Original Research

Eliciting regret improves decision making at the end of life

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Received 26 August 2016; accepted 29 August 2016
Available online 3 October 2016

KEYWORDS
Hospice referral; Decisions at end of life; Regret theory

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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http://dx.doi.org/10.1016/j.ejca.2016.08.027
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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...
0% and 100%) and life expectancy (expressed in terms of days/months of expected survival). These models were SUPPORT [18] and Palliative Performance Scale (PPS) [19]. However, because many of the variables in the SUPPORT model are not routinely collected in the end-of-life setting, few predictions were based on the SUPPORT model.

To avoid value-induced bias [20], we did not present the prognostic information to the patients until after their preferences were elicited. We elicited patients’ preferences using regret-based Dual Visual Analog Scale (DVAS) [11]. DVAS is specifically designed to be used in the context of the threshold model; DVAS is particularly suitable for high-stake decisions that are not easily reversible. Under such circumstances, people mostly rely on anticipatory regret to guide their decisions; anticipation of regret leads to more vigilant decisions, which in turn is expected to decrease post-decisional regret [21,22]. DVAS consists of two easily understood questions designed to elicit regret of omission versus regret of commission: 1) ‘On a scale 0 to 100, where 0 indicates no regret and 100 the maximum regret you can feel, how would you rate the level of your regret if you were not referred to hospice but instead continued to receive unnecessary treatment?’ and 2) ‘On a scale 0 to 100, where 0 indicates no regret and 100 the maximum regret you can feel, how would you rate the level of your regret if you were referred to hospice instead of continuing to receive necessary life-prolonging treatment?’ (see Appendix for the actual regret-elicitation script).

According to the threshold model [10,11,14], there must be some probability of death (pD) at which a patient in the terminal phase of life is indifferent (at ‘threshold,’ T) between choosing hospice care versus continuing treatment of their disease (‘curative/life-prolonging’ treatment), the choice of either of which can be regretted. If pD ≥ T, then the patient should choose hospice care; if pD < T, the patient should opt for treatment [10,11]. pD is estimated using predictive models such as those described previously; T is related to DVAS-elicited preferences according to [10,11]:

\[
T = \frac{1}{1 + \frac{\text{Regret of Omission}}{\text{Regret of Commission}}}
\]

Table 1

<table>
<thead>
<tr>
<th>Patient demographics.</th>
<th>(N = 184)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>Median 64</td>
</tr>
<tr>
<td></td>
<td>Min 25</td>
</tr>
<tr>
<td></td>
<td>Max 92</td>
</tr>
<tr>
<td>Gender</td>
<td>Male 107 (60%)</td>
</tr>
<tr>
<td></td>
<td>Female 77 (40%)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>White 139 (75%)</td>
</tr>
<tr>
<td></td>
<td>Black 19 (10%)</td>
</tr>
<tr>
<td></td>
<td>Hispanic 20 (11%)</td>
</tr>
<tr>
<td>Education level</td>
<td>(\geq)High School 79 (45%)</td>
</tr>
<tr>
<td></td>
<td>(\geq)College 96 (55%)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Localized cancer 36 (21%)</td>
</tr>
<tr>
<td></td>
<td>Metastatic cancer 119 (69%)</td>
</tr>
<tr>
<td></td>
<td>No cancer 16 (9%)</td>
</tr>
<tr>
<td>Pain levels (score: 0–10)</td>
<td>(N = 177)</td>
</tr>
<tr>
<td>Mean</td>
<td>2.62</td>
</tr>
<tr>
<td>Median</td>
<td>0</td>
</tr>
<tr>
<td>Min</td>
<td>0</td>
</tr>
<tr>
<td>Max</td>
<td>10</td>
</tr>
<tr>
<td>% of patients without pain</td>
<td>52% ((N = 92))</td>
</tr>
<tr>
<td>% of patients with mild pain (1–4)</td>
<td>20% ((N = 36))</td>
</tr>
<tr>
<td>% of patients with moderate pain (5–7)</td>
<td>14% ((N = 24))</td>
</tr>
<tr>
<td>% of patients with severe pain (8–10)</td>
<td>14% ((N = 25))</td>
</tr>
</tbody>
</table>

By empirically eliciting values about regret towards each of these options, we can determine a relationship between pD and T [11] and predict the patient’s choice. Thus, according to the regret threshold model, agreement with the choice of hospice versus treatment represents the patient’s true preferences.

