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Competing religious and biomedical notions of treatment

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Introduction

In his passionately written book, *The American Religion* (2006), Harold Bloom, literary and religious critic and Sterling Professor of Humanities at Yale University, distinguished five religious communities that he labelled as ‘indelible strands of the American Religion’ (2006: 15). Along with Mormonism, Christian Science, Seventh-Day Adventism, and Pentecostalism, these included Jehovah’s Witnesses. According to Bloom, these religious groups were successful in exporting the ‘American Religion’ abroad, or rather in ‘convert[ing] many millions of people to their idiosyncratic American visions of God, death, and judgement’ (Bloom 2006: 20). There is no doubt that Bloom’s portrayal of Jehovah’s Witnesses is far less sympathetic than other ‘strands’ of the ‘American Religion.’ Speaking on behalf of American society as a whole, Bloom emphasized that

As a public, we think of the Witnesses with some embarrassment, since they seem to offend many of the justified norms of American society. Their refusal of patriotism offends primarily in wartime; in peace it seems not much more bothersome than their reputed denial of birthday celebrations, even to little children. Far more serious is their fierce stand against blood transfusions, since in the name of sanctifying life they so often pragmatically welcome death.

(2006: 176–177)

Bloom’s depiction of Jehovah’s Witnesses (JWs) may be considered biased; nonetheless, it aptly reproduces commonplace ‘knowledge’ about this religious community. Despite the visibility and steady growth of this religious group, JWs have been largely overlooked by both historians and (medical) sociologists and anthropologists; social scientists have mainly been interested in JWs’ religious beliefs, doctrinal issues, conversion, their relationship with the state, and their persecutions in Nazi Germany and Western countries (especially in the US and Canada), and in Central and Eastern Europe after the fall of the Berlin Wall (e.g. Besier and Vollnhals 2003; Côté and Richardson 2001; Knox 2011; Penton 1985). Foregrounding refusal of blood transfusions as one of JW’s major characteristics, Bloom’s view bespeaks a
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troublesome and ethically challenging position that has been shared by representatives of biomedicine, bioethics, and the public alike for the past decades when it comes to JWs and blood.

In the ritual symbolism, imaginaries, metaphors, and lived experience of many religious and ethnic communities, blood occupies a central position. Blood has captured the attention of religious scholars and historians among others (Anidjar 2014; Bynum 2007; Lederer 2008). Within socio-cultural and medical anthropology, by indexing relatedness or ‘relationality,’ blood emerges as simultaneously an object of biomedical procedures and kinship classifications (Carsten 2011). Therefore, it is not surprising that anthropological scholarship has traditionally foregrounded blood donations (e.g. Copeman 2009; Sanabria 2009; Simpson 2011) and has paid little attention to refusal of blood transfusions based on religious and/or ethnic reasons (e.g. Schwarz 2009). On the other hand, bioethical scholarship regularly discusses the refusal of blood transfusions by Jehovah’s Witnesses in relation to informed consent and autonomy (Bodnaruk et al. 2004; Bock 2012; Muramoto 1998; Savulescu 2007; see also Rajtar 2013).

Jehovah’s Witnesses are a religious community of over 8,579,000 worldwide and over 165,000 active members (called ‘Publishers’) in Germany as of 2018 (Watch Tower 2018). Witnesses are a globally active, highly centralized, and hierarchical organization in which worldwide activities had been directed by the Governing Body situated in Brooklyn, New York, since 1909, before moving to Warwick, New York in 2017. Germany belongs to the ‘traditional heartlands’ of Witnesses, along with Great Britain and the United States; Bible Students (the name of JWs was adopted at the convention of Bible Students in Columbus, Ohio in 1931) have been present there since the 1900s.

In the following, I address JWs’ position on blood and blood transfusions and provide some information on the ethnographic data that constitute the background of this chapter. I further illuminate the blood-transfusion-related hospital experiences of a Jehovah’s Witness that are representative for many Witnesses whom I encountered during my fieldwork in Germany. I argue that by refusing blood transfusions, JW patients challenge the authority, agency, and efficacy of physicians.

