Disparities Between Preferences and Practice for End-of-Life Care

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The study by Dr. Biola et al.1 is one of those good-news-bad-news pieces that certainly points out some areas for growth and improvement, while on a positive note demonstrating that both skilled nursing facilities and assisted living facilities are doing a decent job of at least discussing residents’ preferences with respect to end-of-life care and life-sustaining treatment (LST). Although this study is of limited scope with about 300 residents from a small sample of facilities in 4 states, there are lessons to be learned from its results. Perhaps most importantly, this work highlights the need for improved processes to ensure that we do indeed provide care that is in keeping with our patients’ wishes. We should also be cautious when we use the words “life-sustaining treatment” because they imply to our patients that they actually do sustain life, when in fact we know that in our population, “successful” cardiopulmonary resuscitation (CPR) is a rarity—in spite of the fact that it works almost every time we see it done on television! So it’s good to start from that discussion point with our patients and their families. (Even the term “CPR” explicitly contains a reference to “resuscitation,” so it is no wonder that people think they will survive it, even without the TV shows!)

The good news is that we seem to be discussing and eliciting treatment preferences with our long-term care patients in most cases. This is not unexpected for residents of skilled facilities, where some discussion and documentation of code status, and so forth, in the form of a Preferred Intensity of Care (PIC) or Preferred Intensity of Treatment (PIT), or more recently a Physician Orders for Life-Sustaining Treatment (POLST), or its kin such as MOLST (Medical Order for Life-Sustaining Treatment), MOST (Medical Orders for Scope of Treatment) or POST (Physician Orders for Scope of Treatment) is part of the admission process for every resident. The finding that a large majority of assisted living residents had also discussed and clarified their preferences as to at least some aspects of advance care planning (most notably DNR [Do Not Resuscitate] status) is a bit more of a surprise, but a welcome one. Most residents of both assisted and skilled facilities did not want to be resuscitated with CPR. Preferences as to enteral feeding were also known for most residents of both types of facilities, again with most subjects in this study also not wishing tube feeding. When antibiotic use was discussed in advance, most residents chose in favor of receiving antibiotics to treat an infection.

Preferences as to whether or not to hospitalize were much less frequently discussed or known, and this is a potential growth area. This may be because most residents would want to be hospitalized if it were “necessary,” as that is standard care for someone who becomes seriously ill. Some patients (or families) may not want to consider a “Do Not Hospitalize” or “No Transfer to Acute” order because they fear it may equate to poor care or even “No Care.” However, it is probable that many patients are simply not given this option when discussing their preferences. In today’s skilled nursing facility climate (and the geriatric literature), with the ongoing trend toward more subacute care and a higher acuity level of residents, it is well known that a hospital transfer can do more harm than good. Many interventions can be implemented within the “home” (the facility where the patient is currently residing), and avoiding hospitalizations is certainly an admirable and usually preferable goal of treatment when feasible. What’s more, a “Do Not Hospitalize” order in the chart can help focus staff on more palliative goals of treatment when that is in keeping with the patient’s desires. Some PIC/PIT/POLST forms have a specific box or section for hospitalization, and those that don’t should have areas for free text to specify the desire not to be hospitalized.

But the decision whether or not to hospitalize is something that physicians, other clinicians, social services personnel, and nursing staff should cover with patients and families as part of the routine discussion of advance care planning in our facilities. All of us have seen the unfortunate results of our patients being treated in a manner that is not in keeping with their wishes, usually in the form of aggressive, heroic interventions. Dr. Biola and colleagues’ study demonstrates that this occurs much more often that we would like to think, and the numbers are sobering. One can only hope that with the advent of more enduring documents, especially those that carry the weight of an actual physicians order (that is to be honored across settings of care) like POLST, the instances of people being subjected to things like CPR, intubation/ventilation, tube feeding, and so forth, against their expressed wishes, will become a rarity. Interestingly, in this study population, the older the resident, the less likely his/her expressed wishes were followed. Also, residents of nursing homes were less likely to have their wishes honored compared to assisted living residents. This may relate to liability concerns and nursing-related issues that are less of an issue in the assisted setting. This study also parses out some interesting demographic and socioeconomic differences in preferences of care, which are rooted

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somewhat in cultural and educational issues that may be of interest for further research.

If there is a take-home message, it is that we have a responsibility to determine and honor our patients’ preferences for end-of-life care and life-sustaining (or not) treatments, and that we (and our facilities) are doing a surprisingly and unfortunately poor job at the consistent implementation of such orders. POLST and its kin may help us do better, but we must recognize that in crisis situations, the default action is to provide aggressive treatments, as it should be. So, careful education and improved advance care planning for our patients and their families should be a goal for all of us.

REFERENCE