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Terminal rights?

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By Scott Bullock - This month, the U.S. Supreme Court will decide whether to hear a case that not only has profound implications for thousands of terminally ill patients, but also one that addresses vital constitutional questions concerning the Court's protection of "fundamental rights."

The case, Abigail Alliance for Better Access to Developmental Drugs v. von Eschenbach, stems from the tragic death of Abigail Burroughs, a 21-year-old college student who died of head and neck cancer in 2001. She fought her cancer for two years and then ran out of government-approved treatment options. Her highly renowned Johns Hopkins University oncologist wanted to put Abigail on an experimental cancer drug whose early trial results proved very promising. Unfortunately for Abigail, she could not get into the clinical trials for the drug and died three years before the Food and Drug Administration (FDA) finally approved the drug.

The Abigail Alliance was founded by Abigail, her father and other patients and their families who seek greater access to drugs approved for clinical trials. They sued in federal court in Washington, D.C., represented by the Washington Legal Foundation. After an initial victory by a three-judge panel of the D.C. Circuit, the entire circuit court ruled 8-2 that terminally ill patients have no constitutional right to access potentially lifesaving drugs that the FDA has already found safe for clinical trials but has not yet decided to be effective.

Of course, the dying patients hope the drugs will be effective, but they do not have time to wait for studies to prove that; experimental drugs may be the only hope to save their lives.

The powerful dissent in the case, written by Judge Judith Rogers, and joined by Chief Judge Douglas Ginsburg, concluded: "Denying a terminally ill patient her only chance to survive without even a strict showing of governmental necessity [for denying access to the drugs] presupposes a dangerous brand of paternalism."

This case, like many important constitutional issues today, came down largely to an issue of semantics. The majority opinion in the D.C. Circuit characterized the right at issue as an extremely narrow one — "the right to access experimental and unproven drugs in an attempt to save one's life."

In contrast, the dissent characterized the right at issue as the right to life, explicitly protected by the Fifth and Fourteenth Amendments, and the right to self-preservation, a right, while not set forth directly in the Constitution, is unquestionably "implicit in the

concept of ordered liberty" and "deeply rooted in our nation's history and traditions." Thus, according to the dissent, the right should be recognized as a "fundamental" due process right and the FDA's prohibition should be subject to strict scrutiny.

As the dissent notes, it is "startling" that the right "to marry, to fornicate, to have children, to control the education and upbringing of children, to perform varied sexual acts in private, and to control one's own body... have all been deemed fundamental... but the right to try to save one's life is left out in the cold despite its textual anchor in the right to life."

The dissent is not alone in recognizing this. There is an ample and growing body of scholarly support recognizing a constitutional right to control personal medical decisions.

The research comes from an ideologically diverse group of scholars. The scholarship is bound by a recognition that it is indeed "startling" — and wholly unjustified — that the court has recognized constitutional protection, for instance, to engage in certain sexual practices but not for the right of individuals to make decisions concerning the treatment of life-threatening illnesses, especially considering that these decisions are perhaps the most momentous and private decisions one can make.

Not surprisingly, given its characterization, the majority in the D.C. Circuit found no fundamental right to "access experimental and unproven drugs." The dissent described the majority's characterization of the right as "tragic word play."

And there is no doubt that the dispute between the majority and dissent did come down to the exact wording chosen to describe the right at issue. This kind of "word play" has become the defining feature of modern fundamental rights analysis. When a court wants to uphold a right, it gives a more general characterization. When it wants to belittle a right, it describes it in the narrowest and most absurd way possible.

Because of the current state of this doctrine, lower courts can effectively decide how they want to rule and then choose how to describe the right in question to fit that ruling. The defining of the right decides the case.

Now is the time for the Supreme Court to take up this case to ensure that the protection of essential constitutional rights do not become a matter of word games and semantics.

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