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# THE TOTAL PATIENT

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## The burden of care decisions: Helping surrogates follow through with patients' wishes

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The subject of surrogacy, “a solution to a problem created solely by advancing medical technology,” was recently discussed on *Pallimed: A Hospice & Palliative Medicine Blog*.<sup>1</sup> The entry was inspired by a very comprehensive review article published in the *Annals of Internal Medicine*, “Systematic review: the effect on surrogates of making treatment decisions for others” by David Wendler and Annette Rid.<sup>2</sup> The premise of the *Annals* piece was that, although surrogates often help make treatment decisions for patients who cannot do so themselves, there is an effect on the surrogate that has not been assessed. Wendler and Rid undertook their review to ascertain just how burdensome this responsibility is.

### STRESS ON FAMILY MEMBERS

The authors researched 40 studies of 2,854 surrogates and found that in more than 50% of cases, the surrogates were members of the patient's family. At least one-third of the surrogates felt “a negative emotional burden” such as anxiety or stress from the process. In one study, the surrogates, who were relatives, felt guilt about their treatment decisions. Symptoms of posttraumatic stress disorder among family members who had participated in making decisions were also present in several of the reviewed studies. Wendler and Rid wrote, “Our evaluation of more

than 2,800 surrogates indicates that this practice places emotional stress and burden on at least one-third of surrogates, which is often substantial and lasts months or, in some cases, years.”<sup>2</sup>

A group in Munich, Germany, also looked at the role that family members play in making decisions about life-prolonging treatment in seriously ill patients. The researchers followed 70 patients with terminal cancer in whom physicians were considering whether to

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limit life-prolonging treatment. They recorded the patients' wishes about end-of-life care, the roles of their family members, and how both groups felt about limiting treatment. More than half of the relatives were spouses (59%); 21% were children.

Although the family members were present during their relative's hospitalization, only 32% of them were involved in decisions to limit treatment. When patients did discuss their treatment preferences, their families were in agreement and supportive of

their decisions. However, one-third of the relatives “acted against the known or presumed wishes of patients.... In six patients (14%) who were unable to communicate, clinicians thought relatives did not represent authentic patient wishes. Five patients did not allow their relatives to play an active role in decision making.” The conclusion was that serious health care decisions should involve concerned relatives. The authors suggest that strategies be developed to ensure that treatment decision making is in the best interests of both the patient and the family.<sup>3</sup>

### SURROGATE CHARACTERISTICS

In another investigation, researchers in England constructed an empirical exploration of “what people want in a decision-maker whom they themselves select.” For the study, 30 undergraduate students were presented with a hypothetical scenario proposing that they were expected to lose mental capacity in the future and asking that they consider whom they would choose as surrogate.

Although the majority of the subjects said they would choose someone who was caring and competent, only a few of them stressed how important it was for the surrogate to know their preferences with regard to making important treatment decisions. The study participants were more concerned with the

surrogate's social role, honesty, and loyalty than with the attitudes and values they had in common.<sup>4</sup> However, studies conclude that everyone involved in the process derives maximum benefit and experiences reduced stress if the patient selects a surrogate early; if the patient explains his or her treatment preferences; and if the patient, physician, and surrogate share in the decision-making process.

### ADVANCE CARE PLANNING

In a recent study on advance care planning, Iowa gerontologists acknowledged that, by law, older patients must be able to determine their own health care. Although seniors often have the mental capacity to make their own significant treatment and end-of-life decisions, sometimes they do not. Older adults should plan for the possibility of losing their mental capacity. To do so, they should select a surrogate and discuss with him or her which decisions they would like that person to make for them. This

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should occur as part of advance care planning.<sup>5</sup> Documenting and then sharing these treatment preferences on an advance directive can further help patients guide their own health care and reduce the surrogate's burden.

### CONCLUSION

Choosing a health care surrogate is not an easy decision, and it can certainly be stressful for the patient and surrogate alike. Despite these challenges, the consensus of the studies reviewed was that, although it is difficult to make end-of-life decisions for someone else, most surrogates find their roles satisfying.<sup>2</sup> Moreover, quite a few of them felt that they had "honored their loved ones' wishes and values."<sup>1</sup>

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