After eliciting regret values and contrasting pD against T, we presented the model prediction to each of the patients who consented to the study. We started the conversation by first conveying the message in the following way: ‘based on what you told us about which treatment you would regret more and our assessment of how long you have to live, we think that you seem to prefer to receive care through hospice rather than treatment X (or, you seem to prefer to receive further care as treatment X rather than being referred to hospice).’ We then asked the patient if she/he agreed with our suggestions/recommendations (see Appendix).
Table 2
Patients’ comprehension and satisfaction with the preference elicitation interview process.

<table>
<thead>
<tr>
<th>The question/statement</th>
<th>Response* (N; %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patients’ comprehension of regret of omission1 (1 = major problem in understanding the question; 7 = perfect understanding) (N = 95)</td>
<td>1 = 0%; 2 = 2 (2%); 3 = 9 (9%); 4 = 26 (27%); 5 = 36 (38%); 6 = 22 (23%); 7 = 0% (median = 5; range: 2–6)</td>
</tr>
<tr>
<td>The patients’ comprehension of regret of commission1 (1 = major problem in understanding the question; 7 = perfect understanding) (N = 95)</td>
<td>1 = 0%; 2 = 3 (3%); 3 = 9 (9%); 4 = 25 (26%); 5 = 35 (36%); 6 = 23 (24%); 7 = 0% (median = 5; range: 2–6)</td>
</tr>
<tr>
<td>‘Do you find this information helpful?’ (Yes/No/Unsure) (N = 178)</td>
<td>‘It was the right decision’1 (1 = strongly agree; 3 = neither agree nor disagree; 5 = strongly disagree) (N = 108)</td>
</tr>
<tr>
<td>‘I would make the same choice again’1 (1 = strongly agree; 3 = neither agree nor disagree; 5 = strongly disagree) (N = 108)</td>
<td>‘It was a wise choice’1 (1 = strongly agree; 3 = neither agree nor disagree; 5 = strongly disagree) (N = 108)</td>
</tr>
<tr>
<td>‘The choice did me a lot of harm’1 (1 = strongly agree; 3 = neither agree nor disagree; 5 = strongly disagree) (N = 108)</td>
<td>‘I regret my choice’1 (N = 108) (change mind about regret (N = 178))</td>
</tr>
<tr>
<td>‘I regret a wise choice’1 (1 = strongly agree; 3 = neither agree nor disagree; 5 = strongly disagree) (N = 108)</td>
<td>‘I regret the choice that was made,’</td>
</tr>
<tr>
<td></td>
<td>c) ‘I would go for the same choice if I had to do it over again.’</td>
</tr>
<tr>
<td></td>
<td>d) ‘The decision did a lot of harm to me,’</td>
</tr>
<tr>
<td></td>
<td>e) ‘The decision was a wise one.’</td>
</tr>
</tbody>
</table>

a The numbers may not add to 100% due to rounding error.

b Data available from the last 95 patients as this assessment was not included at the start of the study.
c Data available from the last 95 patients as this assessment was not included at the close of the interview.
d At the one month of follow-up (the patients not interviewed died between the interview and the follow-up call).

Subsequently, we asked the patient if she/he is interested in learning the actual prognostic estimates related to their life expectancy/probability of survival, which was typically the case. To avoid framing effect [23], we presented data as survival probability (i.e. the percentage of dying as predicted by the prognostic model), probability of death (the percentage of dying as predicted by the prognostic model) and life expectancy (in days/months). We then re-iterated the process as many times as the patient desired, but most patients made their decision during the first round of the interview and rarely revised their level of regret (Table 2). Although the patients and their referring physicians enrolled in the study because they had not settled on the desired course of action, given the nature of their disease, the majority of patients who found themselves in the end-of-life setting had already given some thought as to how they wanted to spend the remaining days of their lives. We, therefore, also asked the patients about their initial inclination towards the choice of hospice versus continuing treatment (and before administrating DVAS); we did this to assess the differential effect of regret model above and beyond the patient’s commitment to one course of action over another.

