Letter

HIV disclosure to surrogate decision makers: privacy versus presumption

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Published: 5 June 2007
This article is online at http://ccforum.com/content/11/3/416

Critical Care 2007, **11:**416 (doi:10.1186/cc5927)

See related commentary by Vernillo *et al*., http://ccforum.com/content/11/2/125

In their recent commentary, Vernillo and coworkers [1] argue that disclosure of a critically ill patient's HIV status to a surrogate is appropriate when 'necessary for the surrogate to make decisions that reflect the patient's values and interests, or when failure to disclose poses direct and foreseeable risks to the surrogate.'

Although few would disagree with the latter precept, the ethical and legal permissibility of the former is less obvious [2]. Dispensing with patient confidentiality under the rubric of 'beneficence' does not guarantee preferable end-of-life outcomes. Even if the emotional impact of this disclosure has minimal influence on surrogates' decision making abilities, they are, *ceteris paribus*, left no better informed of their loved one's wishes than before.

HIV-infected patients may have various rational reasons for refusing to disclose their seropositivity or declining antiretroviral treatment, which are unlikely to be easily divined by most critical care teams. What is known about many of these patients is that they have chosen to keep their HIV status confidential, often at great sacrifice. Surmising that they favor 'the timely withdrawal of painful or futile interventions' - precisely when these patients can no longer speak for themselves - both begs the question and stretches the bounds of human inference.

The authors' proposed framework for disclosing privileged information risks positing knowledge of patients' attitudes and beliefs where there is none and threatens the privacy and health care interests of an already vulnerable population. Physicians must ultimately remain vigilant of unwarranted supposition when caring for the critically ill and interacting with their surrogates.

Authors' response

Anthony T Vernillo, Paul R Wolpe and Scott D Halpern

Mr Lott correctly points out that HIV-infected patients may have rational reasons for declining antiretroviral therapy. However, it is difficult to see how one might rationally refuse antiretroviral medications yet desire aggressive care at the end of life. The former suggests a limited tolerance for even noninvasive medical intervention, whereas the latter suggests a high tolerance for invasive interventions. Thus, determining that a patient has chosen to forego antiretroviral therapy clearly can assist in determining a patient's end-of-life preferences, and may thereby usefully inform surrogate decision making.

Mr Lott also raises the very real concern about the range of inferences that intensivists and surrogates might make regarding the treatment preferences of a critically ill patient. Unfortunately, he fails to appreciate the reality of critical care - that physicians and surrogates often have to make 'best guesses' as to patients' end-of-life treatment preferences. There is often no alternative, and decisions sometimes must be made with limited information [3,4]. This is regrettable, but to deny the ability to limit invasive interventions under conditions of limited knowledge is to deny the possibility of providing palliative care. We believe that it is not only wholly unrealistic to require perfect knowledge of patients' values before implementing palliative interventions at the end of life, but it is also potentially inhumane.

Finally, Mr Lott suggests that our proposal 'threatens the privacy and health care interests of an already vulnerable population'. Our recommendations are not meant to be specific to HIV-related information, but rather to be applicable to all health-related information that might be hidden from, but germane to, surrogate decision makers. Just as we are evolving to view HIV infection as being similar to other chronic illnesses [5,6], we should also view terminal HIV-related illness in the intensive care unit (ICU) as being similar to other terminal illnesses in the ICU. As such, knowledge of underlying advanced HIV disease may usefully inform surrogate decision making in the same way that knowledge of an underlying advanced malignancy often does.

Competing interests

The author declares that he has no competing interests.

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