Jehovah’s Witnesses and blood

Early on, the Watch Tower Society expressed little interest in health and sickness; interestingly ‘the Governing Body generally shied away from any official involvement in caring and curing’ (Cumberland 1986: 472). According to William H. Cumberland (1986: 473), Witnesses’ ‘preoccupation with blood’ became an issue discussed in The Watchtower, the flagship magazine of JWs, as well as in the book Creation penned by the second president of the Society, Joseph F. Rutherford, in 1927. In those early years before the establishment of blood banks (1937; see Starr 1998: 82) and the widespread use of blood transfusions during WWII, debate focused on the consumption of (improperly) bled meat. This changed in 1945, when The Watchtower denounced the movement of blood between bodies as ‘pagan and God-dishonoring’ (Lederer 2008: 187), based on, among other scriptural references, Genesis 9:3–4, Leviticus 17:13–14, and Acts 15:28–29. The latter passage requires Witnesses ‘to keep abstaining from things sacrificed to idols, from blood, from what is strangled, and from sexual immorality’ (Watch Tower 2013). This prohibition concludes by promising that ‘If you carefully keep yourselves from these things, you will prosper. Good health to you!’ (ibid.). According to the Society’s interpretation, the recipient of a transfusion ‘was “feeding upon a God given soul contained in the blood vehicle of man or of fellow man.” Thus, there was no difference between taking blood orally and taking it intravenously’
(Cumberland 1986: 474). By claiming ‘the sacredness of life and blood’ as one of the religious community’s ‘major doctrines’ (Penton 1985: 202–206), the Watch Tower Society insists on participation in a sound relationship with God through the act of ‘abstaining from blood.’ Between 1961 and 2000, accepting a blood transfusion was considered a ‘disfellowshipping offence’ that would result in exclusion from this religious community. Since 2000, the Watch Tower Society no longer ‘disfellowships’ such Witnesses; instead ‘the individual revokes his [sic] own membership by his own actions’ (Muramoto 2001: 37).

A ‘no blood transfusion’ policy

Anthropological and social science scholarship has often drawn on Mary Douglas’ analysis of blood as a natural symbol (see Copeman 2018 for a succinct review). Thus, it is not surprising that in his analysis of the ‘blood transfusion taboo,’ the Dutch anthropologist Richard Singelenberg referred to Douglas and claimed that

Rules of pollution and purity are instrumental in creating structural boundaries around group members. . . . For the faithful, the relinquishing of this possibly life-saving medical therapy can be considered a sacrifice as part of the price of membership.

(1990: 520–521)

He further argued that the excommunication (i.e. ‘disfellowshiping’) of Witnesses who agreed to blood transfusions might have been interpreted as the Society’s answer to the increasing application of blood transfusions and rapid progress of medical science, ‘in particular in the field of cardiac technology’ prevalent in North America during the 1960s (see also Cumberland 1986: 474–477; DeMichelis 2017: 2153–2155). According to Singelenberg, ‘gradually, the medical work was confronted with the doctrine, resulting in an increasing tension between two value systems’ (1990: 517). Hence, medical journals from the 1940s,’50s, and ‘60s depicted Witnesses as ‘irrational,’ ‘troublesome,’ and ‘primitive’ (DeMichelis 2017: 2154). As Carey DeMichelis among others, put it

Witness patients and families challenged biomedical authority by insisting on a fundamentally different interpretation of what blood means and how it ought to be used—a subject on which the medical discipline also claimed authority.

(2017: 2154)

To sum up: drawing on their interpretation of the Bible, Witnesses contend that the biblical directive to ‘abstain from blood’ applies to consumption, storage, and transfusion of blood in its entirety and its major components: red blood cells, white blood cells, plasma, and platelets (Ridley 1999). Both JW literature (e.g. Watch Tower 2006) and JWs I encountered during my fieldwork (2010–2012) were unanimous in citing the necessity of making a choice and their own responsibility in holding true to their decision in regard to blood fractions and common medical procedures involving JWs’ own blood (e.g. cell salvage, hemodilution, or use of a heart-lung machine). The result of this decision was to be documented in their advance directive: a document that is commonly understood, albeit criticized, in bioethics as an expression of patients’ autonomous choice in their treatment.

It is worth noticing that Witnesses refuse blood transfusions—standard and commonly utilized biomedical procedures—on religious grounds (irrespective of donor identity) while they simultaneously insist on obtaining the best possible medical treatment. In doing so,
they have become the best-known religious proponents of a ‘no blood transfusion’ policy in the last decades and thus present a challenge for medical and legal professionals. JWs’ impact on American legal history has been well documented (e.g. Knox 2013). In the US, where courts have long played a ‘significant role in policy-making’ (Hirsch 2008: 2) and in Europe more recently, JWs have significantly contributed to the ‘judicialization of religious freedom’ (Richardson 2015: 7–9). Nonetheless, as I have outlined elsewhere (Rajtar 2016), contrary to the Witnesses’ active engagement with the judiciary in regard to religious freedom, JWs in Germany, for the most part, do not turn to courts to sue physicians who could have ordered a blood transfusion against their wishes. This is especially the case in medical malpractice litigation that is a rare occurrence in Germany or England, unlike in countries such as the US; the majority of medical malpractice claims are settled out of court there (Roudik et al. 2009).

