



Original Research

Acceptable regret model in the end-of-life setting: Patients require high level of certainty before forgoing management recommendations



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Abstract Background: The acceptable regret model postulates that under some circumstances decision-makers may tolerate wrong decisions. The purpose of this work is to empirically evaluate the acceptable regret model of decision-making in the end-of-life care setting, where terminally ill patients consider seeking curative treatment versus accepting hospice/palliative care.

Methods: We conducted interviews with 48 terminally ill patients to assess their preferences about end-of-life treatment choices. We first elicited the patient's regret of potentially wrong choices with regards to the recommended management and provided information on life expectancy estimated by two prognostication models. We then elicited the patients' level of acceptable regret by assessing their tolerance for potentially wrongly accepting hospice care versus continuing unnecessary treatment. Using the levels of acceptable regret, we computed: (1) the probability of death above which a patient would tolerate wrongly accepting hospice care and (2) the probability of death below which the patient would tolerate unnecessary treatment. We also assessed patients' understanding of the interview questions using a 7-point Likert scale.

Results: We found that the median probability of death above which a patient would tolerate wrongly accepting hospice care was 96% (95% CI 94–98%), whereas the median probability of death below which a patient would tolerate unnecessary treatment was 2.5% (95% CI 0.3–5%). We also found that the levels of acceptable regret measured for wrong hospice referral (mean = 1.52; SD = 2.26; min = 0; max = 7.72) were similar to the levels of acceptable

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regret measured for unnecessary treatment (mean = 2.10; SD = 4.33; min = 0; max = 23) (KW test; $p = 0.68$) indicating that acceptable regret levels for either of the wrong decisions is felt similarly. The results were independent of the estimated probability of death communicated to patients before the acceptable regret interview.

Conclusions: We have elicited empirical data that corroborated the acceptable regret hypothesis. The requirement for high level of certainty before accepting recommended management may explain the difficulties related to decision-making in the end-of-life setting.

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1. Introduction

Medical decisions, particularly those with direct implications to patients' well-being, involve substantial uncertainties that affect every aspect of a clinical encounter. Decision tools relying on evidence-based prediction models are designed to manage clinical uncertainties and support clinicians in providing better care for their patients. However, regardless of the quality and quantity of evidence driving our decisions, there is no guarantee that a recommended strategy will be a correct one [1,2]. In turn, every patient faces the consequences of a wrong decision. For example, patients predicted at risk of a serious, life-changing event (e.g. stroke) may never experience the event (regardless of treatment); hence, any treatment targeting the event, and its associated harms, would be considered unnecessary in such cases. Or, as we will see later in this article, terminal patients who, based on the recommendation of a decision tool, chose treatment over hospice care may die within days of the decision, thus losing benefits of hospice care [3].

We have argued in earlier work that decisions resulting in undesired outcomes may bring a sense of loss or regret to the decision-maker [2,3]. This feeling of regret can be experienced in terms of omission (e.g. a patient loses benefits of treatment) and of commission (e.g. a patient incurs harms from treatment), both of which can be quantified using a dual analogue scale [2,3]. In our previous work [2], we showed that together regret of omission and regret of commission relate directly to patient's preferences towards alternative forms of treatment expressed via (pT) threshold probability (i.e. the probability of an event [pE] at which a decision-maker is indifferent between treatment choices). By contrasting the patient's preferences elicited via determination of the threshold probability and the estimated probability of an event generated by a prediction model, we can theoretically derive the optimal management strategy for the specific patient. If $pE > pT$, then the patient should accept recommended management; if $pE < pT$, he/she should not. This optimal strategy corresponds to the action that will bring the least amount of regret if, in retrospect, it is

deemed wrong. Recently, we provided an empirical evaluation of this model; 85% of patients agreed with the model's recommendations and the model predicted the actual choices of 72% of patients [4].

However, we have also postulated that there are situations where the regret resulting from a wrong decision may be tolerable [1–3,5,6]. For example, it is not uncommon that a physician order diagnostic test or administer treatment, but feels no regret because she/he judged them to be insignificant [6]. We model these situations as *acceptable regret*, which is formally defined as the utility a decision-maker is willing to forgo if she/he adheres to a decision that may be wrong [2,6]. Psychologically, acceptable regret represents a form of satisficing according to which people pursue a good enough outcome and not a maximally desirable outcome [7–9]. A *satisficer* evaluates his or her choices until they reach a threshold of acceptability [7,8]. In turn, he or she feels less regret [6]. However, despite strong theoretical appeal, acceptable regret has not been previously subjected to the empirical analysis. In this article, we report an empirical study of acceptable regret in the end-of-life setting, where terminal patients had to decide whether to continue with their current treatment, which may end up to be beneficial or harmful, or accept a peaceful death under hospice care. Specifically, we used acceptable regret to investigate the conditions under which patients are willing to forgo life-prolonging treatment versus hospice care, forfeiting the benefits of hospice care to undergo a potentially harmful treatment (and *vice versa*).

2. Methods

2.1. Participants

We conducted interviews with 48 consecutive enrolled patients capable to participate in the acceptable regret interview. These patients represent a subset of the larger study aiming at improving prognostication in terminally ill patients and facilitate hospice referral [4]. This prospective study was performed by University of South Florida researchers at the Moffitt Cancer Center and at the Tampa General Hospital. Patients included in the study were aware of their terminal status and, at the

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