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The Rose of Sharon: What Is the Ideal Timing for Palliative Care Consultation versus Ethics Consultation?

Jennifer La Via and David Schiedermayer

ABSTRACT

Ethics committees and palliative care consultants can function in a complementary fashion, seamlessly and effectively. Ethics committees can "air" and help resolves issues, and palliative care consultants can use a low-key, longitudinal approach.

In their moving and well-written essay in this issue of *The Journal of Clinical Ethics,* "Stories and the Longitudinal Patient Relationship: What Can Clinial Ethics Consultants Learn from Palliative Care?" Morrison and Derrington tell us the story of Sharon, a 14-month-old child with a fatal chromosome abnormality.[1] Like a hibiscus (colloquially called the Rose of Sharon) whose blooms last only for a day, her time is limited from the start. At the beginning of the story she is already in the intensive care unit dying of aspiration pneumonia.

The characters we meet are her biological mother and father, who come to the hospital separately and are often not on the "same page," an overworked and under-appreciated resident who is inadvertently caught in the middle between them, the attending pediatrician, a medical foster mother who is biased toward continuing treatment for various (unstated) reasons, a small and caring group of nurses and docs (eight or so), and the palliative care team (one or two people) as well as the ethics committee (five people or so).

The dilemma is the withdrawal of life-sustaining treatment—here the ventilator. Sharon's father and foster mother wish to start and continue treatment and her mother wishes to withhold it and/or withdraw it.

The clinical symptom which requires ongoing palliation is dyspnea.

The outcome is a peaceful resolution. Sharon dies comfortably in the arms of both of her parents and her foster mother. The nursing team was present throughout. It is unclear if either the palliative care team or an ethics con-

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sultant is present at the time of Sharon's death, but is it doubtful that either were there, because she dies at night.

The writers tell us that the moral of the story is that palliative care uses a one-on-one, gentle, daily, low-key approach, which could benefit ethics consultants as well.

We are right with the storytellers until they tell us the moral of the story. We just don't see it that way.

Our concern is this. It is true that we have argued recently[2] that ethics consultation needs to be more active and "clinical." This would promote certification and credentialing as well as reimbursement. This line of reasoning would certainly fit with Morrison and Derrington's conclusion. Why not combine palliative care consultation and ethics consultation right from the start? Why shouldn't ethics consultants use the exact same approach as palliative care specialists?

But this example, in which the palliative care consult team and the ethics committee are consulted simultaneously, seems inadvertently to prove the opposite point.

Maybe we need to reconsider these roles yet again.

Maybe ethics consultation just can't do a good job being "longitudinal." Perhaps palliative care does a better job hearing the full story. Perhaps the active clinical role is meant only for palliative care. After all, treating the dyspnea is the main concern when the withdrawal of life-sustaining treatment appears imminent. We can't expect the ethics committee to be responsible for discussing shortness of breath at the bedside.

In addition, for palliative care specialists, certification and credentialing issues are already solved. Reimbursement follows this clearly defined clinical role. Documentation easily matches standard work flow. Daily follow up is assumed, and is not a burden on unpaid volunteers. And despite the authors' concerns about palliative care availability, it is an increasingly common service even at community hospitals.

It is also cost-effective and efficient. In our hospital, the palliative care service requires only one full-time nurse practitioner (JLV) and one half-time physician (DLS). Our metric is to do about 1.5 consults per hospital bed (in our case 80 beds x 1.5 = 120 consults) a year. This is a manageable number for us, but this would be a crushing expectation for an ethics committee.

It would be reasonable for the ethics committee to be consulted on, say, 10 to 20 percent of the total cases (15 to 30 a year). These would be the very hardest cases. Volunteers could be expected to be willing to work on a fewer number of cases, so payment, credentialing, and certification issues would be less pressing.

In most consulting situations, an ethics committee would meet together only once. An individual from the committee could still serve as the "consultant" and the point person, but, as in this story, a group meeting would air all of the issues. Even though Sharon's resident and attending ordered both consults to occur simultaneously, note that the ethics committee appears to meet formally only once, and that the ethics consultant(s) follow up with the medical team, not with Sharon or her family members.

Our point is emphatically not to say that palliative care and ethics committees can't work together. Nor is it to say that ethics committees and consultation are unhelpful. Sharon's situation demonstrates that ethics committees and palliative care consultants can function in a complementary fashion, seamlessly and effectively. They have unique styles and roles.

It seems to us that Sharon needed both groups of consultants, but at different times and in different ways. For example, the actual decision to withdraw the ventilator is two weeks in the making. That's why the story is longitudinal. Time itself is a variable in most of these difficult and tragic situations. Along the way, unsung heroes (the nurses in the intensive care unit) and an unwitting scapegoat (the resident physician) must emerge. The main character needs to be seen through the eyes of others. The parents and the foster mother have come to terms with their own expectations for Sharon's future. "She's a happy kid," says her father, "even though she can't do much." Prior to this admission, Sharon was becoming "much more interactive" says her foster mother. "You should have had both of us sign," says the patient's

mother angrily when she finds Sharon intubated despite her specific prior written wishes to the contrary.

Faced with this apparent impasse, the palliative care team reaches out to Sharon's mother and learns her own story. The ethics committee determines that she is "an appropriate surrogate." Both are helpful actions. So let's combine the two. But let's use palliative care early and often and ethics consultation late and sparingly.

The story of the Rose of Sharon teaches us that even in the toughest situations, when the beautiful and the good and the innocent die young, this approach actually works.

NOTES

1. W. Morrison and S. Derrington, "Stories and the Longitudinal Patient Relationship: What Can Clinical Ethics Consultants Learn from Palliative Care?" in this issue of *The Journal of Clinical Ethics.*

2. D. Schiedermayer and J. La Puma, "Credentialing and Certification in Ethics Consultation: Lessons from Palliative Care," *The Journal of Clinical Ethics* 23, no. 2 (Summer 2012): 172-4.