Ethnographic research

Ethnographic fieldwork with Jehovah’s Witnesses was conducted in Germany, mainly in Berlin primarily between 2010 and 2012 (nine months in total). It focused on the entanglements of religious, legal, ethical, and emotional issues emerging from the refusal of blood transfusions. Along with participant observation in Kingdom Halls, at Witness congresses, and homes, numerous informal talks that continued long after the ‘core’ of my fieldwork was concluded, I carried out biographical and semi-structured interviews with adult Witness patients, Witness nurses (all female), members of the Hospital Liaison Committees and of the Hospital Information Services in the German Branch Office in Selters/Taunus, all male. In total, I conducted forty audio recorded interviews with fifty-one Witnesses aged between twenty-six and over eighty, out of which thirty-three were female. There were about fifty-five Hospital Liaison Committees (HLCs) in Germany that counted five members on average. The ten-member HLC in Berlin belonged to the biggest. Members of HLCs are responsible for publicizing the Society’s position on blood transfusions and advising doctors and patients on treatment alternatives. On a daily basis, the HLC in Berlin is responsible for Witnesses living in Berlin and large parts of the federal state of Brandenburg. Additionally, I interviewed seven physicians (anaesthetists, surgeons, and a gynaecologist), three of whom were JWs.

In the following, I present a narrative of three hospital encounters of Mrs. Elsa Biene, a Jehovah’s Witness in her sixties who lived in Berlin. Elsa was an energetic and good-humoured woman as well as an active member of her congregation; she was a full-time pioneer for many years and regularly visited other, usually elderly and severely ill, members at their homes and care homes. Elsa’s hospital experiences illuminate changes to the physician-patient relationship for German JW patients in recent decades; in this sense, her narrative may be ‘representative’ for many other Witnesses I met during my fieldwork.

The story of Mrs. Elsa Biene

Elsa was baptized as a JW when she was in her early twenties. She recalled that while blood never seemed significant during her study of the Bible, she had been surprised to find out how often health topics were covered in its pages. She told me:

I was just surprised that the Bible [says] a lot about health issues, quarantine, infectious diseases, and I really thought that was great. When I heard that JWs refuse
blood transfusions, it wasn’t an issue for me. Because I said to myself, God created humans so he knew what he was doing when he forbade blood and so on. This was not an issue and it . . . didn’t concern me.

In the early 1970s, while in advanced pregnancy, she was hospitalized after her amniotic sac broke. Her husband was sent home and subsequently, the attending (female) physician, citing the rhesus factor, demanded that Elsa consent to a blood transfusion. When she strongly opposed the idea and emphasized that she is a JW, the doctor’s behaviour changed. As Elsa remembered: ‘She said, you know that your child will be insane. And I answered: “You know, this will be my insane child that I will have to cope with?”’ And she was so angry.’ The physician departed, leaving Elsa in the hands of a completely inexperienced midwife apprentice who did not understand German. Nevertheless, the baby was delivered quickly and without complications. Having suffered from anaemia her whole life, Elsa was given iron supplementations post-delivery that were intended to strengthen her blood volume. She was not informed, however, that the iron could affect her baby, who she was then breast-feeding. Elsa recounted that the baby, whose blood was rhesus positive, broke out in a ‘terrible rash.’ The child was taken to the children’s clinic and the attending physicians saw fit to immediately conduct a blood transfusion. Elsa recalled:

We went to the children’s clinic, at [X] road; we wanted to talk to the physician. And she asked us: ‘Did you reconsider the blood transfusion?’ My husband answered: ‘I will agree under one condition.’ She was pleased and I was shocked and I thought that he couldn’t do it. And he told her: ‘I want it in writing from both you and your chief physician that blood transfusions are completely harmless and that this will definitely work.’ He wanted to have three or four signatures. She answered that this would be impossible. So, he said, in this situation, ‘I don’t understand why we should sign. Why should we assume the responsibility? We don’t want a blood transfusion.’

Elsa’s account of the hospital encounter highlights the ultimate ambivalence of blood transfusions as seen from a Witness perspective. Elsa’s husband did not question the treatment itself; neither did he mention biblical reasons for their refusal. Rather he challenged the implicit biomedical ‘truth’ that governs the utilization of blood transfusions: that they are always beneficial to the patient’s body.

