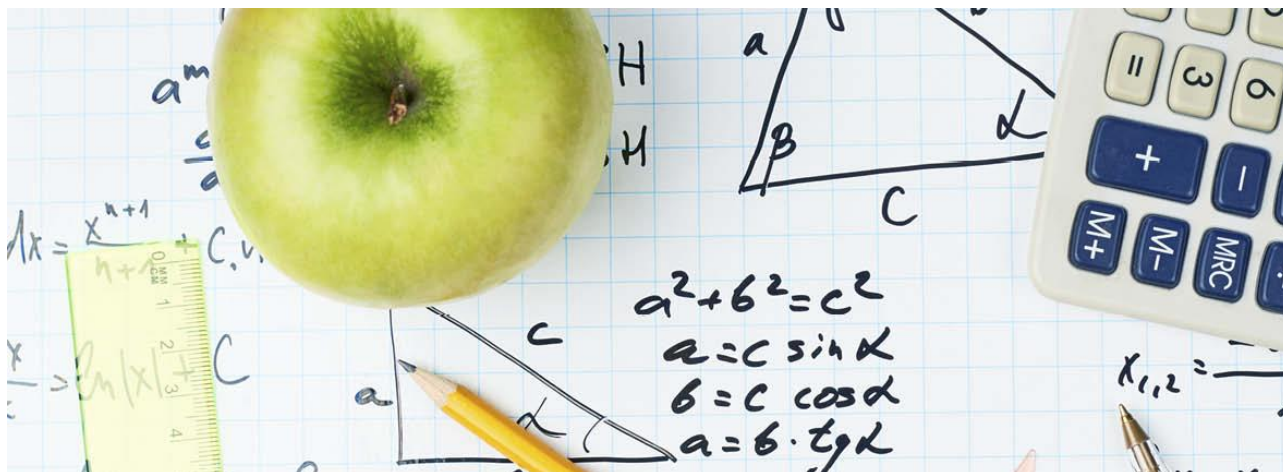**COHERE - Centre of Health Economics Research**

Is there additional value attached to health gains at the end-of-life?
A re-visit

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Summary

Researchers have in recent years sought to establish whether the general public value treatment at the end-of-life (EOL) more highly than other treatments. Results are mixed, with social preferences most often exhibiting lack of preferences for EOL treatments. This nul-result may be driven by the often applied study design, where respondents are to choose between treatments targeting patients with varying fixed life-expectancies. When remaining life is certain and salient, a rule-of-rescue sentiment may drive preferences across all scenarios. This study presents a different design, where the comparator is a preventive intervention. We study preferences from both an individual and social perspective, and find no preference for an EOL premium when age is held constant. We test the interaction between age and EOL treatment, and finder stronger preferences when patients face premature death.

Introduction

A pertinent issue in health policy in recent years is whether to place a premium on the value of health gains at the end-of-life. There are today various treatments available that offer limited extension of life, or improved quality of life, at the end-of-life. In 2009 NICE established that in cases of end-of-life treatment the Appraisal Committee should consider giving greater weight to QALYs (NICE, 2009). NICE's end-of-life (EOL) guidance for its Committees thus effectively advises them to deviate from the Institute's threshold range and to value the lives of EOL patients more than the lives of those suffering from other, potentially curable, chronic or acute conditions (Chalikidou, 2012). In the aftermath of this decision researchers have sought to establish whether the general public do indeed have a preference for an EOL premium (Pennington et al 2015, Linley and Hughes 2013, Shah et al 2014, Shah et al 2015, Pinto-Prades et al 2014, Olsen 2013, Rowen et al 2016, Skedgel et al, 2015). These studies apply different perspectives (primarily social but in some cases individual) as well as different comparators when measuring preferences. In all studies the perspective is *ex post* in the sense that respondents are asked to choose between providing treatment to others (or themselves) after diagnosis when they face a shorter or longer life-expectancy (LE) without treatment. The problem with this study design is that although analysts may define EOL as e.g. equivalent to less than 2 years of remaining LE, this definition is not necessarily shared by (all) respondents. The mere presentation of LE as certain and salient may be interpreted as a life sentence irrespective of whether LE is 1 or 10 years, thereby inducing an EOL premium for all. Rowen et al 2015 present LEs of between 3 months and 5 years, and find a preference for EOL treatment (defined as LE less than or equal to 2 years). Shah et al (2015) operate with similar LEs (3 to 50 months, also with a cut-off at 2 years), but find no support for an EOL premium. In Shah et al (2014) the trade-off involves 1 versus 10 years of remaining LE, and the authors find weak evidence of preference for EOL treatment. In contrast Olsen (2013) asks respondents to trade-off treating patients with 1, 3 or 10 years of remaining LE versus treating the young or obtaining larger health gains, and finds no preference for EOL treatment. The majority of the studies that look at how length of LE without treatment affects preferences demonstrate no support for EOL. Skedgel et al (2015) even find an aversion towards EOL treatment (when operating with LEs of 1 month, 5 years and 10 years).

