Original Research

Eliciting regret improves decision making at the end of life

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Abstract   *Introduction:* Management choices at the end of life are high-stake decisions fraught with emotions, chief among is regret. Our objective in this paper is to test the utility of a regret-based model to facilitate referral to hospice care while helping patients clarify their preferences on how they wish to spend the remaining days of their lives.
Methods: A prospective cohort study that enrolled consecutive adult patients (n = 178) aware of the terminal nature of their disease. The patients were at the point in care where they had to decide between continuing potentially 'curative/life-prolonging' treatment (Rx) versus hospice care. Preferences were elicited using a Dual Visual Analog Scale regarding the level of regret of omission versus commission (RgO/RgC) towards hospice care and Rx. Each patient's RgO/RgC was contrasted against the predictive probability of death to suggest a management plan, which was then compared with the patient's actual choice. The probability of death was estimated using validated Palliative Performance Scale predictive model.
Results: Eighty-five percent (151/178) of patients agreed with the model's recommendations (p < 0.000001). Model predicted the actual choices for 72% (128/178) of patients (p < 0.00001). Logistic regression analysis showed that people who were initially inclined to be referred to hospice and were predicted to choose hospice over disease-directed treatment by the regret model have close to 98% probability of choosing hospice care at the end of their lives. No other factors (age, gender, race, educational status and pain level) affected their choice.

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Conclusions: Using regret to elicit choices in the end-of-life setting is both descriptively and prescriptively valid. People with terminal disease who are initially inclined to choose hospice and do not regret such a choice will select hospice care with high level of certainty.

1. Introduction

Evaluation of the quality of decision making in the end-of-life setting over the last two decades continues to show that it is woefully inadequate [1–3]. There is widespread consensus that for the care of patients with a terminal illness would improve if the patients were provided with an accurate assessment of their prognosis, risks and benefits of the alternative management options (e.g. timely referral to hospice/palliative care versus continued treatment targeted at underlying disease), and have their true values, wishes and preferences elicited to enable them to pass the remaining time of their lives on their own terms [1]. Such practice is legally mandated in New York and California [4], and since January 1, 2016 the Center for Medicare & Medicaid Services has begun to reimburse providers for advance, end-of-life care planning discussions for Medicare beneficiaries [5]. However, the problem related to poor end-of-life care is not 'what' [needs to be done to improve quality of care of terminally ill patients] but 'how' [that can be achieved]. Practitioners and patients lack reliable tools that are fully integrated within the clinical workflow, that are capable of relating the patients' prognosis (life expectancy, probability of survival/death) to the patients' preferences to enable their true informed choices at the end of life.

Modern cognitive science increasingly accepts dual processing explanation of human cognition, according to which medical decisions can be truly consistent with patients' values and preferences only if they take into account both affect-based (type 1) and analytical (type 2) cognitive processing [6,7,8]. The extent to which one process dominates over another depends on the context of a decision situation [9]. Decisions at the end of life are arguably the most consequential decisions that any human has to make. These are high-stake decisions fraught with emotions. To date, however, elicitation of patient preferences in the end-of-life setting has typically relied on analytical reasoning using hypothetical vignette scenarios without an explicit attempt to tap into the emotional domain that characterizes the nature of terminal illness [1,10]. Frequently, a patient in the terminal phase of his or her life has to decide whether to forgo potentially life-prolonging treatment, or to accept a peaceful death that may involve hospice services. Facing such a decision, patient preferences become dominated by emotions, chief among which is regret

[10,11]. Because regret is a unique human emotion (i.e. type 1 process), which involves counterfactual deliberations (i.e. quintessential type 2 processes), we have previously proposed that regret, as a cognitive emotion, can activate both cognitive domains by serving as a link between type 1 and type 2 processes [8,12,13]. Theoretically, elicitation of (anticipatory) regret of omission (e.g. failure to be referred to hospice care) versus regret of commission (e.g. wrongly referred to hospice) can be linked to the estimates of the patient's prognosis (e.g. probability of death within certain time frame) via the regret threshold model [10,11,14–16]. According to the threshold model, a patient should accept referral to hospice if the probability of death within the time of interest is greater than the threshold probability at which the patient is indifferent between the hospice referral versus continuing treatment [10,11,17]. In this paper, we report the application of the regret threshold model to facilitate preference-based choices in the end-of-life setting. We demonstrate both descriptive and prescriptive validity of the model, which can be easily integrated within the workflow of a typical medical practice.

2. Methods

2.1. Eligibility criteria

All terminally ill patients (or their proxies) older than 18 years who were aware of the terminal nature of their disease were eligible for the study. Patients had to be at a point in their treatment plan when they were deciding between either continuing current treatment targeted at their disease (potentially 'curative/life-prolonging' treatment), or hospice care. The goal of the study was to a) help patients clarify their choices and b) assess whether the actual choices agreed with the predicted choices.

2.2. Study design

This was a prospective study in which consecutive patients meeting eligibility criteria were approached in Tampa General Hospital and H. Lee Moffitt Cancer Center & Research Institute, Tampa, Florida by registered nurses. Fig. 1 shows the study flow. We used two validated and widely used models to assess the patient's probability of death (expressed as a percentage between