

Turning Off the Implantable Cardioverter Defibrillator to Prevent Pre-Death Electrical Shocks: An Exercise and Right in the Refusal of Medical Treatment

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Citation

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Abstract

There is disagreement between medical professionals about the ethics of ICD (Implantable Cardioverter Defibrillator) deactivation in end of life cases. Deactivation is requested to prevent a patient from feeling ICD-induced shocks (shocks that attempt to restore normal heart beat) at the end of the patient's life. Some are morally opposed to it while others argue that it is a patient's right to deactivate it and have a dignified death. Such a disagreement leads to varying approaches that healthcare professionals take when patients want to deactivate their ICDs. Variation inevitably means that some patients will be forced to feel the end-of-life shocks brought on by the ICD. Such shocks, on the surface, depart from the traditional notion of a peaceful and dignified death. Because of the prevalence of heart disease around the world, resolving this ethical dilemma will benefit thousands, if not millions. Without a discussion regarding a potential ethical right to ICD deactivation, millions may be forced to feel end of life shocks. This paper compares the ICD deactivation to active killing, withdrawing treatment, and refusing treatment. Once ICD deactivation is properly labeled in one of these categories, other concerns such as autonomy, pain, and future education are discussed in an effort to resolve the disagreement between medical professionals on this subject and determine if there is an ethical right to deactivation. ICD deactivation fits best under the "withdrawing treatment" category and has similarities with DNRs (Do Not Resuscitate orders). It can also be distinguished from direct killing by looking at the patient's intentions under the ordinary/extraordinary care distinction. Therefore, it is an ethical right for people to be allowed to deactivate their ICDs at the end of their lives. Autonomy is hindered when one experiences the pains associated with ICDs at the end of life. Autonomy is of paramount importance in ethics and must always be honored. Deactivating ICDs honors this moral norm, while refusing to deactivate trumps this norm. Medical professionals must always respect patients' wishes and take the necessary actions to give them a peaceful death by deactivating their ICD.

INTRODUCTION

The Implantable Cardioverter Defibrillator (ICD) is a device that shocks the heart back to its beating state when a person who has the ICD installed inside them goes into cardiac arrest (or irregular cardiac activity).¹ After some unsuccessful tries (up to fifty) to attempt to bring the heart back to its normal beating pattern, the ICD stops the shocks and the person dies.² The person experiences horrible pains from the shocks before dying.³ Although many in the academic and medical community would agree that this goes against one's autonomy and dignity, some are morally against deactivating the ICD because it is "considered as a part of the body," and may be akin to murder.⁴ Even if some doctors do not hold this view, others may be uncomfortable with discussing deactivation because according to Zellner et. al., "Allowing death to occur, even at the end of life, runs against the grain of physician training to heal patients and

often is perceived as a form of failure."⁵ This ethical dilemma needs to be resolved or else numerous heart disease patients will be subjected to an incredibly painful death.

This paper attempts to resolve this ethical dilemma by stating the right to refuse medical treatment and then looking into the function of the ICD and comparing it to euthanasia, withdrawal of life support, and refusal of medical treatment. Once a proper comparison is made, this paper looks at the ethical principles behind that comparison to determine whether patients have the right to have their ICDs turned off. This paper argues that turning the ICD off is akin to refusing treatment, like a Do Not Resuscitate Order (DNR). Implicit in such orders are philosophical principles of autonomy and dignity.⁶ In addition, the ICD constitutes extraordinary care, which the patient is morally allowed to reject. Under this analysis, the intent of patients trying to deactivate their ICDs

is further distinguished from direct killing.

Therefore, forcing patients to keep fully-functioning ICDs inside their bodies against their wishes is an affront to their autonomy and dignity, which all humans have by virtue of their humanity. Patients are ethically justified in requesting that their ICDs be turned off to prevent pre-death shocks from occurring. The medical professional is ethically obligated to comply with the request or find another physician willing to deactivate the ICD.

THE IMPLANTABLE CARDIOVERTER DEFIBRILLATOR

The Implantable Cardioverter Defibrillator (ICD) is a device that shocks the heart in an effort to get it to beat again when it senses that the heart has gone into cardiac arrest (or irregular cardiac activity).⁷ This tool is considered by medical professionals as life saving and has kept many cardiovascular disease patients alive. Although its benefits are widely known, little is known about what happens to patients with the ICD when their heart muscle is so deteriorated that shocking it back to life would be futile.

For many with chronic and deteriorating hearts, there will come a point when the heart is no longer able to function and no matter how much it is electrically shocked, the heart muscle's death is imminent. Barring a life-saving heart transplant, this means death. However, the ICD does not differentiate between a non-deteriorated heart going into cardiac arrest (which can be saved) and one going into cardiac arrest when the heart muscle is close to dead. To the ICD, all that matters is that the heart in question has stopped beating (or exhibits highly irregular beating patterns). It will initiate electrical shocks to attempt to get the heartbeat going again. This takes place numerous (the number varies but has been reported as high as fifty) times before the ICD stops shocking the arrested heart.⁸ These shocks will cause the patient who is dying (because of a weakening heart muscle) to suffer intense pain, repeated numerous times before one finally passes away. This is hardly the picture that we in society have of a peaceful death. Those with ICDs in their bodies will experience a death far from "peaceful."

