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Response from Elliott and Olver

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We agree with many of the points raised in Nelson and Lindemann's commentary on our article, "Autonomy and the Family as (In)appropriate Surrogates for DNR Decisions," in this issue of *JCE*.

To address a few issues: Regardless of our or any other persons' appraisal of the merits of positing individual autonomy as the primary good in dealing with decision making at the end of life, current Australian and U.S. policy, as we state, takes individual autonomy as fundamental (illustrating ethical principles applied at the quaternary level, as described by Diekema in his commentary, "The Armchair Ethicist: It's All about Location," also in this issue of *JCE*). Patients are required to make decisions, and their family members are typically enjoined to make decisions for the incompetent patient who has not done so pre-emptively. Similarly, whether or not we or others deem it appropriate to request patients or families to make decisions regarding the provision of cardiopulmonary resuscitation (CPR) to dying patients, and whether or not they are informed of the likely outcomes of this, current policy dictates that they are so asked.

We wholeheartedly agree that instituting CPR as default is flawed as a policy and that patients typically don't realize the probable outcomes. However, we note first, this is irrelevant to our argument: We examine how patients and families negotiate the consequences of the current policy requiring that this default is rescinded, preferably by them; and second, providing information on statistical outcomes was beyond the remit of the study. Patients were not asked to make a decisions about do-not-resuscitate (DNR) orders, they were asked to talk about how these decisions should be made, who should be involved, and when discussions centered on these decisions should take place. Many patients spoke about their own experiences, and we demonstrate in this (and other publications)¹ that the right of the patient to decide was the dominant discourse drawn upon in these discussions. We hold that our focus on autonomy was not contingent upon our proclivities, but was prompted equally by the institutional policy and practices framing these decisions, and the accounts of the patients and families themselves. We discursively analyzed these accounts to show how family and patients were positioned, how their accounts reflected and re-presented particular versions of autonomy, and drew out some of the moral and social consequences that ensued.

At several points Nelson and Lindemann inferred our position as critical of patients' points of view, often through overlooking critical clauses in our analysis. We do not make a moral judgement regarding Sean's desire to delegate the decision to his wife Vicky. Whether or not this is appropriate is irrelevant. What is relevant is how Vicky counters his desire through asserting her desire that he make the decision. Time and again in this data set, the decision is batted back to the patient, reinstating as normative and appropriate that

he or she make the decision, and thus implicitly positioning any other option as less than desirable. As we said "To this extent . . . Sean could be subject to moral censure."

Similarly, we do not pass judgement upon Sally, nor do we (as they do) offer a "plausible interpretation" of what she is saying. We examine rather what she is saying, and how she says it, arguing that she beautifully and discursively manages the paradox of autonomy in this process. She attends to family, but she is positioned (by herself and, by her account, her family) as ultimately responsible for making the decision.

Finally, we note that individual musicians do not an orchestra make: Any orchestra requires a conductor who will decide what they are to do. By contrast, a family may have no or too many potential conductors — and disharmony will ensue. Conductors are more easily established in a hierarchical medical community, and the relationship between the patient and the doctor is historically and contractually distinct from the relationship between the patient and the family. We agree, we need to attend further to the latter, and we need to do so through empirical analysis of their talk. This is a start.

NOTES

1. J.A. Elliott and I.N. Olver, "Hope and Hoping in the Talk of Dying Cancer Patients," *Social Science and Medicine* 64 (2007): 138-49; J.A. Elliott and I.N. Olver, "The Implications of Dying Cancer Patients' Talk on Cardiopulmonary Resuscitation and Do-Not-Resuscitate Orders: A Discursive Analysis," *Qualitative Health Research* 17 (2007): 442-55; J.A. Elliott and I.N. Olver, "Choosing between Life and Death: Patient and Family Perceptions of the Decision Not to Resuscitate the Terminally Ill Cancer Patient," *Bioethics* (in press); J.A. Elliott and I.N. Olver, "(Using) Complementary and Alternative Medicine (CAM): A Thematic Analysis of Dying Cancer Patients' Talk," *Journal of Palliative Medicine* (in press); I.N. Olver and J.A. Elliott, "The Perceptions of Do-Not-Resuscitate Policies of Dying Patients with Cancer," *PsychoOncology* (in press).