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Karrie A. Oertli, DMin⁶

ED is a 39-year-old African American male with a history of primary sclerosing cholangitis (PSC) and is on the liver transplant list at a major state-funded university hospital. He has been battling PSC for years and developed other comorbid problems, including loss of appetite, chronic nausea, and vomiting, along with advanced cirrhosis of the liver. Primary sclerosing cholangitis is a chronic liver disease caused by progressive inflammation and scarring of the bile ducts of the liver. The inflammation impedes the flow of bile to the gut, ultimately leading to liver failure. Primary sclerosing cholangitis is felt to be an autoimmunity disease. However, the definitive treatment is liver transplantation.

Due to chronic abdominal pain, nausea, vomiting, and loss of appetite, and since he lives in a state where it is legal, he obtained a prescription to use marijuana from his primary care provider (PCP). In addition, he uses oxycodone for pain also under prescription from his PCP.

His liver score worsened over time, but eventually he moved up on the transplant waiting list and finally was called in for a pretransplantation physical examination. This testing included a urine drug screen, where he tested positive for opiates and cannabis. The transplant surgeons and the transplant team had no issues with his use of oxycodone. However, when he tested positive for marijuana, the transplant team rejected him, labeling him as “using drugs of abuse.”

He immediately obtained an attorney and pursued an appeal. An ethics consult was requested by the primary team.

Nursing Perspective

Paige Mingle, RN, MSN, CEN, CCNS, APN

This case shows again why the use of medical marijuana needs to be discussed. This is a young man with a family and due to a chronic condition had to find something to help him “live” with his condition. ED needed “medications” to help his chronic abdominal pain, nausea, vomiting, and loss of appetite and due to his “medication” choice he is denied a life-saving procedure.

As a nurse involved in ED’s care, I would need to know his complete medical history to understand what care/treatment he has already gone through or is currently going through. Second, I need to know my state laws regarding the use of scheduled drugs including the use of marijuana. Third, I need to know the policies of my hospital regarding the schedule drugs including marijuana. Fourth, I need to know the benefits and risk of using marijuana.

It is disheartening to know that ED was following his primary doctor’s treatments and the transplant team turned him down. Patients trust their care providers to do what is best for them. It is so hard to imagine that the transplant team at a state-funded university hospital, in a state that medical marijuana is legal, would or could reject ED. ED had obtained from his primary care provider a legal prescription to use marijuana. ED was not breaking any laws. Labeling him as “using drugs of abuse” due to his marijuana use was inappropriate. ED was also taking oxycodone which is a drug of abuse but the team had no issue with it.

ED problems related to his PSC can be treated with marijuana. Medical benefits of marijuana include amelioration of nausea and vomiting and the stimulation of hunger and general analgesic effects. Yes, marijuana has risk, but all medications including oxycodone have risks. As health care providers we have to weigh the risk and benefits when providing patients with medications to help determine the best options for care and treatment.

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This case shows the need for more research on the medical use of marijuana to examine laws regarding the use of marijuana; for states that have made marijuana legal to examine how the laws affect the policies for state-funded hospitals; and state-funded hospitals also need to examine their policies in regards to the laws. As health care providers we need to examine our personal views on the use of medical marijuana; how our views will affect our practice; and how our practice is affected by the state laws regarding the use of medical marijuana. As health care providers we must remember we are there to care and advocate for the patient's needs. If we are unable to meet our patient's needs due to our own personal views, we need to turn the care over to another provider that can meet the patient's needs.

Social Work Perspective

Dianne Harrington, MSW

It certainly appears that this person was poorly served by his medical community. It is unfortunate that his situation was not resolved in a timely fashion to prevent his untimely death. It appears to be more of a legal matter than an ethical one, as his request was within the law and within accepted medical standards. He was receiving appropriate, effective, and legal medication under the care of a physician but was denied care because the values of the transplant team were not in alignment with the patient's wishes.

We would have recommended that this case be presented to the hospital compliance officer and the designated patient advocate for review. This person's rights for medical care appear to have been violated. If the surgeons were not willing to participate in this procedure, the hospital should have looked at its own policies regarding a conscience clause, and the case should have been referred to a different team or a different hospital where the care could have been provided. Beyond that, the hospital legal department should provide education to the transplant team to make sure they are upholding their mission to provide care for their patients.