THE RIGHT TO REFUSE LIFE-SUSTAINING TREATMENT

The law surrounding the turning off the ICD is not explicitly laid out in modern legal systems. As this paper explains later, turning off the ICD is akin to refusing medical treatment. A look at the law in this area is helpful to our

discussion. In England, if a patient is deemed to be mentally competent and demands that life saving treatment be withheld, healthcare professionals must comply with that person's decision.⁹ The healthcare professional's own personal views are irrelevant to the patient's demand.¹⁰

In 1997, the U.S. Supreme Court ruled that refusing life-saving treatment was a constitutional right.¹¹ However, this right did not include a right to physician assisted suicide (which would be, for example, a doctor injecting a terminally ill patient with a fatal level of morphine to cause immediate death).¹² Then Chief Justice William Rehnquist wrote:

"When a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed ... he is killed by that medication."¹³

Chief Justice Rehnquist's argument mirrored a 1990 Nevada Supreme Court case where the judges ruled that patients who were refusing life saving treatment:

"have not sought to contract the disease or condition that threatens both the quality and duration of their lives. Rather, they have evaluated their circumstances and determined that a future sustained by radical medical treatment or artificial means ... is not a valued alternative despite its effectiveness in extending life or delaying death."¹⁴

Therefore, when one refuses treatment in the United States, medical professionals must legally honor that decision. Using the above legal lines of reasoning, turning off the ICD mirrors the refusal of life-saving treatment. What ends up causing death for patients that have ICDs in them at the end of their life is their underlying disease, not the removal of their ICD. This is different than removing a respirator which causes death due to a lack of oxygen. The ICD plays no role in the cause of death. Even if the ICD is not turned off and performs its function, the patient still dies of end stage cardiovascular disease or cancer (for example), not due to the lack of a functioning ICD. Therefore, turning off the ICD is not euthanasia nor is the removal of life sustaining treatment. It is the refusal of medical treatment.

However, there is an added element to this case that can cause medical professionals to disagree with the characterization above. In most refusal of care examples, doctors withhold treatment from patients. This is passive. In the ICD case, the doctor must turn off the device. This could

be considered an active move by the doctor. This active versus passive difference between the two cases may cause some healthcare professionals to morally blur the line between treatment refusal and physician-assisted suicide (where the legality and ethics of the two are different). Even some academics do this. This is shown by the Tom L. Beauchamp's argument on the issue. According to Beauchamp, the difference between letting die (such as refusing treatment or tuning off a respirator) and killing is whether the doctor was the relevant cause of death.¹⁵ If the patient died due to a lack of technology, then the doctor is letting the patient die.¹⁶ If the patient died due to a physician's action rather than the lack of technology, this becomes killing.¹⁷ Using that line of reasoning, turning off someone's ICD would be akin to killing. If an academic postulates such a view, it should not be alien that medical professionals may possibly blur the line between killing and refusal of treatment because of the doctor's "active" role in turning off the ICD.

Beauchamp's line of reasoning as it relates to our issue is flawed. In the example of removing a respirator from a patient, the patient dies from a lack of the technology (the lack of artificially produced oxygen). The premise of this argument is that it is the respirator that is keeping the patient alive. In the ICD example, the patient does not die of a lack of the ICD being turned on. The ICD does nothing while the heart is beating. Saying that removing the ICD is like removing a respirator (the first step to the blurring between killing and letting die) assumes that the ICD is like a second heart that maintains circulator flow in the body (like the respirator is like a second set of lungs). This is not the role of the ICD. The ICD merely shocks the heart back into beating upon cardiac arrest or irregular beating patterns (that show that cardiac arrest is imminent).¹⁸ Patients with turned off ICDs do not die from the lack of the ICD (like those who would die from a lack of a respirator). These patients die from heart failure.

The fact that such flawed ethical arguments exist and are accepted by some may cause some healthcare professionals to refuse to turn off the ICD. No matter how fast courts act to enforce one's rights to refuse treatment, often, it is not fast enough to enforce decisions to turn off the ICD. The case cited by Steve Stiles in *Heartwire* involved a patient who experienced shocks on the day of death. Even if an expedited judicial decision was handed down, this patient (and others) would have experienced the shocks (because of the closeness

of the time of a deactivation request and when his heart finally arrested). The dying patient would have been subjected to the treatment (from the ICD) while waiting for the court decision. This causes people to undergo unnecessary treatment. Therefore, to prevent people from being forced to endure these shocks while courts or higher bodies review the ICD termination request, the equivalency of refusing treatment and turning off ICDs must be established. This will frame our ethical discussion of the topic and will allow one to make a convincing case that dying patients with ICDs implanted in their bodies have an ethical right to choose their ICDs to be turned off.

TURNING OFF THE ICD IS AKIN TO REFUSING TREATMENT

The doctor's action of turning off the ICD is irrelevant to the ethics of this topic. If it was relevant, we would be comparing turning off ICDs to cases where the doctor administered a lethal dose of barbiturates to terminally ill patients that would kill them immediately. In both cases, the doctor takes an active role in allowing the person to die peacefully. However, arguing that a lethal dose of morphine and turning off an ICD are morally equivalent is flawed because the former causes death due to poisoning while the latter allows death to occur due to heart failure. Therefore, we must remove the doctor's action of turning off the ICD from our philosophical discussion.