To assess the descriptive validity of the regret model, we used a Likert scale (1–7 or 1–5) to ascertain the patients’ comprehension and their satisfaction with the process by responding to the following statements/questions: a) ‘Do you find this information helpful?’ and b) ‘How strongly do you agree with our best advice?’ We also used Decision Regret Scale (DRS) [24] to assess the post-decisional regret in follow-up via telephone on a monthly basis until the patient’s death. DRS consists of the following questions: a) ‘It was the right decision,’ b) ‘I regret the choice that was made,’ c) ‘I would go for the same choice if I had to do it over again,’ d) ‘The decision did a lot of harm to me,’ e) ‘The decision was a wise one.’ Because all our patients were aware of the terminal nature of their disease, we also predicted that default choice (hospice) would lead to the lower overall post-decisional regret than treatment strategy (change from the default) [21]. Fig 1 shows overall study design. A web version of the regret-based decision making tool can be accessed at: https://hsccf.hsc.usf.edu/ebm/.

2.3. Statistical analysis

Descriptive statistics were used to summarize the data on patient demographics and disease features. Pearson correlation and Cramer’s V statistics were used to assess the agreement between the regret model recommendations, the patients’ agreement with recommendations, and the actual choice about the enrolment into hospice versus decision to receive ‘curative/life-prolonging’ treatment. To determine the overall accuracy of the regret model, we also constructed receiver-operating characteristic (ROC) curve and calculated area under curve (AUC) of association between two variables tested. We employed the intention-to-treat analysis as in some cases patients, e.g., may have wished to receive treatment but in the judgements of their doctors that was not possible (e.g. high bilirubin preventing administration of chemotherapy). The nonparametric Mann–Whitney test was used to assess for the differences in post-decisional regret. We also performed a multivariable logistic regression analysis to assess the association of age, gender, race/ethnicity, type of diagnosis, pain level at the time of the interview, effect of initial decision
disposition, and the regret model recommendation with the probability of choosing hospice care. Because of the estimated high event rate (death), we assumed that between 170 and 200 patients would provide adequate power for the main goals of the analysis [25].

We also performed external validation of PPS model by calculating measures of discrimination (the ability of PPS to distinguish between different risk groups) and calibration (the accuracy of the prediction) at different time points [26]. For discrimination at specific time points, we used the area under the ROC curve. Model calibration was tested using methods as reported by Royston [27]. All statistical analyses were performed in STATA statistical software (version 14) [28].

All patients signed informed consent before participation in the study. Our study was approved by the USF institutional review board (#Study ID: Pro00000220).

3. Results

Between March 1, 2013 and November 30, 2015, we approached 1052 consecutive patients meeting eligibility criteria. One hundred eighty-four patients consented to the study, of whom 178 patients agreed to all aspects of the study (six patients consented to data collection but not to the interview). The low consent rate is indicative of the intense emotional state of the patients and their families when decisions on end-of-life treatment have to be made. Of 178 interviews, 170 were completed by the patients and eight by the patient surrogates. Fig. 2 shows the study flow. As of the last follow-up (December 31, 2015), 97% (172) of patients of the 178 patients were dead. Because the results remained identical when the data based on the interview with the surrogates (N = 8) were dropped from the analysis, we report all analyses based on the full data set (N = 178).

Table 1 shows patient demographics. Median age of patients was 64 years (range 25–92) of whom 60% were males; most patients were white (75%) and college educated (55%). The majority of patients had cancer (91%). Pain was well controlled at the time of the interview in the majority of patients (72% of patients [N = 128] had had either mild pain or were free of pain). Median time of the interview was 23 min (range: 5–60 min; N = 177). Eighty-eight percent (158/179) of patients received the material about hospice at the time of consent, which they reviewed before the interview.

Fig. 3 shows discrimination and calibration statistics of the PPS model at various time points. The estimates of the area under ROC curve at days 30, 60, 90 and 120 show good discrimination (AUC ranged from 0.70 to 0.81). The plot of the predicted versus observed probability for high versus low probability of survival (Fig. 3a) and test calibration slope = 1 (the slope did not statistically significantly deviated from 1) (Fig. 3b) also show that the model is well calibrated.

Fig. 4 shows the patients’ agreement with the regret model recommendations related to hospice referral versus further treatment. Eighty-five percent (151/178) of patients agreed with the model’s recommendations (Pearson chi-square test = 150.62; p < 0.000001; Cramer’s V = 0.92; AUC = 0.845). In fact, in no instance did the patients disagree with the proposed recommendations, but 15% (27/178) of patients were unsure about the suggested course of action.

