Human Dignity and Advance Directives: A Black American Perspective

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Maintenance of dignity at the end of life continues to be of concern to both ethicists and laypersons. Even nine years after the Patient Self-Determination Act was enacted which encouraged the use of advance directives as a means of protecting patients' dignity, concerns about affronts to dignity remain all too real for those whose dignity is most threatened. Participants in a qualitative research study to determine the attitudes of Black Americans toward advance directives indicated that such directives did little to alleviate their concerns about threats to dignity. The results of this study were published in the Journal of Transcultural Nursing 11 (2000).

"Threats to dignity" was a central theme in semi-structured interviews conducted with seventeen Black Americans ranging in age from 23-74 years. This theme sought to measure ideas related to patients' feelings of usefulness, as well as to their sense of respect from others. Though all of the interview questions asked specifically about advance directives, the participants were invited to share additional information they felt was related to this topic.
Contrary to other reports frequently cited, subjects in this study did not indicate a desire for extraordinary treatment regardless of prognosis. Issues surrounding decisions regarding life-support machines were prevalent in the discussions. All of the participants indicated that they had discussed their wishes regarding life-support machines with their families. Two were adamant about their desire never to be placed on such a machine. However, it was more common for subjects to state that machines could be used if there was a chance for recovery than to starkly refuse them altogether. One participant verbalized this view as follows:

I really did think about it [the use of life-support machines] after this episode last year at the hospital. ...I don't want to be...just a vegetable, and yet if there's still a chance, I want [my husband] to do all he can for me. And, that's kind of a thin line. But, I think we've decided that at some point you don't want to be on a machine, just kept alive because of a machine.

Another subject expressed this sentiment when explaining why she opted for both a living will and durable power of attorney:

I don't want to be put on life-support machines when they know I'm dying - that's useless. If [I had] a temporary condition and normally people survive with it, [life-support would be] fine. If there is no hope I don't want people doing a lot of things to me.

All of the subjects expressed a desire to remain physically and cognitively active regardless of the intervention they received. They were very explicit in describing conditions in which they would not want to find themselves, stating that they did not want to "just lay there" or to "be a vegetable." They also indicated which cognitive states they deemed acceptable by insisting that any intervention must allow them to "be in my right mind" and to be "at myself."

Concerns about threats to dignity were also evident in subjects' statements reflecting their desire for respect from others with regard to their decision-making authority and their basic wishes. Participants discussed the importance of having made funeral and burial arrangements prior to their death so that family members would be relieved of that task. They saw this responsibility as being inherent to garnering respect from others and believed that they would be criticized if they burdened their families with tasks that they could have completed themselves. Participants also verbalized ideas about the conveyance of respect and disrespect from health care professionals. In an idea not mentioned elsewhere in the current literature, some subjects felt that completing an advance directive would cause white health care professionals to respect them as individuals who had thoughtfully planned. For example, when questioned about the importance of advance directives, one male subject stated:

People are treated differently if they have an advance directive versus not having an advance directive. Having an advance directive [is equated with] having a plan and
when doctors and nurses see that you have a plan, it commands respect. They will respect you more because you have made a plan.

Comments such as these seem to express a belief that Black American patients have to do something to merit respect from white health care professionals. In other words, Black Americans are not intrinsically respected, but must do something in order to earn respect. The idea of respect was also reflected in participants' stories about feeling disrespected in illness/care situations in which subjects' opinions were ignored or disregarded. One participant relayed the following experience of being informed about advance directives, upon admission:

Well, the way the nurse explained it to me I had to do it [submit a directive]. And, I hate for somebody to tell me I got to do it. Just ask me if I want to do it, and I probably would do it. So when they pushed and pushed and said I had to, I said no, I don't have to do anything. I can take care of my own business.

Black Americans' concerns about dignity were evident in the subjects' discussions about when further care becomes inappropriate. This study allowed for expression of opinions about specific contexts in which life-sustaining measures should be employed. That other studies have shown a strong bias toward extraordinary treatment regardless of prognosis might be explained by their focus on preferences regarding particular procedures rather than on other concerns. Such studies may not have allowed for an adequate assessment of issues of importance to the subjects. Rather than insisting that they be offered all available treatment, Black Americans, as well as all Americans, actually may be more concerned about how care will fit into their lives and whether or not it is consistent with the way they want to die.

Attention to maintenance of dignity for patients of any race should entail decision-making that considers the patient's roles, lifestyle, goals, beliefs, and relationships. Maintenance of dignity necessarily includes attention to ideas about characteristics of a desirable death. Information that does not allow for the explication of contexts should be used cautiously. Finally, no information should ever be applied stereotypically. Such would constitute one of the biggest threats of all to human dignity.


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