The other two choices we have left are removing life-saving care and refusing medical treatment. The respirator (in a removing life-saving care example) is keeping the patient alive while the ICD performs no function until the heart stops beating. The treatment of the respirator begins the second it is placed into the person's body. The treatment of the ICD only begins when the heart goes into cardiac arrest. This is what differentiates these two cases. Removing the respirator is removing the source of one's oxygen, like removing the lungs (the lungs are already unable to perform, thus requiring the respirator). If this was morally equal to turning off ICDs, turning off the ICD would be like removing the patient's fundamental heart function. It would also assume that the ICD is the device that is controlling circulation in the body, not the heart muscle. This assumption is incorrect. The heart still beats (as long as its muscle can endure) irrespective of whether the ICD is in the body or not. Therefore, turning off the ICD is not removing life-saving treatment.

The only option left is the refusal of medical treatment. This

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seems to be the most plausible area for ICD terminations to fall under. Many terminally ill individuals ask that they not be resuscitated in the event that they go into cardiac arrest. This is called a Do Not Resuscitate Order (DNR). Resuscitation usually consists of Cardiopulmonary Resuscitation (CPR), the use of an external defibrillator, and potentially some drugs used in critical care units to extend life. Individuals who sign DNRs want to pass away peacefully on their own terms. The resuscitation team in the hospital, which resuscitates people that go into cardiac arrest, as a result of the DNR, refrains from intervening in the event of cardiac arrest. The DNR is the closest comparison to turning off ICDs.

When a person goes into cardiac arrest (without the DNR), the resuscitation team promptly arrives and attempts to resuscitate the person. For ICDs, when the heart stops beating, the ICD initiates electrical shocks in an attempt to restart the heart.¹⁹ When the resuscitation team cannot resuscitate the person, they stop and the person is declared dead. When the ICD is unable to keep consistent heart beat after several shocks, it stops. This shows their similarity. Some people may argue, however, that the resuscitation team is external to the person whereas the ICD is installed into the person's body. This argument has no effect on the similarity between ICDs and DNRs. The resuscitation team is available in the hospital for all patients. Patients are individuals staying in the hospital. Therefore, they are availing themselves to the resuscitation team's services by being physically present in the hospital. Note: this argument does not change if the DNR is executed for someone who is staying at home. Without a DNR, someone in a home care environment, for example, will be subjected to resuscitation treatment in the event of bodily arrest.

The ICD is placed into the person's body and does nothing until cardiac arrest or irregular cardiac activity (like the resuscitation team). By one allowing the ICD to be installed into their body, one is agreeing to the possibility of the device attempting to resuscitate them in the event of cardiac arrest. The ICD is like the hospital. It acts as the medium to allow for potential treatment in the case of cardiac arrest. Therefore, the ICD itself is not medical treatment but merely the medium where treatment to potentially save someone's life can be administered, just like the establishment of a resuscitation team in a hospital. If cardiac arrest takes place, the ICD shocks the person. If the heart keeps beating normally, the ICD is not active. The same applies to

resuscitation teams. They only act when cardiac arrest takes place. They do not act when a patient is not in cardiac arrest. Therefore, the ICD is like the resuscitation team in a hospital.

When the DNR is signed, the patient is asking that the resuscitation team not provide their medical treatment in the event of cardiac arrest. When the ICD is turned off, the patient is asking that the ICD not provide its form of medical treatment in the event of cardiac arrest. Thus, turning off the ICD is like executing a DNR. The DNR is considered to be refusal of medical treatment. Therefore, turning off the ICD is refusal of medical treatment.

DNRs are usually signed when medical treatment would be futile to saving someone's life. Similarly, a patient would ask that the ICD be turned off when one realizes that the shocks will not do their intended job, which is restore normal heart beat. Therefore, asking that an ICD be turned off understands that the ICD's medical treatment would be futile. This is another characteristic that strengthens the similarity between DNRs and ICDs.

Some may argue that the doctor merely signs the paper order approving the DNR whereas in the ICD, the doctor physically turns the device off. Therefore, they would argue that ICDs are different from DNRs. However, this argument must also fail. In a DNR order, the doctor must sign the order in order for the resuscitation team to refrain from acting during cardiac arrest. In the ICD example, the physician's turning off the device removes the possibility of the shock system in the ICD device from acting. Both physician actions prevent future medical treatment from taking place. How they did it is irrelevant. Using a pen to sign a paper or using one's hand to press a button to turn off is irrelevant when the intent and result is the same. The result is the removal of the facility to perform life saving procedures on a dying patient.

When DNR requests are being evaluated, often, an ethics consultation will take place. Various ethical principles including autonomy and dignity will be evaluated in determining whether one should be allowed to execute a DNR. Although executing a DNR is right that cannot be refused, medical professionals make sure that the decision is autonomous and also take into consideration the reasons the person wants for the DNR. The doctors are not looking at the patient's reason as a way to approve or deny requests but to understand the motivations of people desiring DNRs.