Ethics Perspective

Matt Stolick, PhD

Here we have a state-funded hospital in a state where medical marijuana is legal, and yet the transplant team disqualifies a patient for using medical marijuana. Is the transplant team using a federal guideline here? If not, then it seems this case can be resolved by revising their application of the "use of drugs of abuse" criterion to make medical marijuana an exception. Although it is true that the US federal government absurdly continues to label marijuana a Schedule I drug, a relic from the first of the 2 US "wars on drugs," this wrongly forces upon the physicians the socially constructed belief that there are no recognized therapeutic uses of "marijuana." This belief is maintained even when it clearly has many therapeutic uses, such as for nausea, vomiting, and loss of appetite being treated

in this case. The ethics committee should do everything within their power to have ED placed back on the list, exactly where he would have been if he was not eliminated because of marijuana use.

Another absurdity of this decision is that the transplant team is rejecting ED as suitable for a transplant because of the successful palliative treatment as recommended by his physician. Instead of being hailed for providing successful care, the physician now likely feels guilty for having harmed ED, ironically by alleviating his suffering. Yet the dilemma remains; physicians cannot comfortably prescribe cannabis to alleviate the suffering of patients in the United States because of possible negative repercussions for the physician. At least in this case we are in a state that recognizes the right to alleviate suffering using marijuana. The physician and all of the palliative care team involved must be up in arms, so to speak, realizing they are unable to practice medicine because the federal department of justice disallows such practice.

ED is, from the information here and for the purposes of the transplant team, a potential recipient of a liver but for his marijuana use. ED is representative of those for whom I dedicated my recent book, *Otherwise Law-Abiding Citizens: A Scientific and Moral Assessment of Cannabis Use*.¹ The cannabis debate is essentially one of science versus tradition. Scientifically, this plant acts on the brain to produce specific, repeatable results as do synthetic drugs. The neurological facts of cannabis are basically that there exist delta-9-tetrahydrocannabinol (THC) receptors (called CB1 and CB2) throughout the brain. The locations of high concentrations of these receptors are the locations of impairment for certain current diseases (perhaps even PSC as with ED in this case).² Hall, MacDonald, and Currow explain where CB1 and CB2 receptors are primarily located and how this correlates with the effectiveness of cannabis for specific symptoms and diseases. The distribution of CB1 and CB2 in the brain, immune system, and reproductive tissues is consistent with many therapeutic and recreational effects of cannabis. CB1 is mostly concentrated in brain systems involved in mood control, motor function, memory, food intake, pain, immune function, and reproductive functions. A high density of CB1 in the basal ganglia and cerebellum explains why cannabinoids interfere with coordinated movement. The absence of cannabinoid receptors in the lower brain stem explains why high doses of THC are rarely lethal.³

The cannabis plant consists of 483 chemical compounds, only 1 of which is THC (discovered in 1964), many showing evidence of therapeutic effectiveness of their own as well as making THC more therapeutic than without the other compounds.^{4,5} In addition to the sclerosis suffered by ED in this case, strong evidence and a plethora of case examples exist of cancer chemotherapy patients who regain their appetites and ability to smell and taste food when using cannabis (and not being asked to choke down the expedient synthetic THC capsules, therapeutically a poor substitute for smoked cannabis).^{3,6,7} If research was dictating policy rather than policy dictating research, cannabis would be available in safe, pharmaceutical grade form and recreationally would be over the

counter with an age limit and controlled as is ethanol/alcohol.⁸ The main fear preventing this from happening is the focus of the final chapter of my book.

Beauchamp and Childress (*Principles of Biomedical Ethics*, 6th ed.) emphasize that justified rationing of something such as a scarce liver should be done based upon 2 main factors: the likelihood of success and medical utility/need for the transplant. Ironically, ED's use of marijuana may actually increase the likelihood of success of a liver transplant. His use of marijuana neither increases nor decreases his need for the transplant, which at this point is apparently dire (given he is meeting with the team itself) and has a reasonable chance of success. An example of a relevant reason for excluding ED would be that the liver was incompatible with ED's body and would be surely rejected. Giving him the organ in such a case would be wrong and a waste of a valuable organ. Medical utility that need not be the only or primary criterion but certainly 1 criterion of any rational policy would instead give it to someone else who had a chance of success and equal or greater need than ED.