The baby was eventually returned to the couple in a state that made Elsa think about the consequences of their decision. She admitted that:

I had no idea how bad it was. You have to imagine: he looked like someone put a cigarette out on him. Really very, very big . . . round spots. As if his whole body was covered in blotches. I had to ask myself for the first time: was it right what you just did? But we took the child.

However, once a paediatrician recognized that the boy had ‘had an allergic reaction’ and intervened, the baby recovered within days.

In the late 1980s, Elsa was taken to the hospital due to a severe attack of diarrhoea. The situation was such that Elsa could not even recognize herself in the mirror due to her grey complexion and weight loss. Upon arrival at the hospital, six or seven physicians approached
her claiming that she ‘need[ed] a blood transfusion.’ This is how Elsa recounted her conversation with doctors:

I said, ‘No, no, no.’ ‘But you have to.’ I said, ‘I don’t have to do anything. I told them, I still can walk and I will certainly manage to make a call. A telephone was right there.’ I said, ‘I can call my husband and I can call a cab. Even if I have to crawl on all fours, I am leaving without a blood transfusion.’ . . . Anyway, there was a physician and she said: ‘You know what you need? You need a psychiatrist. Would you agree [to meet with a psychiatrist]?’ I answered: ‘as long as I am not getting a blood transfusion, I can even meet with a psychiatrist. I don’t care!’ ‘Very well, I’ll make you an appointment.’

The next day Elsa went to a psychiatrist for the first time in her life. She recounted being deeply disappointed, for instead of the ‘warm-hearted, motherly person’ (einen warmherzigen, mutterlichen Typ) that she expected, she was greeted by a young, ‘very modern’ looking woman (Frauchen). After asking about Elsa’s childhood, the psychiatrist inquired ‘So, what is your problem?’ Elsa’s answer was simple: ‘My problem is the hospital and blood transfusion.’ In the final report the psychiatrist wrote that Elsa is not approachable (mit dem Menschen ist nicht zu reden). This diagnosis was characterized as a ‘joke’ by Elsa’s gynaecologist. Elsa left the hospital and was prescribed over twenty pills daily which she was unable to digest and as a result, she quit taking them. In their stead, she was given injections of iron and, as she put it, ‘something else’ by her physician and within four weeks felt better.

In the early 1990s, Elsa was diagnosed with ulcerative colitis (colitis ulcerosa) and underwent a colectomy. In order to avoid her prior negative experiences, she decided to choose the hospital herself. She phoned a member of the recently established Hospital Liaison Committee of JWs and received the name of an elderly professor, well known for his ‘bloodless’ surgeries on JWs. Carrying her very first advance directive, she went to the hospital, but had to be examined by another physician initially. Like the others, the doctor concluded that Elsa needed a blood transfusion, to which she again objected:

I told him that is why I’m here because I don’t want to have [a blood transfusion]. . . . He said, ‘well, nobody will ever know if you have a blood transfusion or not. It doesn’t matter. . . . You don’t have to tell anybody.’ But I answered: Somebody else [God] is listening and I will have a bad conscience. ‘Oh, it can’t be so bad.’ I said, ‘It is. . . . At any rate, it is against my faith [Glauben].’

What is striking in this narrative of the conversation between Elsa and the doctor is his insistence on the autonomy and confidentiality of her choice. In the doctor’s view, Elsa is both solely responsible for her own (healthcare) choices and accountable only to herself. Simultaneously, he expects her to make what he would consider the ‘right’ and ‘reasonable’ decision. Contrary to this view, Elsa’s response illuminates her embeddedness in a network of relationships that go beyond herself and include allegiances to God and her religious community.

Eventually, Elsa met the professor to whom she had been referred to by the HLC who agreed to perform a ‘bloodless’ surgery under the condition that she accompany him to another hospital where she and her case would be presented to what she understood as ‘five students.’ Elsa welcomed this as an opportunity to give her ‘testimony’ (Zeugnis) to the students. The next day, however, she was overwhelmed by the at least 500 students in attendance at the
lecture. Labelling the display of her case as ‘a show’ performed by the professor and herself as the subject of it, Elsa described the whole event to me as follows:

First he showed the video taken during the examination. And then [he showed] a long video of my ruptured intestine. Enter a small professor like Rumpelstiltskin and the show starts. ‘Aren’t these beautiful pictures? In my whole life I’ve never seen anything this wild, this messed up.’ And I stood in the back, . . . fascinated, . . . and the students started to laugh. You know, when the professor started to talk, he forgot the world around him, that I was sitting there [Elsa laughed], that he was talking about my intestine. . . . And he said: ‘I promised to perform surgery on this patient. There is a problem, however,’ he added. He put his hands on my shoulders and continued: ‘this patient is a Jehovah’s Witness.’