Doctors feel that it is necessary to look at the ethical reasons for the DNR. Most importantly, there are ethical principles that make the refusal of medical treatment a moral right. In order to give the ICD termination issue full breadth, we must discuss the ethical reasons for why turning off the ICD is as much a right as executing a DNR.

FURTHER PROOF THAT ICD DEACTIVATION IS MORALLY EQUIVALENT TO REFUSAL OF TREATMENT

The following argument from W. V. O. Quine (a former colleague of John Rawls) provides us with the framework where we can make moral arguments concerning ICD terminations:

“A moral theory should aim at codifying the norms of a human morality; it must be concerned with the kinds of problems arising from our human conditions, and the moral ideals it captures should be realizable by human creatures. In other words, good moral theorizing requires knowledge about human motivation, emotion, reasoning, and other mental activities. Moral psychology should have a central role in moral theorizing, and a model of reflective equilibrium analogous to that in the study of rationality ...”²⁰

As ICDs are equal to DNRs, the philosophical principles that the DNR serves are ones that the ICD also serves. Thus, we must look at the human being’s innate autonomy and dignity.²¹ In addition, based on Quine’s statement, we must also look at the intention of the patient when developing a moral theory concerning the deactivation of ICDs in end stage heart disease patients. Applying these moral principles produces further proof that ICD deactivation is akin to refusal of medical treatment.

OUR INNATE RIGHT TO AUTONOMY AS HUMANS

It is no surprise that autonomy is a central tool in decision making. It is the central capacity for one to make decisions to determine his/her life. This ideal has been articulated in the abstract view on autonomy.²² That view stipulates that autonomy is primarily used for decision making purposes.²³ It goes on to further argue that: “Its standard formulation relies on an idealized image of the rational patient who calculates from a list of social goods and freely chooses among them.”²⁴ The Universal Declaration on Bioethics and Human Rights, Article 5 further articulates this ideal.²⁵ It states: “The autonomy of persons to make decisions, while

taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.”²⁶ In order for autonomy to exist, the individual must be able to calculate “from a list of social goods and freely (choose) among them” according to Anne Donchin.²⁷ This assumes that the people are mentally competent to make such decisions and are giving their informed consent (discussed in detail in a later section of this article). Donchin writes about the classical view of autonomy in the patient-doctor relationship, “the model patient in such accounts is typically a male in the prime of life who meets the physician as his intellectual and moral equal.”²⁸

Assuming that the person has the faculties to be autonomous and has given informed consent, autonomy cannot be taken away from them. For Kantians, autonomy is something that all humans possess by virtue of being alive.²⁹ It does not matter how often this autonomy is exercised.³⁰ Kantians believe that autonomy “cannot be earned and cannot be taken away.”³¹ Therefore, humans have the right and capability to make choices including the choice to refuse medical treatments. That is why autonomy is such an important reason behind the right for patients to execute DNR orders. In addition, Kant further goes on to state that all humans have autonomy.³² Thus, all humans have the capability and the right to make decisions that affect their lives.³³

By not allowing dying patients with ICDs implanted in their bodies the opportunity to exercise their autonomy to prevent the shocks from ravaging their bodies before death, we are denying them their human right to make decisions about their lives. We are not allowing them to freely choose between their personal lists of social goods. This directly goes against one’s fundamental humanity. Doctors would take away these patients’ right to decide how they want to die, how they want to spend the final chapter of their lives. How one wants to leave this world is a social good and thus falls into the genre of autonomy. Human dignity and autonomy are directly related with each other.³⁴ According to Jyl Gentzler, Kantians believe that autonomy is the foundation for human dignity.³⁵ Because the foundation for dignity has been hindered, one’s dignity is also taken away if one is forced to feel the ICD shocks before dying.

HOW AUTONOMY AND INTENTION FURTHER DISTINGUISHES ICD REFUSAL FROM DIRECT KILLING

Autonomous decisions are motivated by a person's intent. Therefore, it is helpful to study the intent of individuals who request that their ICDs be terminated. Not only is ICD deactivation for end stage heart disease patients logically equivalent to refusal of care, examination of these dying patients' intentions adds further logical evidence for this distinction.

The intent of the patients will be examined under the ordinary/extraordinary distinction. Under this autonomy-driven distinction, ICD deactivation is similar to the more morally acceptable refusal of medical care. In essence, if a patient's intent is to have a dignified death (like an end stage heart disease patient requesting deactivation) and is using his/her autonomy based on that intention to refuse "extraordinary care," then the patient's decision is akin to the refusal of medical treatment. If a patient's intent is merely death and is using his/her autonomy based on that intention to refuse "ordinary care," then the patient's decision is more akin to direct killing.

Ordinary care is defined as: "those means commonly used in given circumstances, which this individual in his present physical, psychological and economic condition can reasonably employ with definite hope of proportional benefit."³⁶ Extraordinary care, on the other hand, is defined as: "those means not commonly used in given circumstances, or those means in common use which this individual in his present physical, psychological and economic condition cannot reasonably employ, or if he can, will not give him definite hope of proportionate benefit."³⁷

To illustrate the ordinary/extraordinary distinction, Reverend Benedict M. Guevin uses the example of an end stage cancer patient and a middle aged man who is depressed following the death of his wife.³⁸ Both contract pneumonia and need treatment.³⁹ Both opt not to get treatment.⁴⁰ The care is extraordinary for the cancer patient and ordinary for the depressed middle aged man. For the cancer patient, the pneumonia treatment will only prolong a period of suffering before an imminent death. For the depressed man, the pneumonia treatment will allow the man to live at least another 30-40 years (on average), which most would deem to be a considerable benefit to the middle-aged man. Therefore, the difference in these two cases is the benefit-burden ratio. In the cancer patient, because the burdens

exceed the benefits, the proposed treatment is extraordinary. In the depressed middle-aged man, because the benefits exceed the burdens, the proposed treatment is ordinary.