The situation such as this one with ED is stunning and sadening. There are neither good scientific reasons nor good moral reasons for continuing to demonize cannabis as we do in this country. Those in palliative care and hospice who work around death and dying for a living continue to experience the socially constructed negative stigma against all cannabis use as a nuisance interfering with their ability to do their best palliative work. Cannabis is a safe recreational drug and has many therapeutic applications. Although President Obama has carried out his campaign promise that the Drug Enforcement Administration (DEA) would not conduct raids of any clinics in states with a medicinal marijuana law (currently 15 states), he has done little else. Although he has claimed to use science rather than ideology, he has yet to remove cannabis from Schedule I, a place where it rests only because of ideology. The broader campaign promise was for "change." In lieu of this promise, it is time to finally legalize cannabis for both medical and recreational use.

Physician Perspective

Gregory T Carter, MD, MS

To date, 14 of 50 states currently have approved the medical use of marijuana for qualified patients. There are many more states with propositions on upcoming ballots so this is a very pertinent topic. I happen to practice in one of those states that does allow a physician to authorize marijuana for medical use to treat a variety of ailments including nausea and vomiting, as well as chronic pain.

Irrespective of one's viewpoint on medical marijuana, there are a number of ethical issues of concern in this case. First and foremost, the transplant team should never make a unilateral decision on possible "drug abuse" based solely on the results of a urine toxicology screen (although this happens all the time in medical practice). The transplant team should have

expressed their concern to the patient's primary care provider (PCP). If they had done that in the first place, the PCP could have told them that the patient had a valid authorization to use marijuana for medical purposes. Once again, the model of a "medical home" with the PCP orchestrating the decisions proves the best. However, another huge issue here is rejecting someone for an organ transplant simply for using marijuana, even when the use is legal. Remarkably many major hospitals, including academic medical centers, have a policy of zero tolerance for marijuana use, even when it is authorized for medical use by the patient's physician. While I was preparing to write my medical response to this ethics case, I did informally interview several bioethicists from local regional medical centers. Virtually all of the people I interviewed were against the refusal of an organ transplant simply on the basis of marijuana use. Indeed, bioethicists seem less concerned with the issue of whether it was legal but rather are more concerned that the patient was afforded the opportunity to receive a life-saving organ transplant.

There is scant medical literature examining whether there is any negative impact of marijuana use on the survival of organ transplant patients. One recent study at the University of Michigan looked at whether patients with chronic liver disease who were also marijuana users had inferior posttransplant survival rates.⁹ They did a retrospective cohort study with the primary outcome measure being time dependent, adjusted patient survival from the time of liver transplant. The primary exposure variable was a positive urine toxicology screen, just as in our case with ED. Marijuana users were significantly younger, more likely to be male, and less likely to receive a transplant (21.8% vs 14.8%). However, survival rates were similar between cohorts, that is, patients who did and did not use marijuana had similar survival rates.

In reviewing the medical literature, it is clear that there is no obvious known contraindication between using marijuana and using prescribed drugs after transplant.¹⁰ Moreover, there are really no other medications that have the same mechanisms of action as marijuana. Dronabinol (marinol) is available by prescription in capsules but has the distinct disadvantage of containing only THC, which is only 1 of many therapeutically beneficial cannabinoids in the natural plant. Interestingly, it is the most psychoactive of the cannabinoids and is the one that the federal government allows to be prescribed!

Cannabinoids are now known to have the significant capacity for immunomodulation, via direct, receptor-based mechanisms.¹⁰ These provide therapeutic properties that may be theoretically applicable to the management of organ transplant patients, although further investigation is needed.¹¹ In my opinion, urine drug screens are too often used solely as a screening process to try and get people off the waiting list, summarily passing judgment that they might be high-risk organ recipients simply because they use marijuana. This assumes one is comfortable making the leap from a positive urine screen to being a person who abuses drugs, is in poor health, and has limited social support systems! Surely that raises some bioethical red flags. To me it would seem to

be a backhanded way of rationing organs based on perceived social worth and unhealthy lifestyles. In other words, prejudice! Accordingly behavioral concerns such as a history of substance abuse or dependency would be a valid concern. If such a history exists, then it would be appropriate to have the patient demonstrate a period of abstinence. However, marijuana use under a doctor's supervision is not "a history of substance abuse," even though some hospital transplant teams have cited the federal law categorizing marijuana as an illegal drug. As such, transplant team members may see it as an illegal substance and cite that as grounds for automatic rejection. Thus, it is clear that the federal laws still create major stumbling blocks in this area and allow for a scientifically unjustified bias to exist in the transplant community against medical marijuana users. This is particularly odd when the use of many other powerfully addictive prescriptions, particularly opiate-based pain medications, does not disqualify patients from transplant lists. Any defined transplant policy should be based solely on the best available scientific evidence.

