Michael Pritchard's Commentary on "Family Decision-Making about End-of-Life Care"

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Family Decision-Making about End-of-Life Care

It is certainly understandable, even commendable, that those who provide palliative care consultation services would want to have a better understanding of variables that may affect the quality of care they provide. Some of this understanding will be acquired “on the job,” as one provides these services—at least by perceptive consultants. But systematic research is likely to bring other important matters to light, challenge assumptions that might otherwise adversely affect the services offered, and so on. In short, the recipients of these services can benefit even more from consultants who effectively incorporate research results into their practice. The sort of research interests that Dr. Menendez has are consistent with her concern to provide the best services she can — and to help others do so as well.

At the same time, she should have some real concerns about whether it is appropriate for her to serve as therapist and researcher for the same clientele, whether individuals or family units. The informed consent issues raised in Part II of this case illustrate why. Apparently some primary care physicians, intentionally or inadvertently, have led family members to believe that the quality of service they can expect will be adversely affected by not agreeing to participate in the study. If this worry is engendered by their primary care physician, who is not providing the therapeutic services in question, it makes good sense to suppose that the therapist/researcher could be seen as equally, if not more, threatening. Will the therapist/researcher be less interested in those patients, or their family members, who indicate they do not want to participate? The very fact that patients or family members might worry about this could have a negative affect on the therapeutic relationship they have with Dr. Menendez.

So, as researcher, Dr. Menendez might restrict her research to patients and their families who are not under her care. This means that if her own patients and their families are to be participants in the sort of research project she is interested in, another researcher would be needed. There is still no assurance, of course, that the problem will be solved. Patients and their families would be informed that, in addition to consulting with their therapist, there will be someone else involved, albeit for research rather than therapeutic purposes. Will they worry that the therapist and researcher are cooperating with each other in such a way that their therapeutic services will be affected by not participating in the study?

Adding a researcher to the mix may raise other patient and family concerns. Not only are they expected to discuss sensitive, private matters with a therapist, they are to be observed by a third party, a researcher with whom they have no other relationship. Aside from causing them discomfort, this might also have a negative affect on the therapeutic relationship by, say, causing them to be more reticent. If this factor cannot be ruled out, this could also affect the validity of any claims about what goes on between therapist and patient/family that they are *not* being observed for research purposes — whether by their therapist or a third party.

There does not seem to be a sure way of totally eliminating such worries about the possible adverse affects of the research on therapeutic services, or worries about the validity of the research data itself. A point to be emphasized, however, is that special care needs to be taken in regard to informed consent. Patients and their families need assurances that participating (or not participating) in the research project will not affect the quality of services they will receive. The scenario in Part II suggests that very little, if any, monitoring of the informed consent process was done in regard to the role of the primary care physicians. At the very least, this issue should be addressed. The concern is that undue pressure might have been used on patients and their families, or that this is their perception. But the concerns do not stop there. As just pointed out, additional worries about the quality of care provided by the therapist/researcher remain, even if referring physicians handle things very well.

These problems aside, Dr. Menendez, and perhaps her patients as well, would like to have full participation by both patients and family members. What if one or more of the family members express reluctance to participate, or outright refuse? Noncoercive efforts to persuade may be appropriate, although it can be very difficult to determine where to draw the line when attempting to persuade the reluctant to

join with their already willing family members. The researcher already has strong allies in this circumstance, unless, of course, there is a history of significant tensions or divisions among family members. So, additional efforts to recruit family members can easily become a matter of undue pressure. Dr. Menendez may be disappointed at not gaining the consent of all patients and family members, but this need not be fatal to her project — especially if she is joined in her research efforts by other researchers, thus enlarging the potential pool of participants.