This difference in benefit-burden reveals another crucial difference between the two people in Rev. Guevin's example: their intention. The cancer patient wants to be free from medication that would only prolong a painful existence and be allowed to die with peace and dignity. The cancer patient is using her autonomy to maximize her remaining quality of life where the benefits increase and exceed the burdens. The depressed man, on the other hand, wants to be free from life-saving medication so that he can die and "be with his (deceased) wife."⁴¹ The depressed man is using his autonomy to turn down a treatment (that has considerable benefits to him) because he knows that doing so would lead to something he desires: his death. The man possesses no intention, unlike the cancer patient, to have a quality of life where the benefits exceed the burdens. If the man wanted such a life, he would accept the pneumonia treatment. Instead, the man is acting opposite to the cancer patient's intent by trying to take away all benefits in his life via death.

Therefore, the ordinary/extraordinary distinction is useful in assessing the patient's intent when he/she requests that doctors deactivate his/her ICD. When the care being rejected is ordinary care, the intent of the patient is to die. This desire of death is far more important to this patient than any thoughts of being pain free (because this patient is not at the end of his/her life and the benefits of the treatment outweigh the burdens). When the care being rejected is extraordinary care, because of the lack of benefits and the presence of great burdens, the intent of the patient is to maximize quality of life by being pain-free and suffering as little as possible at the end of life. Here, death is accepted (because no treatment can add any benefit that would exceed the burden of imminent death), not intended. Therefore, patients are morally allowed to reject such extraordinary care.⁴²

In the case of ICDs implanted in end stage heart disease patients, the only benefit that the ICD provides is prolonging life for a short period of time (sometimes even a few seconds). The burdens far outweigh the benefits. The patient will endure painful shocks as he/she dies. This prevents the patient from having an acceptable quality of life and a peaceful and dignified death, something most humans assign value to. In addition, Rev. Donald E. Henke defines ordinary care as "(care that) can reasonably employ with definite hope of proportional benefit."⁴³ The ICD is intended to

restore normal heart activity, which would constitute a proportional benefit for the pain caused by the ICD shock. However, for end stage heart disease patients, the heart muscle is so weakened that adequate heart function cannot be restored. Therefore, the benefit the ICD would have is nullified, only leaving its burdens. For these reasons, the ICD cannot be considered ordinary care in the context of an end stage heart disease patient. The lack of benefits and sizeable amount of burden to the patient make ICDs at the end of life extraordinary treatment. Therefore, patients are morally permitted to deactivate their ICDs.

As argued above, extraordinary care can be distinguished from ordinary care based on the patient's intent. Individuals intending to stop extraordinary care are not intending death but intending to maximize their quality of life by being free of the pain and suffering caused by those treatments. Individuals intending to stop ordinary care are intending death because the pain and suffering caused by such ordinary treatment is less than the benefits it provides (similar to the depressed man with pneumonia in Rev. Guevin's example). In the case of end stage heart disease patients requesting ICD deactivation, because the burdens far outweigh the benefits, the patients' intent is not to cause their own death but is focused on using their autonomy to maximize their quality of life by being free from pain and suffering before dying (after accepting that death is imminent and cannot be stopped). This decreases their burdens and increases the benefit to their lives. The thought of death itself is present (acceptance of one's imminent death), but takes minor precedence compared to the need for dignity and peace. Here, death is accepted, not intended.

Because of this acceptance, their focus shifts to maximizing the quality of whatever amount of life is remaining for them. This matches the cancer patient in Reverend Guevin's example. The decision to deactivate the ICD ensures that at death, the patient will not feel ICD shocks. If deactivation does not take place, even before the patient's heart stops, the ICD may shock the heart because its functioning is weakening. Therefore, this gives an end stage heart disease patient the following quality of life: periodic (or even many) shocks during the end stage of their disease with several shocks coming on their last living day, and even the possibility of being brought back to life after dying due to the shock, only to die again. This quality of life involves little to no benefit and involves considerable burdens. The decision to deactivate the ICD is intended to maximize any

remaining quality of life by making sure the patient does not feel these horrible pains, which would compromise this remaining quality of life. Deactivation is meant to increase the benefit to one's end of life and minimize the burdens. As argued above, this is different than undertaking an active method that is intended to cause death in ordinary care cases.

Thus, stopping treatment that is burdensome to patients who have little chance of recovery (extraordinary care) in order to minimize suffering is morally permissible. On the other hand, stopping treatment that offers great benefits compared to burdens (ordinary care) because the patient wants to die is morally impermissible. The former is akin to refusal of medical treatment while the latter is akin to direct killing.

