Advance Care Planning

Does It Benefit Surrogate Decision Makers in the Intensive Care Unit?

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Surrogate decision makers for patients receiving care in an intensive care unit (ICU) often suffer from stress-related psychological maladies (1–3). These painful outcomes are often precipitated or amplified by requests to make consequential “substituted judgment” decisions without the benefit of concurrent patient input or previous advance care planning (4–7). In this setting, surrogates frequently experience decisional conflict accompanied by negative emotions related to uncertainty (8).

Advance care planning is the process by which patients and family members reflect on the patient’s values and goals and discuss how these values and goals should inform future health care decisions in the event that the patient is unable to participate. Advance care planning has been shown to improve patient-centered outcomes, including completion of advance directives (9), increased likelihood that patient’s wishes are followed by clinicians and family members (6, 9, 10), increased use of palliative care services (11), and increased likelihood a patient will die in her/his preferred place (12). Little is known regarding the effect of advanced care planning on surrogates’ decision-making in the ICU and, specifically, regarding the uncertainty surrogates feel about their decisions.

In this month’s issue of the *AnnalsATS*, Chiarchiaro and colleagues (pp. 1528–1533) evaluate whether prior advance planning

discussions are associated with the burden of decision making on surrogates of critically ill patients (13). The authors’ approach was to enroll family members who were surrogate decision makers for critically ill patients with acute respiratory distress syndrome in several types of U.S. academic ICUs. The primary outcome was the surrogates’ score on the Decisional Conflict Scale, which measures the state of uncertainty about a course of action (8).

Included in this study were 471 self-reported surrogate decision makers representing 251 patients. Before usual family conferences in the early part of the patients’ ICU admission, surrogates were asked whether they had previously participated in advance care planning with the patient and how well they thought they understood the treatments the patient would want. Advance care planning was used to predict surrogates’ score on the Decisional Conflict Scale regarding the decision to continue life support.

The researchers found that after adjusting for important confounders, surrogate-reported advance care planning before the ICU admission was associated with lower decisional conflict for the surrogates. The benefits of advance care planning to critically ill patients have been amply demonstrated (6, 9–11); this study shows that benefits accrue to their surrogate decision makers as well.

The Decisional Conflict Scale has not been widely used in studies of critical care, but in other settings, high levels of decisional conflict are associated with vacillation between choices, delayed decision-making, physical signs of distress or tension, and questioning personal values and beliefs (11). By reducing decisional conflict, advance care planning can make surrogates feel they are able to make informed, value-based decisions and can increase surrogate satisfaction with these decisions (8). In this scenario, advanced care planning likely served as a supportive guide for surrogates in decision-making, a form of “shared decision making” between surrogates and patients.

Chiarchiaro and colleagues also found in their study that surrogates who participated in advance care planning gave a higher rating when asked how well they understood the patient’s treatment preferences. Although this understanding likely contributed to the decisional conflict results, previously surrogates have reported less guilt (14), reduced stress (15), and greater satisfaction (16) in making decisions when the patients’ treatment preferences were understood. Surrogates characterize decision making in this context as less stressful and more likely to be associated with higher satisfaction or consolation (14).

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The short-term benefits of advance care planning to surrogate decision makers in the ICU have been demonstrated by the authors; however, comparatively little is known about the effect of these benefits on long-term psychological outcomes for surrogates. Other studies have found that advance care planning reduces surrogate stress and depression scores assessed during an ICU stay (17) and results in improved psychological outcomes for surrogates approximately 3 months after hospital discharge (9). Decisional conflict theory also suggests that lower Decisional Conflict Scale scores are associated with higher postdecision quality of life (8); however, the longevity of these effects is not well understood. Future critical care research should focus on the potential effect of advance care planning on the long-term emotional burden surrogates experience, often for years, after ICU encounters.

One critical element of advance care planning was not fully captured in the study by Chiarchiaro and colleagues: It is likely that the quality, and not mere occurrence of prior care planning discussions, is the most important in

determining outcomes for surrogates.

Chiarchiaro and colleagues measured the occurrence of advance planning based on a single nonvalidated question that does not fully capture the core constituents of high-quality advance care planning. This measure of care planning activity likely overestimates the percentage of surrogates who engaged in high-quality advance planning. Whereas 57% of the study subjects indicated they participated in previous care planning, rates of advance care planning previously reported in the U.S. population are generally much lower (6). In addition, prior care planning may improve surrogates' feelings that they made value-based decisions and their satisfaction with these decisions. However, advance care planning does not consistently improve surrogates' decision-making accuracy (7).

We applaud the authors for bringing attention to the prevalence of decisional conflict in this population. Acting as a surrogate decision maker in the ICU is fraught with significant adversity that may have lasting negative effects, the ramifications of which are just beginning to be appreciated. The Chiarchiaro study highlights the potential benefits of advance

care planning to ICU surrogates and is a novel contribution to knowledge in this field.

During the last several decades, advances in the uptake of advance care planning have occurred with programs such as Respecting Patient Choices (<http://www.advancecareplanning.org.au>) and Physician Orders for Life Sustaining Treatment (<http://www.or.polst.org/>). However, rates of patient and clinician participation still have considerable capacity for improvement. Advance care planning is desired by patients (18); nevertheless, clinician initiative remains a significant barrier (19). The Chiarchiaro study highlights the need for improvement in the underuse of advance care planning in primary care settings before the development of a critical illness. Critical care researchers should continue to investigate ways of supporting surrogates and reducing the burden of decision making with a focus on improving surrogates' long-term psychological outcomes. ■

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