An hour before the ‘big surgery’ Elsa was approached by an anaesthetist, who inquired as to whether she would agree to a blood transfusion after all. Like other Witnesses whom I encountered during my fieldwork and who were urged by medical personnel to undergo a blood transfusion, Elsa dug her heels in one last time. The surgery was a success and she left the hospital after several weeks.

The ‘body as specimen’

In her analysis of three conceptions of the body implicated in bioethics, Nora Jones (2011) writes about the ‘body as specimen’ ideology engendered in medical encounters that has managed to be ‘diffused’ into society as a whole. The ‘body as specimen,’ as she puts it, ‘characterizes the way in which Western biomedical practice and practitioners, infused with the legacy of Enlightenment philosophy and Cartesian materialism, have come to view the body of the patient as an object, as something in need of repair’ (Jones 2011: 74). In this ‘specimenization’ process a holistic image of the patient’s body is supplanted by isolated images: results of tests, CT or PET scans, and disease labels. Jones juxtaposes this conception of the body as specimen/-as-piecemeal with the ‘body as patient’ that is ‘bound up intimately with identity and worldview’ (2011: 74).

In his analysis of the body as specimen ideology, into which US physicians are conditioned in medical schools, Byron Good (2006) showed ‘how medicine constructs its objects,’ with no intention of ‘criticiz[ing] medicine or physicians for the “objectification” or “commodification” of health or personal suffering’ (2006: 66). Rather the phrase aims at highlighting ‘those distinctive “formative processes” through which medicine formulates or constructs that dimension of the world to which medical knowledge refers’ (ibid.). The experiences of Elsa and other JW patients and nurses confirm that the training of German physicians may have produced similar results. On a summer afternoon in 2010, I spoke with two Witnesses. Commenting on the approaches that doctors take with patients at her workplace, one of them, a JW nurse in her mid-fifties, emphasized that their approach is determined by their ‘training program.’ One approach, the nurse explained, was to focus on ailing body parts instead of the patient as a whole. She further continued:

They used to say before: where is the ear? Where is the nose? Yes, it was really like that. . . . As nurses then we always dealt with that [saying], yes, we all have a nose, we all have ears. If you could give us an additional name, then we could tell you which ear [you were looking for].
In her experience, the situation has changed and nowadays the physicians are, as she put it, ‘ready to speak [in] lengthy sentences.’ Nonetheless, even if the physician—(JW) patient relationship has transformed and even though one physician agreed to operate without the transfusion of blood, Elsa’s body in general and her intestines in particular were specimens for the medical students and other health practitioners.Furthermore, physicians perceived their patients as mere assemblages of body parts instead of seeing them as interconnected wholes and their decisions regarding medical treatment as embedded in a relational understanding of autonomy (Rajtar 2018). As Elsa’s encounters testify, young physicians are particularly prone to such a view. Let me cite the JW nurse again:

There are many young physicians in the clinic where I work. All are younger than me. The senior physicians too. They compete intensely against each other and now, when a patient comes and he has his own idea of how something should or should not be done, then they have a bit of a problem. . . . [They should] show a certain humility [Demut] and to be able to say: this is not a problem, we’ll see how we can solve it. Only mature people are able to do something like that. And I have to say, these are senior physicians or chief physicians [Professoren] who have some work experience that may be engaged on this level, not younger physicians. . . . If I say, ‘this has nothing to do with them [as physicians]: their quality is not doubted, [but] this is simply the wish of the patient’ . . . they should learn how to adjust to the [needs of the] patient.

According to Good, among others, medicine plays a special role in ‘mediating physiology and soteriology’ (2006: 70). He further argued that ‘however materialist and grounded in natural sciences, medicine as a form of activity joins the material to the moral domain’ (ibid.). Drawing on Max Weber, Good emphasized that ‘in contemporary Western civilization, medicine is at the core of our soteriological vision’ (ibid.). The observation of the JW nurse may be read along these lines. Adhering to a patient’s wishes regarding their treatment requires the physician to admit that their way of restoring health may not be universally shared and/or may be questioned; this ‘questioning’ has, however, nothing to do with physician’s skills and knowledge as such. Rather, it may be an expression of a different ‘soteriological vision.’

