

Commentary

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Mark Ebell and his colleagues have provided us with a study that advances our understanding of do-not-resuscitate (DNR) decisions in important ways, but that also displays major limitations. The advances come primarily from adopting a primary care research perspective, and the limitations result from adhering to quantitative research methods when other methods might have been more appropriate. I will address these points briefly in turn.

An extensive literature on DNR decisions exists, and most of it explores the issue from the perspective of the hospitalized, severely ill patient. Ebell et al add to both our practical and our theoretical understanding by surveying a population of ambulatory family practice patients, and by using for their theoretical base an instrument designed specially to facilitate decision making in a primary care setting before health crises supervene.¹ They show us that while physicians remain fearful that raising the DNR issue will scare or depress patients, the typical patient has probably already thought about or even discussed these matters with others. They indicate how the decisions patients may make around DNR arise from more deeply held values regarding life extension and the environment of terminal care. And they indicate the presence of important biases that could contaminate DNR decisions, including an increased willingness to withhold life support in the presence of advanced age, drug or alcohol abuse, and (perhaps most worrisome) wheelchair dependence.

The particular value of the work of Ebell et al can be seen by comparing another recent study² designed to test the impact on DNR orders of an especially detailed and restrictive state law in New York. The authors concluded that despite the announced intent to enhance patient autonomy in decision making, a very small percentage of patients were directly consulted about their wishes regarding resuscitation; in most cases the patients were too sick, by the time DNR was considered, to participate optimally in the choice. This sad result, however, can be linked directly to the research methods—the authors investigated *deaths of hospitalized patients* before and after the law took effect. They therefore had no way of identifying patients who had recorded DNR orders but who

survived hospitalization. This latter group of patients might have been better able to participate in the DNR decision, and a much higher percentage of them may have been consulted.

Despite these important contributions, the study by Ebell et al displays a significant problem. In two places, the authors state that their primary research goal is to “understand how patients make this difficult decision.” They appear oblivious to the fact that they never answer this question, and they cannot so long as they employ a quantitative, questionnaire design.

It would seem that only by structured or semistructured interviews involving smaller subsets of the patients identified through their questionnaire could Ebell and his colleagues have learned the following:

1. How does the almost universal desire to maintain quality rather than mere length of life express itself within *specific* clinical contexts? That is, how does a general statement of value get combined with clinical and prognostic facts so as to produce a particular decision at a particular time?

2. The subjects indicated that they thought that certain persons (particularly spouses and physicians) would be very helpful consultants in making DNR decisions. Why? Exactly what were these persons expected to contribute? By what process was their input to be incorporated with the patient's own desires?

3. The subjects were able to state what they valued in terminal care. How would they respond to clinical situations in which tradeoffs were inevitable, eg, if being able to communicate with loved ones meant accepting more pain? How would these tradeoffs affect the DNR decision process?

In retrospect it seems that a small number of intensive discussions would have answered the stated research question much better than a large number of questionnaire responses. That this method was not employed seems to reflect the almost universal bias, within family practice research, against qualitative research methodology despite the many advantages of qualitative approaches.³⁻⁵

The obvious rejoinder from defenders of quantitative methods is that we can much more readily generalize these questionnaire findings than we could the results of a small number of interviews. It is therefore worth reminding ourselves of the limits of this study. Do we really know what values regarding life prolongation are held by patients who do not go to family physicians and who do not live in or near Chelsea, Michigan? Even more important, do we know anything about what DNR decisions *would actually be made* by these subjects when they later become ill and are hospitalized, and why? (How, for example, are we to relate these values, which would seem to accept a relatively low-technology approach to dying, to the views of other patients and families who indicated a high appreciation for treatment in an intensive care unit and lesser regard for quality-of-life concerns?)⁶

The most important question, however, about ability to generalize results is simply this—what is the value of being able readily to generalize from data that do not really answer the stated research question?

Ultimately the best answer to the problem of generalizability lies in the conjoint use of qualitative and quantitative methods.^{5,7} The Ebell et al questionnaire study, for example, could have been used to identify a selected subset of patients for intensive interviews (possibly including both those who had previously participated in DNR decisions and those who had not). Based on the results of those interviews, a follow-up questionnaire might have been designed to test the hypothesis that the factors identified as critical in the interviews were widely shared by the larger study population.

Good decisions around the use of life-sustaining treatment will ultimately require active cooperation between patients and primary physicians. Studies like this one

advance us toward that goal. But ultimately, in this and in many other areas of primary care research, the appropriate melding of qualitative and quantitative methods will be necessary to answer some of the most pressing questions.

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