If the model is descriptively correct, then we would expect that the patients would demonstrate comprehension of the questions asked during the interview and find the entire process of eliciting their preferences useful. Table 2 shows the results indicating the descriptive validity of the model. The majority of patients comprehended the DVAS regret questionnaire with no difficulties, which is probably why only 3% (5/178) of patients changed their minds about their level of regret at the end of the interview. In addition, the follow-up assessment demonstrated that few patients found our methods harmful (4%) and not helpful (4%). The vast majority of patients found that the interview and regret-based elicitation of their preferences were very helpful to enable them to make ‘the right and wise’ decision (93% and 89%, respectively), which they rarely regretted (2%) and would choose again (87%).

Because what people say often differs from what people actually do, and to evaluate if the model is prescriptively correct, we also assessed the agreement of the
model recommendations with the actual choice about treatment versus hospice referral (Fig. 5). The regret model predicted the actual choices for 72% (128/178) of patients (Pearson chi-square test \( Z^2 = 32.2473; p < 0.00001; \) Cramer’s \( V = 0.43; \) AUC = 0.715).

As explained, the patients eligible for our study were all aware of the terminal nature of their disease and the majority were given information about hospice services before elicitation of their preferences about the management choices. This means that at the time they consented to our study, patients had already contemplated the choice between hospice and treatment continuation. Although all patients expressed desire to discuss available management choices, 81 patients (45%) were
already leaning towards hospice care versus 51 (29%) who were thinking about further treatment versus 46 (26%) who were ‘not sure’ about further management before the interview. To further assess how the initial disposition towards hospice affects the actual decision to choose hospice, we performed a multivariate logistic regression. As seen in Table 3, the only two variables that were statistically significantly associated with the probability of hospice choice were initial disposition towards hospice care (odds ratio [OR] = 6.5; 95% CI: 1.45—29.12 with respect to ‘Not Sure’) and regret model recommendation for hospice (OR = 6.3; 95% CI: 1.43—27.8 with respect to ‘recommend treatment’).

Fig. 6 shows the probability of choosing hospice care as a function of these two variables. People who were initially inclined to choose hospice, rarely changed their minds, while those who were ‘not sure’ or were inclined towards treatment often changed their minds in favour of hospice care as a result of regret model recommendations.

Table 3

<table>
<thead>
<tr>
<th>Actual choice</th>
<th>Odds ratio</th>
<th>Standard error</th>
<th>z</th>
<th>P &gt; z</th>
<th>95% confidence interval</th>
<th>Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>1.018204</td>
<td>0.0175367</td>
<td>1.05</td>
<td>0.295</td>
<td>0.9844059</td>
<td>1.053162</td>
</tr>
<tr>
<td>Cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>0.5155111</td>
<td>0.4237897</td>
<td>−0.81</td>
<td>0.42</td>
<td>0.1029165</td>
<td>2.582070</td>
</tr>
<tr>
<td>2</td>
<td>0.9123048</td>
<td>0.6650747</td>
<td>−0.13</td>
<td>0.9</td>
<td>0.2185797</td>
<td>3.807764</td>
</tr>
<tr>
<td>2. Gender</td>
<td>1.584483</td>
<td>0.6829094</td>
<td>1.07</td>
<td>0.286</td>
<td>0.6808026</td>
<td>3.687686</td>
</tr>
<tr>
<td>2. Education</td>
<td>0.4428064</td>
<td>0.1901731</td>
<td>−1.9</td>
<td>0.058</td>
<td>0.1908299</td>
<td>1.027499</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>0.3054635</td>
<td>0.2256433</td>
<td>−1.61</td>
<td>0.108</td>
<td>0.0718098</td>
<td>1.299376</td>
</tr>
<tr>
<td>2</td>
<td>1.582397</td>
<td>1.101463</td>
<td>0.66</td>
<td>0.51</td>
<td>0.4044056</td>
<td>6.191752</td>
</tr>
<tr>
<td>Pain Level</td>
<td>1.10984</td>
<td>0.0787249</td>
<td>1.47</td>
<td>0.142</td>
<td>0.9657879</td>
<td>1.275379</td>
</tr>
<tr>
<td>initialDecision (hospice)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>0.2865171</td>
<td>0.2094535</td>
<td>−1.71</td>
<td>0.087</td>
<td>0.0683744</td>
<td>1.200624</td>
</tr>
<tr>
<td>2</td>
<td>6.494877</td>
<td>4.9722148</td>
<td>2.44</td>
<td>0.015</td>
<td>1.448553</td>
<td>29.12109</td>
</tr>
<tr>
<td>Recommendation</td>
<td>6.326332</td>
<td>4.777488</td>
<td>2.44</td>
<td>0.015</td>
<td>1.439945</td>
<td>27.79445</td>
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<tr>
<td>initialDecision#recommendation</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1 1</td>
<td>1.992873</td>
<td>2.25027</td>
<td>0.61</td>
<td>0.541</td>
<td>0.2179407</td>
<td>18.22305</td>
</tr>
<tr>
<td>2 1</td>
<td>0.195565</td>
<td>0.2010871</td>
<td>−1.59</td>
<td>0.113</td>
<td>0.0260648</td>
<td>1.46733</td>
</tr>
<tr>
<td>_cons</td>
<td>0.2202322</td>
<td>0.2986847</td>
<td>−1.12</td>
<td>0.265</td>
<td>0.0154333</td>
<td>3.1427</td>
</tr>
</tbody>
</table>