**The stakes: the nature of blood and life**

In their refusal of blood transfusions, Elsa and other JW patients challenge the authority, agency, and efficacy of physicians (see DeMichelis 2017: 2154). For them, blood is ‘sacred’ and abjuring a blood transfusion is grounded in the Bible. Blood indexes a full and absolute trust in God in the life/death situation. For instance, Ms. Neumann, a woman in her early seventies who had converted to JW in her early fifties, stating her reasons for refusing blood transfusion, insisted that,

I want Jehovah to be pleased with me. I want to be obedient; also obedient when it comes to my life. It won’t matter to me if I live longer on earth because of a blood transfusion, a few years perhaps. It could be possible. But eventually I wouldn’t be recognized in God’s eyes. . . . It’s very important to me to stay loyal.

If she had to die, Ms. Neuman continued, it would not be due to the lack of a blood transfusion, but rather because of failing organs or something bodily. She used a descriptor I so
often encountered during fieldwork: the general ‘imperfection’ (Unvollkommenheit) of human nature. Ms. Meier, a retired widow in her mid-seventies was one of rather few Witnesses I met—more common in elder than younger generations and including all Witness nurses at my field site—who has completely refused transfusions of both whole blood (and its major components) and blood fractions isolated from major blood components. For Ms. Meier, accepting a blood transfusion and thus becoming ‘disloyal’ (untreu) to God seemed the worst thing imaginable. She emphasized that she ‘would rather die than be disobedient to my Creator.’

The body’s ‘imperfection,’ its ‘temporary’ character, and the hope of everlasting life dependent on loyalty make the prolonging of life by a ‘futile’ and ‘lawless’ medical procedure meaningless to the believers. This is what JWs in my field site might have told physicians if given time and attention (see Cordella 2012). Instead, a growing number of JWs utilized a different strategy: they adopted a more medically ‘appropriate’ discourse and referred to the ever-present potential harm of a blood transfusion (see Ringnes and Hegstad 2016). Biomedical concerns about the safety of blood and blood products in the wake of the HIV/AIDS crisis (see Dressler 1999 on the HIV-contaminated blood supply in Germany) allowed JWs to draw on this narrative. Already in 1990, Singelenberg noted that ‘AIDS has become the ideal case to convince the outside world that the doctrine is legitimate’ (1990: 518). DeMichelis argues that ‘during the HIV/AIDS crisis, the foundational truth of the discipline (i.e. that blood was safe) was challenged, and knowledge about bloodless medicine became increasingly valuable. As a result, bloodless medicine was incorporated into the realm of biomedical truth’ (2017: 2156).

Due to the development of better screening techniques and a more restricted use of blood products, the ‘HIV/AIDS crisis’ in countries such as Germany may seem like a bygone era. Nonetheless, the transfusion of blood and blood components may still involve some health risks. According to a report of the Paul Ehrlich Institute (2012: 10), an agency of the German Federal Ministry of Health, there were 7,320 suspected cases of transfusion-associated reactions in Germany between 1997 and 2012. The same report stated that there were fifty cases of confirmed virus (Hepatitis B and C, and HIV in total) transmissions within the same time period (2012: 17); eighty-four patients died from transfusions of blood products, including a patient who died due to transfusion-associated graft-versus-host disease (TA-GVHD) (2012: 10), a rare reaction with a very high (about ninety per cent) mortality rate. TA-GVHD may be underdiagnosed, so its overall incidence is unknown. Its ‘primary pathology,’ as Randeep Jawa et al. (2015: 126) noted, lies in ‘the inability of the host to mount an immune response against donor lymphocytes.’

TA-GVHD is connected with microchimerism, a phenomenon that in recent years has gained increasing attention from scholars in medical humanities. It refers to the coexistence of two genetically different cell types in a receptive host; between ten and fifty per cent of transfusion recipients develop microchimerism ‘at least transiently’ (Jawa et al. 2015: 126–127). Microchimerism may be perceived, as Margrit Shildrick put it, as ‘a very specific form of somatic multiplicity’ (2019: 11). Shildrick argues that the very category ‘contest[s] the separation of self/non-self and disrupt[s] the expectation of genetic singularity’ (2019: 12) that lies at the heart of the biosciences. As such, microchimerism has the potential to destabilize ‘the socio-cultural imaginary of the autonomous, clearly defined and temporally situated individual’ (2019: 13).

