

Not Justice but a Gift: Advocacy for Hospice Care

NICHOLAS PROBOL

nicholas.probol@sju.edu

Health Administration Department, Saint Joseph's University, Philadelphia, Pennsylvania, U.S.A.

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In my position as an account liaison working for a hospice company, I encounter ethical issues nearly daily as weighing out what is best for our patients. I would like to introduce one perennial problem which I believe is endemic to hospice organizations. Recently, a local hospital affiliated to our company needed a hospice care for a terminally-ill, incompetent patient. The case was what the hospital deemed as a safe discharge plan. The patient's son who was her durable power of attorney for healthcare (DPOA) demanded that a feeding tube should be placed. Meanwhile, we were informed that the patient, during the period of cognitive stability, had voiced that she would opt for DNI and DNR when she would become incompetent. In honor of the patient's wish, all the family members, except the DPOA, insisted that the feeding tube should not be placed. However, because there was found no documented living will which indicated the patient's alleged wish, an intense debate between the hospital staff and my clinical hospice team ensued over what to do with the patient. Since the patient was considered incompetent by two physicians and there was no documented living will, we were legally bound to follow the DPOA's decision. But we suggested that there should be a family meeting so that the DPOA's decision and the wish of the entire family may be in unison. After the meeting, the family was able to come up with an undivided answer to put the feeding tube in place.

So far, so good. However, a real, practical problem occurred. The patient had no healthcare insurance. The cost of the needed care, i.e., hospice care with the feeding tube service, was immensely high, and there was no financial resource for the patient or her family to offset the cost. Thus, my hospice organization had to decide whether to provide the service requested or not and, if we decided to provide, how long we could. Hospice companies like us rely on Medicaid and Medicare, and other insurance payer sources. However, these funding resources do not guarantee a full coverage at all. In many cases, we need to embrace a financial loss to provide the care requested and, if we do so, we cannot do it for all patients in the same situations. We select whom to get the service or not.

It is a reminiscent of the 1962 case of the Admissions and Policies Committee of the Artificial Kidney Center at Swedish Hospital in Seattle, which later become known as the "God Committee." However, the difference between the God Committee and the hospice organizations is that the former decided on whom to live and the latter would choose whom to die well. For both, what is at issue is justifiable criteria for the decision-making. In our case, it is incredibly difficult to legitimize being able to take a certain individual under our care while refusing to offer our helping hand to so many other patients in similar circumstances.

I believe that most hospital organizations including ours do not have formal committees to draft and implement any policies to admit or decline the patients. The reason for that, I believe, is not because most hospice organizations are small companies and thus do not have financial resources like major hospitals like Swedish Hospital in Seattle. It is rather that we do not wish to make it a high-profile case. Again, the hospice care does not offer aggressive treatment to heal but palliative care to die well; we provide not an active but passive care. More importantly, taking on the patients may place ourselves at financial risks, so we can offer the free service on some limited occasions while seeing the care as a gift for those who cannot financially afford. However, an extra caution

*Address correspondence to: Nicholas Probol, Health Administration Department, Saint Joseph's University, 5600 City Ave, Philadelphia, PA 19131., U.S.A. E-mail: *nicholas.probol@sju.edu*

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is always called for because a word of mouth travels fast. It is easy for community members to consider our decision to be a discrimination rather than a gift given to some people. But I want to emphasize again. It is not justice but a gift. To the family above, we approved to assist with the service, yet notifying the family their option to discontinue the feeding tube at any time if that were their wish. Also, as part of our standard of care we offer, we promised to assist with the family throughout their grieving process during and up to thirteen months after the event of death.