Logistic regression Number of obs = 165. LR $\chi^2$ (13) = 66.18. Prob > $\chi^2 = 0.0000$. Log likelihood = −78.715972.

a Hosmer–Lemeshow test shows a good fit: $\chi^2$(8) = 12.02; prob $\chi^2 = 0.1502$.

b Testing for interactions between ‘initialDecision’ and ‘recommendation’ was not statistically significant at conventional p < 0.05 value (p = 0.07).

c Reference category = not sure; 1 = inclined towards treatment; 2 = inclined towards hospice care.

d Reference category = recommend treatment.
Finally, we assessed post-decisional regret related to the patient’s choices 30 days after the original preferences elicitation. Fig. 7 shows that people who chose hospice had lower median post-decisional score of 5 (range: 0–55) than those who selected active treatment in the final days of their lives (median 15; range: 0 to 70; p = 0.05).

4. Discussion

About 2.6 million people died in the United States of America in 2014 and 55 million worldwide [2]. Many of them did not experience a ‘good’ death, mostly due to poor discussion about prognosis, and failure to elicit patients’ preferences about how they would like to live the final days of life. Inadequate care at the end of life often results in delayed referral to hospice services, and this remains the key barrier to better end-of-life care [1]. According to US Medicare regulations, patients are eligible for hospice care if their estimated survival is of less than 6 months and they choose palliation over disease-directed treatment [29]. However, median survival of patients referred to hospice is typically very short from 17.4 days to about 6 days in some studies [26]—indicating that patients often cannot reap the benefits of hospice services because they are referred to hospice only when death is imminent. Recently advocated system changes such as incentives for physicians to spend more time counselling patients and families, improvements in palliative training with an aim towards delivering patient-centred, family-oriented end-of-life care [1] will certainly improve the care of terminally ill patients.

However, in the final analysis it is the lack of easy-to-use appropriate tools that can reliably elicit patient preferences about the choices they face that has hampered better care at the end of life. In this paper, we report an empirical study using such a tool. We relied on regret approach as a dominant decision-making process in the most consequential decisions that people can face—making their decisions on how to live when their life journey approaches the end [8,12,13]. We showed that a simple tool consisting of two easily understood questions about regret of omission versus regret of commission [11] (that is at the heart of regret threshold model), is both descriptively and prescriptively valid. The patients enrolled in the study appreciated the help they received and found that recommendations about their care choices based on the model were highly consistent with their true values and preferences. At the
same time, our model demonstrated high predictive power related to the patient’s actual choice about hospice versus receiving further treatment. Most testing of decision models described in literature so far has relied on hypothetical, vignette-based scenarios in healthy people. This is the first time that a theoretical decision model has been satisfactorily tested in a real-life setting in people who actually face the very decision that model was designed to address.

Most interesting, when we evaluated the factors that can potentially be useful for improving referral to hospice, we found that only two factors (initial inclination towards hospice care and regret model recommendation for choosing hospice over treatment) had high statistically significant association with the actual choice of hospice care. As shown in Table 3, if the patient had an initial inclination towards hospice, there is 6.5 times higher odds that s/he would actually be enrolled in hospice versus those patients who were not sure how they want to spend the remaining time of their lives. If in addition to being inclined towards hospice, the patient actually prefers hospice over treatment, there is close to 98% probability that this patient will actually opt for hospice care \( p = \text{combined odds}/(1 + \text{combined odds}) = 97.6\% \) (where combined odds = odds of initial inclination towards choosing hospice \( \times \) odds of choosing hospice according to the regret model). Here, it is important to note that the patients who actually elected to have hospice care had lower post-decisional regret on DRS scale than those people who wanted to be treated, which typically included chemotherapy associated with adverse events, often leading to lower quality of life.