From the Witness perspective, the phenomenon of microchimerism provides one more example against ‘the safety’ of blood transfusions. The association of microchimerism with TA-GVHD endangers the physical body; thus, JWs are highly discouraged from engaging in activities that could be harmful to the body such as extreme sports. More importantly,
however, microchimerism endangers ‘the uniqueness’ of every single JW. As Aaron Valley, a Witness online commenter put it, ‘Jehovah said that the life is in the blood. These instances of TA-MC [Transfusion-Associated Microchimerism] pollutes [sic] Jehovah’s design of his original human creation’ (Valley 2018). Drawing on one of the key scriptural references (Leviticus 17:11, 14) against blood transfusions, the author emphasized that ‘the life being referred to here could be the sequence of genetic code (DNA) that Jehovah uses to differentiate and remember who each one of us are [sic]’ (ibid., emphasis in original). He further explained that ‘our DNA is what makes us who we are. It is was [sic] makes us distinct and unique. If someone has two sets of DNA... he or she now share[s] the DNA of another individual which was never meant to happen’ (ibid.). The commenter utilizes bioscientific categories and the phenomenon of microchimerism to strengthen the argument against blood transfusions, which he sees as endangering the integrity of the body at the cellular level.

Concluding remarks: oscillating between the principle of autonomy and the relationality of care practices

Elsewhere, I argue that

many Jehovah’s Witnesses like to call themselves pioneers or leaders (Vorreiter). In their understanding, they are pioneers not only in regard to the expansion of religious freedoms. More importantly, they are pioneers in ‘fighting for’ their right to choice in biomedical therapies and for a more ‘conscious’ and restricted use of blood for everyone.

(Rajtar 2016: 63)

A growing number of scholarly publications, written in particular by North American-based scholars, have highlighted the JW’s contribution to the development of bloodless medicine as well as the shifting relationship between Witnesses and the medical community. JW’s contribution to bloodless medicine is usually presented as two-fold: They created ‘an early demand for bloodless procedures’ and they provided ‘a group of consenting participants,’ whose bodies were open to experimentation with bloodless medical technologies (DeMichelis 2017: 2158, 2157). In return, hospitals with established Patient Blood Management programmes ‘attract’ a growing number of patients who are not necessarily JWs alongside acquiring knowledge that can be applied in the treatment of all patients. As Rita Schwab et al. put it,

when caring for patients who decline transfusion, the staff has the opportunity to observe and learn about the body’s response to anemia and effective management of that anemia in ways that would not generally be available, sometimes with surprising results.

(2018: 348; see Rajtar 2016)

As a religious group, JWs may have contributed to the development of bloodless medicine programmes and technologies and perceive themselves as pioneers in fighting for religious freedom and the right to choice in biomedical therapy. This is at least the view forwarded by a number of North American-based scholarly articles and the Witness community itself. In Germany, due to the changing legal landscape, such as the 2009 law on living wills and the role of surrogate decision makers (Taupitz 2013) as well as changes in healthcare policy that favour ‘transparency, efficiency, and enhanced quality in German hospitals’ (Rajtar 2016: 63),
the rights of individual Witnesses to refuse medical treatment, such as a blood transfusion, are to be respected by attending physicians. However, this does not mean that German physicians view Witnesses like their US or Canadian counterparts, who find these patients to be ‘reasonable and cooperative’ (DeMichelis 2017: 2159). Rather, even in the context of a successful bloodless surgery they emphasize the need for physicians to ‘respect even “gross irrationality (grobe Unvernunft)”’ that places them in ‘personally and morally extraordinary circumstances that cannot be ignored’ (Heschl et al. 2018: 128, 129).

As I have argued elsewhere (Rajtar 2013), German physicians (and bioethicists) tend to draw on the Kantian concept of autonomy based on reason, whereas their US counterparts operate on an interpretation of Mill’s concept of autonomy based on choice and self-determination. As one of the ‘indelible strands of American Religion’ (Bloom 2006: 15) and a highly hierarchical religious organization with a US headquarters, JWs have also ‘exported’ the Mill’s Anglo-Saxon interpretation of autonomy through their publications and teachings globally.

Thus, Elsa and other JWs in Germany highlight individual judgement and choice over reason as a universal standard of right. An article written by representatives of the Hospital Information Services for JWs in Canada addresses the changing relationship between JWs and the medical community there. It begins with the statement:

Quality patient care entails more than simply biomedical interventions. Respect for the wishes, values, and preferences of patients are important elements of quality care. Unique aspects of Jehovah’s Witnesses’ beliefs may present physicians with ethical and clinical conflicts.

