

Publication

The role of relatives in decisions concerning life-prolonging treatment in patients with end-stage malignant disorders : informants, advocates or surrogate decision-makers?

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This study examines the extent to which relatives of severely ill cancer patients are involved in the decision to limit treatment (DLT), their role in communicating patient wishes and the incidence of and reasons for disagreement with relatives.; This cohort study followed 70 patients with terminal cancer, for whom a limitation of life-prolonging treatment was being considered. 'Embedded researchers' recorded patients' wishes and the relatives' roles and disagreements with DLT.; Although 63 out of 70 patients had relatives present during their care, only 32% of relatives were involved in DLT. Physicians were more likely to know the end-of-life (EOL) preferences for those patients who had visiting relatives than those without them (78% versus 29%, $P = 0.014$). Most relatives supported patients in voicing their preferences (68%), but one-third acted against the known or presumed wishes of patients (32%). Disagreements with patients' relatives occurred in 21% of cases, and predominantly when relatives held views that contradicted known patient preferences (71% versus 7%, $P = 0.001$).; If relatives are to play an important part in EOL decision making, we must devise strategies to recognise their potential as patients' advocates as well as their own needs.

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