In summary, the end stage heart disease patient has the autonomous right to deactivate his/her ICD for the following reasons: (1) because deactivating the ICD is equivalent to refusing additional care, (2) because one has the autonomous right to a peaceful and dignified death, and (3) because the ICD is extraordinary care and the patient seeking to deactivate the ICD is intending to maximize his/her quality of life, where the benefits exceed the burdens.

OTHER RELEVANT CONCERNS

In addition to the proof that ICD deactivation is akin to refusal of treatment, philosophical discussions about beneficence and nonmaleficence, human dignity, and pain further enforce the patient's right to deactivate the ICD at the end of their lives. Informed consent is also discussed because the decision to deactivate the ICD requires the patient's informed consent. Finally, the role of the physician as a moral agent in these cases is discussed.

BENEFICENCE AND NONMALEFICENCE

The principle of beneficence requires that people must advance the "legitimate interests of others."⁴⁴ In the medical context, this requires physicians to provide care that will benefit the patient.⁴⁵ According to Noreen Henig et. al., this means that the physician must administer treatment "to restore health and to relieve suffering."⁴⁶ Therefore, the interests of the patient needs to be identified in order for the physician to decide what are the necessary steps he/she must take to satisfy those interests.⁴⁷ According to Dreyer et. al., one of those interests is a dignified death.⁴⁸ Beneficence requires that doctors do whatever is necessary to benefit the patients. When there are no reasonable chances that the patient's health will improve, the only patient interest remaining is to have a dignified death. Therefore, to satisfy

the principle of beneficence, physicians must take the necessary actions to allow the patient to die in peace. In this context of end of life heart disease patients, turning off the ICD serves that interest. On the other hand, decisions that cause the patient to suffer harm are not allowed under the principle of beneficence.

Nonmaleficence is the principle of “do no harm.”⁴⁹ In the physician-patient context, this requires that “physicians avoid providing care that is harmful.”⁵⁰ In order for this principle not to conflict with the principle of beneficence, the benefits and burdens are weighed against each other.⁵¹ Nonmaleficence forbids actions where there is a net harm (after considering the benefits). Treatments that involve some harm but have greater benefit are allowed under the principle of nonmaleficence. However, by not allowing end stage heart disease patients the opportunity to deactivate their ICDs, the harm these patients would incur would exceed the benefits (namely, living for another few seconds (or a very short period of time) versus intense pain before death). Therefore, the principle of nonmaleficence would require that physicians deactivate an end-stage heart disease patient’s ICD when the patient requests it.

HUMAN DIGNITY

There are numerous philosophical arguments about how human dignity that are directly applicable to the refusal of medical treatment. 20th Century philosopher Ronald Dworkin in *Life’s Dominion*, argues that human dignity is “the moral right – and the moral responsibility – [of humans] to confront the most fundamental questions about the meaning and value of [our] own lives for [our]selves, answering to [our] own consciences and convictions.”⁵² Dworkin believes that human life is intrinsically valuable because of human dignity.⁵³ To him, the satisfaction of dignity depends on the satisfaction of one’s “critical interests,” which if satisfied make life better off than if not satisfied.⁵⁴ He believed that by living one’s life along the lines of one’s interest, the intrinsic value of life is enhanced.⁵⁵ This, in turn enhances and defends one’s autonomy. Dignity and integrity are intertwined. Dworkin defines integrity as “a steady, self-defining commitment to a vision of character or achievement.”⁵⁶ If one’s dignity is trumped, his/her integrity is also trumped. Timothy Quill elaborated on this concept by arguing that those in a terminal situation facing more medical treatment fear “a loss of control.”⁵⁷ This control is inherent in autonomy and dignity.⁵⁸ It is something that we possess as humans by being able to

control the outcomes of our lives.⁵⁹

As we search for the meaning of our existence on Earth, we hope that by the end of our lives, our deaths will be peaceful. No one dreams or hopes of a painful, horrific death. Such a desire goes towards the question of meaning of one’s life and one’s beliefs. This directly corresponds to Dworkin’s argument on dignity. It goes to the free choice of social goods in autonomy that Kantians argue is the moral foundation of dignity. By being forced to feel horrific shocks before dying, patients with ICDs implanted in their bodies will have their beliefs about life and integrity tarnished. This is also the loss of control that Quill speaks of. By not allowing these patients to turn off the ICD and prevent themselves from feeling excruciating pain, their human dignity is being compromised. As long as these patients are alive, they are human, Dworkin would argue that their dignity cannot be compromised because we all have it. Therefore, the only solution to defend these dying patients’ human dignity is to allow them to turn off their ICDs and have a peaceful death on their own terms. Healthcare professionals must allow them to have as much control (in Quill’s terms) as they can in deciding how they want to spend their final waking moments on Earth. These patients must be allowed to die the way they lived, by being autonomous and dignified. Anything less would be an inhumane violation of their inherent human dignity. The consideration of a dignified, peaceful death is a reason why DNR orders are executed.

One’s control over one’s fate reflects one’s dignity and thus, quality of life. It is widely accepted that pain impedes on one’s quality of life (depending on how severe the pain is). Therefore, pain impedes human dignity. In Jyl Gentzler’s article “What is a Death With Dignity?,” one of the sections of Dr. Gentzler’s article is entitled “The Indignity of Pain.”⁶⁰ To adequately judge the ethical ramifications of forcing these patients to experience pre-death ICD shocks, one must look at the pain due to the ICD shocks shapes our ethical analysis.