Pinto-Prades et al (2014) apply a different methodology. Respondents are asked to trade off health gains targeting intermediate health states with health gains at the end-of-life; and find a preference for EOL treatments. This result is likely driven by the very different prospects characterizing the two health states: return to healthy state versus death. The difference in post intervention outcomes appears to be an important driver of preferences for EOL. The conclusion that can be drawn from this single study is that offering treatment to patients suffering from temporary conditions is prioritized less than offering treatment to EOL patients. Based on these results one cannot, however, infer that EOL treatment should be prioritized over all other types of health care interventions.

Pennington et al (2015) and Pinto-Prades et al (2014) found evidence of preference for EOL treatment when applying an *ex post* individual perspective, and measuring strength of preference by way of willingness-to-pay. However, in both cases respondents are asked to imagine that their

remaining LE is short, which is likely to generate a marked decrease in marginal utility of income. Such a decrease in marginal utility of income will *ceteris paribus* increase willingness-to-pay, and thus confound the association between willingness-to-pay and EOL treatment.

In the present study we seek to extend the aforementioned literature by applying an *ex ante* insurance approach (as opposed to the usual *ex post* perspective). Respondents are randomized to scenarios in which they are asked to act as either themselves or social decision makers. Our design also differs in choice of comparator. We compare EOL treatment (defined as death within a few months) with a preventive treatment, which offers the same expected health gain. An additional contribution is that we test for the interaction between end-of-life and age, in order to test whether there may be a stronger preference for EOL when the context is premature death. This is in contrast to most other studies, which have either ignored age altogether, or asked respondents to trade-off preferences for EOL with preferences for age.

Methods

A random sample of Danish respondents was asked to prioritize between having access to four different treatments. Respondents could not state indifference, but were to indicate the one treatment that they preferred. Respondents were either to make this choice from an individual or social perspective. The four treatments offered the same expected health gain (1 year in good health), but the context differed, see Table 1.

Table 1. The four treatment options as they were presented to respondents. Respondent could choose one preferred option.

	Treatment targeting disease A	Treatment targeting disease B	Treatment targeting disease C	Treatment targeting disease D
Typical age of diagnosis. If untreated the patient will die within a few months.	50-60 years	70-80 years	50-60 years	70-80 years
Probability of effect of treatment	The treatment is preventive: **5** have effect of treatment **out of 100** patients treated	The treatment is preventive: **20** have effect of treatment **out of 100** patients treated	Treatment is given after diagnosis: The treatment is effective for **all** patients treated	Treatment is given after diagnosis: The treatment is effective for **all** patients treated
Health gain IF the treatment has effect	**20** extra years in good health	**5** extra years in good health	**1** extra year in good health	**1** extra year in good health

End-of-life treatment was in the present study exemplified by a certain one-year extension of life after diagnosis of a disease with fatal outcome within a short time horizon without treatment (C and D) as opposed to treatments that are provided to avoid a fatal diagnosis and thus offer longer life extensions, but with a high degree of uncertainty (A and B). Premature death is exemplified as death that occurs when age is 50-60 (A and C) as opposed to age 70-80 (B and D). Respondents were randomized to one of the following two question frames (the original presentation was in Danish):

Individual perspective
"Imagine that you have a private insurance policy. The insurance company offers you a free extension of your policy such that it covers the cost of an extra health care service which is not covered by the national insurance scheme. You can choose between four health care services of which only one can be included in your insurance coverage. The treatments are expensive and difficult to access if one is not insured. There is an equal chance that you may need treatment for illness A, B, C or D which all have similar symptoms. The four treatments offer the same expected health gain (1 year). **Which treatment would you choose to include in your insurance policy?**"

Social perspective
"Imagine that one wishes to introduce one of four new treatment under the national health care service in a country where you do not live. There are available resources for this treatment under the present health care budget, due to efficiency improvements. There is a choice of four health care services of which only one can be included under the national health care service. The treatments are expensive and difficult to access if one is not insured. There is an equal chance that citizens may need treatment for illness A, B, C or D which all have similar symptoms. The four treatments offer the same expected health gain (1 year). **Which treatment do you think the politicians should choose to include under the national health care service?**"

Respondents (aged 25-79 years) were recruited from a Danish internet panel administered by Nielsen. The survey went online 19th of November 2013 and closed on 2nd of December 2013. We aimed at recruiting 2000 respondents. A general invitation was sent out (no information on the content of the survey was provided), and 3303 respondents chose to access the survey. Of the 3303 who accessed the survey 2000 finalised before the link was closed. Due to mode of operation (inviting a large number of panel members to participate by e-mail and closing when sufficient number of responses were obtained), a standard response rate cannot be estimated. The survey was relatively short, and involved warming up questions relating to age, gender, own health and supplementary insurance status.