Chaplain Response

Karrie A. Oertli, D.Min.

The concern regarding Mr ED is primarily that he has been rejected for a transplant that he needs in order to live. This rejection is predicated by his apparent "abuse of drugs." The issues that emerge, then, are imperative for him and significant for the organization in which he is seeking care. They are just as imperative for the transplant team and its members. Hearing the stories of all those involved is key.

One story is that of the state-funded university hospital. The political and emotional ramifications of the pressures faced by the administration at such organizations are significant. Policies and procedures can be dictated to practitioners, and those legislatively dictated actions can offer difficulties in patient care. How has this organization understood the transplant program? What are the challenges this organization faces by offering solid organ transplants?

A second story is that of the transplant team and its members. The decision-making process by the team should be heard. Specifically, the question as to how the decision is made that a person is abusing drugs should be clarified. If such a decision is made based only on one dimension of the clinical outcomes without considering other factors, one must question the process of the pretransplant evaluation itself. Looking at this question, a professional chaplain might engage the transplant team process with some salient questions. Are there hidden or subtle practices of bias in this matter? Has this team experienced poor outcomes in the past with transplanted patients who have not provided good stewardship of the gifts of organs they have received? Have policies and procedures been implemented as reactive safeguards because of past challenges?

Urgently, the hearing of a third story—Mr ED's story—is imperative. The organization, including the transplant

surgeon and the transplant team, must listen to Mr ED's entire story, which includes his appropriate search for relief from his distress related to nausea and in which he appropriately sought treatment through distinctly allopathic avenues. The medical use of marijuana is attended to in a number of studies.¹² While definitive studies have not been published, the evidence points to the efficacy of cannabis in reduction of nausea, which is why Mr ED started using the substance. Fourteen states¹³ allow the lawful medical use of cannabis for patients through physician direction and prescription, and Mr ED lives in one of these states. Mr ED received a lawful prescription from his PCP, someone who knows his health condition well, and he followed his physician's orders specifically. By hearing the patient's entire story, substantiated by his physician's prescription and testimony, the transplant team could have understood the outcome of the toxicology screening quite differently.

A professional chaplain could intervene in this process by hearing Mr ED's entire story and consulting with the transplant surgeons and team to discover whether Mr ED is acting in accordance with his PCP's instructions. Furthermore, the chaplain could also interact with the administrative structures of the organization to provide feedback about the conflict between prescribed policies and procedures and varieties of nuances with particular patients. The chaplain could also act as a broker of information with the transplant team and its members to discover past challenges that prevent flexibility. Such consultation could provide important clarification for the entire matter.

By listening to stories in their entirety, in context, and with compassion—of the patient, the practitioners, the institutions—health care teams can improve the care of the people they serve. One of emerging area of practice within health care is narrative medicine. "Defined broadly as medicine practiced with narrative competence, narrative medicine incorporates textual and interpretive skills into the practice of medicine. When doctors can recognize, absorb, interpret, and be moved to action by the narratives of their patients, they can practice a medicine marked by empathy, accuracy, and effectiveness."¹⁴ The narrative process is one that has been used by professional chaplains for decades. Possibilities also exist for "narrative administration," so that those involved in the process of health care provision might include textual and interpretive skills as well as they develop policies and procedures to provide care for those they serve.

Epilogue

The case was in the evening news a few days later and generated much press coverage. Despite this, the transplant team held firm even when other physicians advocated for the patient and noted that there was no scientific literature showing any increased risk of organ damage or rejection from someone using marijuana. Tragically, the patient died

of liver failure 3 weeks later, leaving behind his wife and 2 children, ages 8 and 12.

In the actual case, the ethics team was never consulted or even formally made aware of this case. This patient was following the state law, allowing him to use marijuana to treat his pain, nausea, and vomiting, which turned out to be the only thing that worked. Despite following state laws, this state-funded university hospital turned him down for a liver transplant.

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