and an institution (Donlevy, Fehan, & Bowl, in press). Because that is the case, it is incumbent upon those in the medical profession and indeed the profession itself to recognize the fundamental importance, not only of freedom of religion, but also freedom of conscience.

Perhaps Chief Justice Dickson expressed it best in the R. v. Big M Drug Mart Ltd., when he wrote:

> An emphasis on individual conscience and individual judgement… lies at the heart of our democratic political tradition. The ability of each citizen to make free and informed decisions is the absolute prerequisite for the legitimacy, acceptability, and efficacy of our system of self-government. [There is a] centrality of the rights associated with freedom of individual conscience both to basic beliefs about human worth and dignity and to a free and democratic political system. (Supreme Court of Canada, 1985)

We are social animals by nature but we must also respect the fact that we create our own meaning in life through our personal experiences and expressions of freedom. The choice of existence or non-existence is therefore not necessarily religious, but rather, it is human in nature. A patient's family is important in such decisions but it finally comes down to each person's freedom of conscience to choose life or death.

Notes

1. Brian is a pseudonym for the physician (M.D., FRCSC) who did not wish to be identified in this article, and who assigned sole authorship and intellectual property rights to Lund. Some personal information has been changed to protect the physician's anonymity.

2. All names used in this account are pseudonyms. The author is grateful to the reviewers of this piece who generously offered suggestions and ideas for its improvement, but takes full responsibility for the final version of the paper.

3. Following the *Carter* decision, the Canadian Parliament – after much ado – passed *Bill C-14*. Section 14 of the *Criminal Code* remains the law, but section 227 protects a "medical practitioner" and a "nurse practitioner" when they provide "medical assistance in dying." Section 241.2(1) states the class of people who may receive assisted suicide:

> **241.2 (1)** A person may receive medical assistance in dying only if they meet all of the following criteria:
> **(a)** they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada; **(b)** they are at least 18 years of age and capable of making decisions with respect to their health;
> **(c)** they have a grievous and irremediable medical condition;
> **(d)** they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
> **(e)** they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

If a person is eligible under section 241.1(1), she may legally be assisted with her suicide provided that all of the enumerated statutory preconditions in section 241.2(2)(3) have been met.

REFERENCES

Bodnaruk, Z. M., Wong, C. J., & Thomas, M. J. (2004). Meeting the clinical challenge of care for Jehovah's Witnesses. *Transfusion Medicine Reviews, 18*(2), 105-116.

Canadian Blood Services. (1999). *Nucleic acid amplification testing for Hepatitis C*. Retrieved from http://www.blood.ca/centreapps/internet/uw_v502_mainengine.nsf/page/NATSCPPRHCV?OpenDocument

Canadian Medical Association. (2004). CMA Code of Ethics. Ottawa, ON: Canadian Medical Association. Retrieved from https://www.cma.ca/Assets/assets-library/document/en/advocacy/policy-

research/CMA_Policy_Code_of_ethics_of_the_Canadian_Medical_Association_Update_2004_PD04-06-e.pdf

DiPietro, M. (1987). Fact finding faith. *Journal of Contemporary Health Law and Policy, 3*, 185-201.

Donlevy, J. K., Feehan, K. P., & Bowl, P. (in press). A community's right to freedom of religion: Loyola High School v. Quebec. *The Supreme Court Law Review*.

Fadiman, A. (2007). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures*. New York, NY: Farrar, Straus & Giroux.

Government of Saskatchewan. (1997). *Health care directives and substitute health care decision makers act*. Saskatoon, SK: Ministry of Justice. Retrieved from http://www.qp.gov.sk.ca/documents/English/Statutes/Statutes/H0-001.pdf

Joshi, K. (2012). Teaching about religion in schools. In J. A. Banks (Ed.), *Encyclopedia of Diversity in Education* (pp. 1796-1801). Thousand Oaks, CA: Sage.

Kleinman, I. (1994). Written advance directives refusing blood transfusion: Ethical and legal considerations. *American Journal of Medicine, 96*(6), 563-567.

Kulvatunyou, N., & Heard, S. O. (2004). Care of the injured Jehovah's Witness patient: Case report and review of the literature. *Journal of Clinical Anesthesia, 16*, 548-553.

Macklin, R. (1977). Consent, coercion and conflicts of rights. *Perspectives in Biology and Medicine, 20*(3), 360-371.

MacLaren, G., & Anderson, M. (2004). Bloodless intensive care: A case series and review of Jehovah's Witnesses in ICU. *Anaesthesia and Intensive Care Journal, 32*, 798-803.

Norris, J. (2008). Duoethnography. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 233-236). Thousand Oaks, CA: Sage.

Norris, J., & Sawyer, R. D. (Eds.). (2017). *Theorizing curriculum studies, teacher education, and research through duoethnographic pedagogy*. New York, NY: Palgrave Macmillan.

Norris, J., Sawyer, R. D., & Lund, D. E. (Eds.). (2012). *Duoethnography: Dialogic methods for social, health, and educational research*. New York, NY: Routledge.

Ontario Court of Appeal. (1990). *Malette v. Shulman*. 67 DLR (4th) 321. Toronto, ON: Ontario Court of Appeal.

Pfeffer, A. (2017, June 15). Ontario doctors challenge policy forcing referrals for medically assisted dying**.** *CBC News*.

Retrieved from http://www.cbc.ca/news/canada/ottawa/medically-assisted-dying-ontario-college-1.4159660

Remis R. S., Delage, G., & Palmer, R. W. (1997). Risk of HIV infection from blood transfusion in Montreal. *Canadian Medical Association Journal, 157*, 375-382.

Sawyer, R. D., & Norris, J. (2013). *Duoethnography: Understanding qualitative research.* New York, NY: Oxford.

Supreme Court of Canada. (1985). *R. v. Big M Drug Mart Ltd.* 1 SCR 295. Retrieved from https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/43/index.do

Supreme Court of Canada. (1993a). *Ciarlariello v. Schacter*. 100 DLR (4th), pp. 609 & 618. Ottawa, ON: Supreme Court of Canada.

Supreme Court of Canada. (1993b). *Rodriguez v. British Columbia (Attorney General).* 3 SCR 519, pp. 607-608. Retrieved from http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/1054/index.do

Supreme Court of Canada. (2015). *Carter v. Canada (Attorney General)*.1 SCR 331. Retrieved from https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do

Thomas, I. G., Edmark, R. W., & Jones, T. W. (1968). Some issues involved with major surgery on Jehovah's Witnesses. *American Surgeon, 34*, 538-544.

Thurkauf, G. E. (1989). Understanding the beliefs of Jehovah's Witnesses. *Focus on Critical Care, 16*(3), 199-204.

Watch Tower Bible and Tract Society of Pennsylvania. (2004). *Transfusion alternatives: Documentary series* [video]. Brooklyn, NY: Author.

Watkinson, A. M. (1999). *Education, student rights and the Charter*. Saskatoon, SK: Purich.

Address for Correspondence
Darren Lund
Professor, Werklund School of Education
University of Calgary
E-mail: dlund@ucalgary.ca