Doctors' questions about end-of-life legalities may result in patient pain

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When treatment options dwindle or are exhausted, terminally ill-patients often opt for pain management and comfort over life-extending therapies. However, a team of researchers from Wake Forest University Baptist Medical Center, University of Rochester Medical Center and Unity Health System, report that a lack of thorough understanding about the laws governing end-of-life care may be leaving many medical providers with an ethical dilemma and causing some terminally-ill patients considerable, unnecessary pain.

The report, appearing in a recent issue of *Mayo Clinic Proceedings*, concerns the legal and ethical issues involved with deactivating an implantable cardioverter-defibrillator (ICD) in patients who are terminally-ill. The ICD is a small, battery-powered electrical impulse generator, much like a pacemaker, that is implanted in patients who are at risk of sudden cardiac death due to ventricular fibrillation. The device is programmed to detect cardiac arrhythmia and correct it by delivering a jolt of electricity, which is often lifesaving. However, the legality of deactivating the ICD in terminally-ill patients who request to stop receiving the therapy is not clearly written, the study shows, and may be causing doctors to subject dying patients to undue pain.

The results stem from a physician survey that collected information about doctors' knowledge and preferences regarding the medical, ethical and legal issues involved in caring for terminally-ill patients with an ICD.

In the brief, Vinodh Jeevanantham, M.D., of Wake Forest Baptist, and colleagues identify a general lack of knowledge among physicians concerning ICD therapy in terminally-ill patients that may result in extra suffering for them.

The ICD has become the most effective treatment for patients at high risk of life-threatening ventricular arrhythmias. It has been shown to improve survival, especially in elderly patients, by sensing changes in cardiac rhythm and delivering an electrical shock to the heart to restore normal rhythm.

Terminally-ill patients may be at increased risk of ICD shocks due to electrolyte disturbances, hypoxia and heart failure. It is estimated that more than 3 million people in North America are now eligible for an ICD. With a growing elderly population in the United States, clinicians are likely to care for an increasing number of elderly patients with ICDs.

The deactivation of an ICD, which may have been placed years before the onset of a terminal condition, may not be a clear-cut decision for patients, families, or physicians. Although physicians are aware that ICDs save lives by delivering an electrical shock and that such shocks are associated with considerable pain, busy clinicians may not always re-analyze the risk-benefit ratio of ICD therapy when their patient experiences a terminal illness, the report states. In this situation, life-prolonging therapy may no longer be desired. However, although guidelines for appropriate ICD use are readily available, a glaring deficiency exists regarding end-of-life care for patients with an ICD, according to the report, and the legality of deactivation is not clearly spelled out. There are also no clear-cut recommendations, Jeevanantham said.

Although voluntary refusal of treatment is a basic patient right, the study highlights a lack of clarity regarding the laws concerning ICD therapy in

terminally-ill patients.

"While 64 of the physicians who participated in our survey had cared for terminally-ill patients with an ICD, they were unaware of any guidelines regarding deactivation of the device in such patients," the authors wrote.

Of the 204 surveys distributed within Unity Health System between February and May 2007, 87 were returned. Among the physicians who responded, 64 reported experience caring for a patient with an ICD and terminal illness. Forty physicians either thought it was illegal or were not sure if it was legal to deactivate an ICD in these circumstances.

However, if the physicians were to be reassured about the legality of discontinuing ICD therapy, 79 of these same respondents said that they would be willing to discuss voluntary ICD deactivation with their dying patients. On the other hand, 16 of the physicians surveyed thought such action was either unethical or possibly unethical, and 19 physicians were uncomfortable deactivating an ICD in a terminally-ill patient, even though 51 of the doctors reported believing that an ICD-delivered shock would be painful for the patient.

"Although patients are better able to tolerate the shock from the ICD with time, they may still find an ICD firing frightening and painful," the researchers stated in their report. "Our study showed that only 51 clinicians thought that the shock therapy would be uncomfortable. This finding highlights the importance of physician education regarding the ICD functioning, particularly symptoms that result from shock therapy.

"With increased knowledge about managing the withdrawal of this potentially life-prolonging therapy, physicians are likely to become more skilled at caring for dying patients with an ICD."

Source: Wake Forest University Baptist Medical Center