Surrogate decision making for patients with end-stage dementia.

Abstract:
We aim to explore how health surrogates of patients with dementia proceed in decision making, which considerations are decisive, and whether family surrogates and professional guardians decide differently. We conducted an experimental vignette study using think-aloud protocol analysis. Thirty-two family surrogates and professional guardians were asked to decide on two hypothetical case vignettes, concerning a feeding tube placement and a cardiac pacemaker implantation in patients with end-stage dementia. They had to verbalize their thoughts while deciding. Verbalizations were audio-recorded, transcribed, and analyzed according to content analysis. By experimentally changing variables in the vignettes, the impact of these variables on the outcome of decision making was calculated. Although only 25% and 31% of the relatives gave their consent to the feeding tube and pacemaker placement, respectively, 56% and 81% of the professional guardians consented to these life-sustaining measures. Relatives decided intuitively, referred to their own preferences, and focused on the patient's age, state of wellbeing, and suffering. Professional guardians showed a deliberative approach, relied on medical and legal authorities, and emphasized patient autonomy. Situational variables such as the patient's current behavior and the views of health care professionals and family members had higher impacts on decisions than the patient's prior
Both the process and outcome of surrogate decision making depend heavily on whether the surrogate is a relative or not. These findings have implications for the physician-surrogate relationship and legal frameworks regarding surrogacy.