THE PHILOSOPHY OF PAIN

Both Kantians and Hedonists agree that pain goes against one’s dignity. Gentzler argues that a Hedonic notion of pain is “that once one’s life no longer offers a greater balance of pleasure over pain, it is no longer worth living.”⁶¹ Kantians argue that “gross, irremediable, and uncompensated pain and suffering” has a “devastating effect” on human dignity.⁶² This view is not only confined to the world of philosophy

and ethics. In 1997, Justice Stephen Breyer of the United States Supreme Court wrote that “dying with dignity is freedom from unnecessary and severe physical suffering.”⁶³

Unnecessary pain is a consideration in DNR cases. When one’s condition is terminal, the prospect of CPR would cause pain. When one’s heart is so weak that even if it was brought back to life, it would die a short time later, CPR adds more pain than benefit. Such a death would be far from peaceful. The last feelings a dying person would have is a resuscitation team performing this procedure, which sometimes breaks ribs.⁶⁴ To be brought back to life (albeit momentarily) to feel the effects of this invasive procedure and then die again would be equal to ICD shocks bringing someone back to life and then having them die again due to a weak heart. This is a prominent reason that DNRs are executed: so that people can have peaceful deaths.

The Kant and Breyer definitions of pain are helpful in our case. The pain these patients would feel would be irremediable because they die after experiencing such excruciating pain. As a result, it is uncompensated and affronts human dignity. The pain would amount to the “severe physical suffering” that Justice Breyer writes about. It is also worth noting that Justice Breyer also mentioned “unnecessary” in his discussion of pain. The shocks produced by an ICD at the end of life are unnecessary because they add no value to the person. Death still results. The unnecessary pain these patients would have experienced affronts their autonomy and dignity.

Therefore, autonomy and dignity ethically justify the following statement: the right to turn off one’s ICD is as much of a right as it is for someone to refuse medical treatment, such as executing a DNR order.

INFORMED CONSENT

Informed consent is required for a patient to deactivate his/her ICD. According to Thaddeus Pope, there are three elements to informed consent: disclosing “(1) the nature and purpose of the proposed intervention, (2) the intervention’s probable risks and benefits, and (3) alternative interventions and their risks and benefits.”⁶⁵ There are two prevailing standards on disclosure in informed consent. In *Canterbury v. Spence* (1972), the United States Court of Appeals for the District of Columbia ruled that the physician must disclose risks when “the physician knows or should know to be the patient’s position, would likely attach significance to the risk or cluster of risks in deciding whether or not to forego the

proposed therapy.”⁶⁶ Therefore, in order for the patient to give informed consent to have his/her ICD deactivated, there are three things the physician should do.

First, the physician needs to discuss the nature and purpose of the ICD deactivation with the patient and his/her family. The physician must explain that the ICD will be turned off and will cease functioning. The physician will explain that this deactivation is being done to prevent the patient from feeling ICD-induced shocks and to prevent the patient from suffering a painful death. The physician must explain that the person will die once their heart becomes too weak to beat or suffers another heart attack if their ICD is deactivated. There is no possibility that the patient can survive another episode of cardiac arrest. In essence, the ICD is the final barrier preventing death for the patient.

Second, the physician needs to discuss the risks and benefits associated with ICD deactivation. The patient needs to understand that he/she may have a shorter life span than if they have a deactivated ICD relative to a working ICD. In addition, the physician needs to disclose any risks and complications with the deactivation to the patient and explain how ICD deactivation will affect the end stages of the patient’s life. In addition, the physician needs to help the patient understand that without the ICD, death may come suddenly. The patient must accept this possibility because the final barrier keeping the patient alive is now being removed. The patient needs to understand all of these risks before proceeding with the deactivation.

The physician should also describe the benefits of the procedure, which include not having to endure the painful ICD-induced shocks to the heart. The physician should communicate with the patient so the patient has a sufficient understanding that the ICD will no longer prevent death and by deactivating it, when death does come, the death will be less painful. This is the crucial trade-off that the patient must understand before choosing to deactivate his/her ICD.

Third, the physician must discuss alternative interventions with the patient. The only alternative to deactivation of the ICD is to leave the ICD in place and allow it to function correctly. The patient must understand the benefits and risks of such alternatives. Regarding the benefits, the ICD could potentially prolong life (depending on the state of the heart muscle). Regarding the risks, the patient needs to understand how ICD-induced shocks feel (either through experience or through the physician’s explanations). The physician should

have a discussion with the patient about whether the patient can endure such shocks and how this will affect their quality of life and dignity in death. It is up to the patient to balance the prospect of a prolonged life (which could be as little as a few seconds) compared to enduring the ICD-induced shocks. Only after all of the above considerations can a patient be deemed to truly give their informed consent to deactivate his/her ICD.

