




RE: “I Think It’s Been Met With a Shrug:” Oncologists’ Views Toward and Experiences With Right-to-Try

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In their publication, Smith et al. (1) presented the first study, to our knowledge, exploring oncologists’ attitudes towards “right-to-try” (RTT) laws in the United States. These include a series of legislative acts at the state and federal levels that permit (certain) severely ill patients to request access to experimental medications without US Food and Drug Administration or institutional review board supervision but through an agreement with the producers of the medications (2). In the study in question, physicians expressed their worries that “RTT legislation might lead patients to (falsely) believe that they have a right to access investigational drugs,” whereas it in fact guarantees no such thing. One of the interviewed oncologists reported needing a 2-hour conversation with a patient to explain that—despite RTT laws—he or she had no right to try the experimental medication he or she wanted. This finding is particularly interesting, because it upholds the previously expressed fear (3) that the language of RTT laws would create misconceptions about what they actually permit. These misconceptions are troubling: they risk generating false hopes and eroding the trust between patients (who could conceive to have subjective RTT investigational drugs) and their oncologists (who might be perceived as denying that right and thus not providing appropriate care). How can the profound dichotomy between the very name and the true content of RTT laws be reconciled? And what can be done to limit its harmful consequences? As to the first question, legal analysis has highlighted that the law on any given topic often contains both “operational rules” (ie, practical rules to be applied in that given field) and also “declamatory statements” (4). The latter do not offer actionable norms of conduct but “make explicit [the] ideology [...] that actually inspired the system in question or the one that a given authority believes to have inspired it or the one this authority wishes people to think inspired it” (4). In our case, the very name “right-to-try” represents a declamatory statement, which reveals the libertarian and anti-red tape ideology at the base of the movement pushing for such legislation (5). This has little to do with the actual operational rules of the laws in question, which allow access to experimental drugs only in specific circumstances and never

oblige the pharmaceutical companies producing the drugs to provide them. Declamatory statements are dangerous because they “encourag[e] a false understanding of what a legal system is doing” (4) but seem to be inevitable, especially for highly politicized subjects. For example, a similar situation occurred with respect to the euthanasia law in Belgium, which many may have misunderstood as granting something like a right to die, whereas actually “the physician is not required to consent to a patients request for euthanasia, which means that there does not exist something like a (subjective) right to euthanasia” (6). Such misalignments between declamatory statements related to a law and its actual operational rules should be rectified by finding instruments that keep the law closer to the reality it regulates. For RTT laws, one important measure is to support oncologists who might come into contact with severely ill patients. With the aid of legal and ethical experts, education should be provided to help oncologists explain to their patients the paths that are legally permitted and thus actually available to deal with life-threatening illnesses without any approved treatment available. Moreover, political and institutional actors should favor—rather than hamper—the development of a genuine understanding by patient organizations and society at large of the law regulating such delicate practices.

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