Results

Out of the 1000 respondents aged +25 years who accessed the web-survey all respondents answered the insurance question (respondents had the option of leaving the question unanswered). Of these, 500 respondents were randomised to each of the two question formats. These respondents were representative of the Danish population with respect to age and gender, but those with higher levels

of education were overrepresented. There was no difference in age, gender, income or education level across the two split samples.

The results of the stated preference choice scenarios for both perspectives are presented in Table 2. Results are presented for all respondents, as well as for those under 50 years of age, in order to ascertain whether older age, and thus proximity to the hypothetical scenarios affect preference structures. Overall, preference structures are the same across age-groups.

Table 2. Choice of treatment across perspectives reported in percentages. Last columns: grouped by treatment type: preventive versus end-of-life treatment; and grouped by timing: 50-60 years versus 70-80 years.

	Treatment of disease A *Preventive* 50-60 years	Treatment of disease B *Preventive* 70-80 years	Treatment of disease C *End-of-life* 50-60 years	Treatment of disease D *End-of-life* 70-80 years	A+B vs C+D *Preventive* versus *end-of-life*	A+C vs B+D 50-60 years versus 70-80 years
Individiual perspective; All n=500	39.4% (n=197)	23.4% (n=117)	24.6% (n=123)	12.6% (n=63)	62.8% vs 37.2% (p<0.001)	64.0% vs 36.0% (p<0.001)
Aged 25-50 yrs n=233	42.5% (n=99)	19.7% (n=46)	27.9% (n=65)	9.9% (n=23)	62.2% vs 37.8% (p<0.001)	70.4% vs 29.6% (p<0.001)
Social perspective All n=500	42.6% (n=213)	14.6% (n=73)	34.0% (n=170)	8.8% (n=44)	57.2% vs 42.8% (p<0.001)	76.6% vs 23.4% (p<0.001)
Aged 25-50 yrs n=230	43.5% (n=100)	17.0% (n=39)	34.3% (n=79)	5.2% (n=12)	60.5% vs 39.5% (p<0.001)	78.8% vs 22.2% (p<0.001)

All percentages across treatment are statistically significantly different (p<0.001) except for B versus C (p=0.699) in the individual perspective, and A versus C in the social perspective (p=0.028) Our results do not indicate that end-of-life treatments are prioritised over treatments that are preventive. There is a preference for preventive treatments that offer longer life extensions (albeit with a small probability). More respondents prefer A to C and B to D, and this pattern is consistent across perspectives and age-groups. Also, A+B > C+D (p<0.001) for both the individual and social perspectives). Strength of preference is unaffected by perspective (p=0.750).

Our results demonstrate a preference for treatments targeting patients (potentially) facing premature death. A is consistently preferred to B and C is consistently preferred to D. Also, A+C>B+D (individual: p=0.041; social: p<0.001). However, the strength of preference is weaker for the individual perspective than for the social perspective (p<0.001).

Discussion

Our results suggest that irrespective of perspective, holding age-group constant, preventive treatments are prioritised over end-of-life treatment. This is despite positive time preferences potentially reducing the value of prevention due to the more distant timing of health gains; and despite the more equitable distribution of health gains generated by the end-of-life treatment, which may generate stronger social preferences. Thus, we cannot confirm that end-of-life treatments are valued more highly due to altruism (via the social perspective) or selfish motivations (via the individual perspective).

The study shows that treatment of patients facing premature death is prioritised over treatments of patients facing a more timely death. This is true irrespective of perspective, but the strength of preference is lowest for the individual perspective. The finding that young age groups are prioritised is in line with a number of studies (see e.g. Mak et al, 2011; Dolan & Tsuchiya, 2005). We find that EOL treatment targeting younger people is preferred over preventive treatments if these are offered to the older age-group. This finding is observed in the social perspective, but not in the individual perspective.

The simplicity of our questions can be criticised for not presenting varying degrees of life extensions combined with different degrees of prematurity of death. However, in order to reduce respondents' cognitive burden we opted for a simple design with very few programme attributes, and a clear definition of EOL. Also, we omitted the concept of willingness-to-pay and chose a framework of a constrained budget where opportunity costs are represented in terms of alternative health care services. We see this as an advantage of the study design as this this is more in line with real priority setting scenarios. Also, our design avoids the problem of marginal utility of income confounding results in the individual perspective.

In conclusion, our results complement the existing literature by measuring the preferences for EOL treatment *vis-a-vis* preventive interventions. We present results from both an individual and a social perspective. We find no evidence of a general preference for EOL treatment over preventive interventions. We observe that it is generally preferred to offer health gains to individuals who are young. This is also true for EOL treatments.

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