In addition, there are two additional concerns which scholars argue must be considered regarding informed consent. First, M. Elizabeth Lanier, a trained nurse and attorney argues that before the decision to refuse is approved, doctors should discuss with the patients to find some middle ground, which may better meet the patient's needs (from a medical standpoint).⁶⁷ This does not usurp the patient's decision making power but provides them with more information to make a more informed decision. Second, there can be confounding factors which can affect one's decision making ability. According to Dr. Paul Rousseau, a medical director and professor, one's ability to make decisions "can be temporarily compromised ... by medications, physiological maladies, comorbid conditions, advanced disease, and healthcare providers' explanations of proposed treatments and outcomes."⁶⁸ In addition, a British Court of Appeal recognized that "temporary factors such as confusion, shock, fatigue, pain, or drugs may completely erode the capacity to make decisions."⁶⁹ Professionals need to ensure these confounding factors are either not present or accounted for before approving any refusal to medical treatment order.

Thus, the end stage heart disease patient's right to ICD deactivation is premised on the patient having conferred with his/her physician(s) about the risks and benefits of deactivation, and alternative treatment plans. It also assumes that the patient has the requisite and sufficient mental faculties to make an autonomous decision.

THE PHYSICIAN'S ROLE AS A MORAL AGENT

In this moral discussion, the role of the physician cannot be ignored. According to Thomas A. Cavalieri, while most focus on the moral right of the patient, the role of the physician in ethical discussions is often overlooked.⁷⁰ Cavalieri writes that: "the physician is a moral agent who serves a major role in the ethical decision-making process; therefore, the physician's values and ethical standards also need to be respected."⁷¹

According to Tove Pettersen, the relationship between

physician and patient is not patient-centric, but it sees them as "mutually interconnected, vulnerable and dependent" because physicians are moral agents in care.⁷² Pettersen goes on to write that: "This amplification is actually derived from the fact that the normative value of care is universal—it includes not only the caree, but also the carer and other persons for whom she might have a caring responsibility."⁷³ Therefore, the moral agency of the physician needs to be accounted for and respected. Pettersen argues that moral agents are participants in "society's wider economy" and can resist practices that they deem to be uncaring, immoral or harmful.⁷⁴

Based on this view of dependent moral agent relationships, Cavalieri argues that "one cannot lose sight of the fact that the physician is an integral agent in moral acts that take place in healthcare. Therefore, physicians should not be compelled to violate ethical convictions or religious beliefs at the request of a patient or the patient's caregiver."⁷⁵ As it relates to this case, a physician who has been requested to deactivate a patient's ICD is allowed to refuse (on personal religious grounds, for example), but "should assist and support the transition (for the patient to seek another healthcare provider)."⁷⁶ This allows both moral agents (physician and patient) to have their moral agency and autonomy respected. Thus, the right of the end stage heart disease patient to have his/her ICD deactivated does not require the physician(s) to turn off the ICDs if the physician is morally opposed to deactivation. However, what is required in such cases is that the doctor transfer care to another physician that is willing to deactivate the patient's ICD.

THE FUTURE OF ICD DEACTIVATION

Now that the right to ICD termination for end stage heart disease patients has been proven, there are some final incidental issues to handle in order to ensure that medical professionals honor the patient's right to turn off their ICD. Like someone who should have been informed about the risks of medical treatment, these end-of-life ICD patients should be informed of these pain-related risks before the ICD is placed into their body.⁷⁷ Such a discussion would reduce the shock and surprise later on and the perceived affront to human dignity when one realizes that they are about to experience excruciating pain before passing away. Also, because heart disease is so prevalent in the United States, this ethical right to turn off one's ICD must be taught in colleges, graduate programs, medical schools, law

schools, and in healthcare environments. The United Nations also asks for bioethical review and training programs to be instituted:

“Article 19(b): Independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to provide advice on ethical problems in clinical settings.”⁷⁸

“Article 23(1): In order to promote the principles set out in this Declaration and to achieve a better understanding of the ethical implications of scientific and technological developments, in particular for young people, States should endeavour to foster bioethics education and training at all levels as well as to encourage information and knowledge dissemination programmes about bioethics. Article 23(2): States should encourage the participation of international and regional intergovernmental organizations and international, regional and national non governmental organizations in this endeavour.”⁷⁹

This way, more professionals will understand the ethics of ICD termination and will not try to stand in the way of the patient’s right. Although a medical professional’s refusal to terminate does not take away from the patient’s right to ICD termination, this cannot be beneficial to the patient who is living his/her final days or weeks on Earth. It will only impede the small amount of time left in their lives.

CONCLUSION

The right for a patient to turn off his/her ICD is a form of refusing medical treatment. It is similar to a patient executing a DNR order. In addition, the ICD is extraordinary care and deactivation is morally permissible. Because the patient’s intent in extraordinary care cases such as this is not to cause death, but to relieve suffering and enhance quality of life, deactivation of the ICD is further distinguished from euthanasia or direct killing. Thus, not allowing patients to do this affronts their human autonomy and dignity. This right to refuse the effects of the ICD shocks is a right that all medical professionals must honor in the present and in the future. With the proper measures taken to make sure the patients understand all risks before the ICD is installed and the establishment of programs to educate healthcare professionals and students about the ethics of ICD termination, this will provide the framework necessary for healthcare professionals to work with patients and assist them in exercising their fundamental right to refuse ICD treatment and have a dignified, peaceful death.

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