(Bodnaruk et al. 2004: 105)

Like other official statements published by JWs (e.g. Ariga 2009; Dirksen 2004; Ridley 1999), it foregrounds autonomy, a bioethical principle strongly rooted in and favoured by mainstream American bioethics (Wolpe 1998; cf. Jennings 2016 on the ‘relational turn in bioethics’) in order to protect JW patients’ right to self-determination.

Yet, as I have also highlighted (Rajtar 2018), the establishment and practices of members of HLCs draw on one more ethical tradition that emphasizes relationality and interdependence: the ethics of care. I argued that Witnesses globally are to be autonomous, choice-driven, and rights-aware citizens. Nonetheless, they also are to acknowledge—as they indeed do—care offered by HLC members and are conceptualized as relational persons.

(Rajtar 2018: 185)

Relational approaches to autonomy commonly question individualistic and rationalistic conceptions of autonomy. They view persons and their agency as socially and ecologically embedded (see e.g. Jennings 2016). Elsa’s story illustrates this ambivalent position in which JW patients find themselves (see Ringnes and Hegstad 2016 for the case of Norway). Upon her third hospitalization, Elsa was finally able to express her autonomous decision regarding blood transfusions in her advance directive. However, she still requested help from an HLC member in seeking a physician who would conduct a bloodless surgery. She also acknowledged her own embeddedness in a network of relationships that include God and her religious community.
Competing religious and biomedical notions

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Notes

1 JW’s statistics are considered reliable (see Stark and Iannaccone 1997: 138).
2 Drawing on internal instructions given by the Society to its local bodies of elders in the spring of 2000, the AJWRB (Advocates for Jehovah’s Witness Reform on Blood) argues that their ‘disfellowshipping’ policy was replaced by one of ‘disassociation.’ This meant that if the conduct of JW’s who accepted blood transfusions ‘becomes known and they are deemed unrepentant, they will be considered to have “disassociated themselves” ’ (AJWRB n.d.). Established in 1998 and critical to the Watch Tower Society Policy on blood and medical treatment, this international organization aims to, among others ‘promote meaningful change to WTS [Watch Tower Society] policy that enforces compliance through coercion, and misinformation’ as well as ‘support those who have been traumatized by WTS policies on blood transfusion and shunning’ (AJWRB n.d.).
3 Very much in line with Bloom’s assessment of JW’s as the strand of the ‘American Religion’ that ‘retain(s) a distinctively American aura’ (2006: 169), Singelenberg (1990: 518) also emphasized the fact that ‘the Society’s decision making . . . is primarily an American affair’ (see Knox 2011: 163 for a more radical statement). In this sense, the existence and practices of American commercial blood banks that paid for blood donations irrespective of donor habits (e.g. alcoholism or criminal tendencies) fueled the JW’s justification of their refusal (see in particular Starr 1998). This is a situation that would be unlikely in Europe where blood donations have usually been voluntary (see the classic work by Titmuss 1997). Nonetheless, the notion of blood as a commodity is echoed in the remarks of a number of German JW’s who claimed that blood transfusions constitute a good ‘deal’ (Geschäft) for participating organizations (e.g. the German Red Cross), hospitals, and/or physicians. An analysis of the latter is beyond the scope of this chapter.
4 For the sake of brevity and following my informants, I use the term ‘advance directives’ in general. In European comparative studies, two types of advance directives are usually differentiated: institutional (such as living wills) and proxy directives. In Germany, however, ‘traditionally,’ three main types of advance directives are distinguished: the living will (Patientenverfügung), the power of attorney (Vorsorgevollmacht), and the custodian directive (Betreuungsverfügung) (Taupitz 2013: 116). The German version of this document issued in 2010 carried by Witnesses emphasized a personal responsibility to God and textually invoked the right to self-determination as guaranteed by the German Constitution (Articles 1 and 2). Advance directives carried by JW’s were thus called ‘Medical Directive and Durable Power of Attorney for Health Care’ (Patientenverfügung und Vorsorgevollmacht in Gesundheitsgelegenheiten).
5 In regard to JW’s in Germany, for instance, Germany’s Constitutional Court ruled in favor of JW’s in 2005, thus enabling them to gain formal recognition as a ‘corporation under public law’ (Richardson 2015: 6); the Society had fought for this recognition for 15 years.
6 Interviews were conducted in German by the author; citations were translated from German into English by the author and edited by Jake Heida. All names are pseudonyms.
7 There are over 1,600 HLCs globally that comprise over 10,000 members (Ringnes and Hegstad 2016: 1678).
8 It has to be emphasized that the report only provides data on reported cases, but not on the incidence of transfusion-associated reactions (Paul Ehrlich Institute 2012: 24).
Bibliography