Interestingly, in a recent systematic review on the application of DRS in health care, which we used to assess post-decisional regret, Becerra Perez et al. [30] found that the median DRS score was 14.3 (standard deviation 2.2–34.5) across 59 studies in various health care settings. While many of the conditions studied in the literature are serious ones, none of them come close in consequentiality as those that are experienced by people whose lives are coming to an end. And, yet, the level of regret we observed in people who selected treatment (Fig. 5) was about the same as in diseases such as screening for melanoma, adjuvant treatment for breast cancer, fertility preservation etc. [30]. Most importantly, the regret experienced by people who chose hospice was much lower than the regret observed in patients who faced treatment choices for many other health conditions (Fig. 5). This observation is consistent with Decision Justification Theory, according to which ‘default’ choices are easier to justify leading to lower regret [21,31].

Aristotle posited that the test of a good life is found in the absence of deathbed regrets [32]. It could be that once patients fully accept the reality that their lives are indeed coming to an end, and that further disease-oriented treatment is not alleviating suffering, acceptance of hospice facilitates the ultimate goal of that each human presumably seeks: a peaceful, graceful exit of a life well-lived, with no regrets of unfulfilled potential weighing on the soul.

Although we believe we devised a tool that can improve decision making in the end-of-life setting, our study is not without limitations. Considerable research over several decades indicates that many factors determine peoples’ decisions. In general, these factors are classified as the effect of a) context or framing (e.g. people may make different decisions when identical information is presented in terms of gains versus losses), b) situational or contextual factors (e.g. emotions, pain, time pressure, cognitive load, social context), and c) individual characteristics of a decision maker [33,34]. These individual characteristics reflect such things as diverse cultural background, race/ethnicity, educational/numeracy level [35,36], and decision-making styles (i.e. intuitive versus deliberative reflective of dual processing theories) [33,34,37,38].

By presenting information in different formats and allowing as much time as possible, we successfully controlled for the effect of framing and time pressure. By using regret approach we aimed to activate both affect and deliberative aspects of dual processing decision making [13,38]. We decided against additional data collection to avoid interfering with clinical care and to avoid the extra burden on patients who found themselves in an already difficult phase of life. Our goal was to codify good medical practice while developing a new tool to facilitate end-of-life decisions that can be easily integrated into clinical workflow. Although we did not restrict time for discussion, we found that the median time for patients to decide on hospice versus continuing treatment was 23 min. That is, in patients who are aware of their terminal disease, further clarification of the way they wish to spend their remaining days can be easily accomplished within the typical time allotted to medical practitioners.

The fact that age, gender, race, college education, or pain level had no effect on the actual choice indicates that numeracy skills or cultural background do not appear to be as important for end-of-life decision making, while regret and inclination towards hospice are (Table 3). Nevertheless, we note that reflective of Tampa Bay demographics [39], the majority of patients consented to our study (75%) were whites. That is, it does not appear that we have selectively enrolled one racial group over another. Nevertheless, the future studies should attempt to enrol larger proportions of non-whites to evaluate more decisively if cultural background, religion, race, and ethnicity affect regret. We believe this will be unlikely because regret is a uniquely human emotion, which appears to be easily understood by people of all races and background regardless how it is elicited [13,40].
Finally, we should note that only 17% of eligible patients actually consented to our study raising the issue of generalisability of our findings. How well will our approach perform in other settings can only be addressed in the future research aiming to replicate our findings. Nevertheless, we should note that 17% of enrolment rates vary from 0% to 90% [41,42] with some studies reporting enrolment of only 1 patient for 68 patients screened [43]. Therefore, we believe that our study is typical of contemporary human study research.

In conclusion, we report empirical validation of regret threshold model, which can easily be used in clinical practice and which can facilitate decision making in the end-of-life setting. The methods we employed both respect the patients’ preferences and have a potential to decrease unnecessary aggressive care at the end of life [44].

Conflict of interest statement

None declared.

Acknowledgements

U.S. Department of Defense grant (#W81 XWH 09-2-0175: PI Djulbegovic). The authors want to thank the patients who participated in this study. Special thanks go to Mr. Orlando Fabelo for his invaluable help as well as the physicians, nurses and physicians assistants at the USF, Tampa General Hospital and Moffitt Cancer Center for helping with conduct of this study.

Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.ejca.2016.08.027.

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