Are life-extending treatments for terminal illnesses a special case? Exploring choices and societal viewpoints

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ABSTRACT

Criteria used by the National Institute for Health and Care Excellence (NICE) to assess life-extending, end-of-life (EoL) treatments imply that health gains from such treatments are valued more than other health gains. Despite claims that the policy is supported by societal values, evidence from preference elicitation studies is mixed and in-depth research has shown there are different societal viewpoints. Few studies elicit preferences for policies directly or combine different approaches to understand preferences.

Survey questions were designed to investigate support for NICE EoL guidance at national and regional levels. These 'Decision Rule' and 'Treatment Choice' questions were administered to an online sample of 1496 UK respondents in May 2014. The same respondents answered questions designed to elicit their agreement with three viewpoints (previously identified and described) in relation to provision of EoL treatments for terminally ill patients. We report the findings of these choice questions and examine how they relate to each other and respondents' viewpoints.

The Decision Rule questions described three policies: DA – a standard 'value for money' test, applied to all health technologies; DB – giving special consideration to all treatments for terminal illnesses; and DC – giving special consideration to specific categories of treatments for terminal illnesses e.g. life extension (as in NICE EoL guidance) or those that improve quality-of-life (QoL). Three Treatment Choices were presented: TA – improving QoL for patients with a non-terminal illness; TB – extending life for EoL patients; and TC – improving QoL at the EoL.

DC received most support (45%) with most respondents giving special consideration to EoL only when treatments improved QoL. The most commonly preferred treatment choices were TA (51%) and TC (43%). Overall, this study challenges claims about public support for NICE's EoL guidance and the focus on life extension at EoL and substantiates existing evidence of plurality in societal values.

1. Introduction

In 2009 the National Institute of Health and Care Excellence (NICE) issued supplementary guidance for the appraisal of life-extending, end-of-life (EoL) treatments (NICE, 2009). This guidance permits such treatments to be recommended, even if they are not cost-effective according to usual standards, if certain criteria are met. These criteria are: 1) the treatment is for patients with short life expectancy normally less than 24 months, 2) the treatment would offer an extension to life of at least 3 months, and 3) the treatment is licensed for a small patient population (NICE, 2009). NICE, like other national Health Technology

Assessment (HTA) organisations, has adopted an approach to economic evaluation based on cost utility analysis and applies a threshold cost per quality-adjusted life year (QALY) of £30,000 (NICE, 2013). For technologies that meet the EoL criteria a threshold of £50,000 per QALY has emerged over time (The Parliamentary Office of Science and Technology, 2015) implying that life-extending QALYs for patients with terminal illnesses are valued 1.7 times more than QALYs gained from all other types of treatment.

By raising the threshold for, or giving additional weight to, life-extending health gains at the EoL, the supplementary guidance suggests that these health benefits are of greater value (to society) than other

types of health gains and that EoL might be considered a special case (Rawlins et al., 2010). However, empirical evidence of societal support for such a claim remains equivocal (Shah, 2017) and there is an opportunity cost to the EoL policy in terms of the health gains that would have arisen if spending had been allocated in other ways (Collins and Latimer, 2013). In this study, we examine societal preferences for provision of life-extending treatments for people with a terminal illness using two types of survey question, presenting respondents with choices between 'Decision Rules' (designed to reflect policies of the type that might be applied by national HTA organisations) and 'Treatment Choices' (of the kind that might be made by a regional health board with a fixed budget).

1.1. Background

Empirical studies that elicit societal values around EoL have deployed a variety of methods, including discrete choice methods (DCM) (Rowen et al., 2016; Shah et al., 2015a; Skedgel et al., 2015), person trade-off (PTO) (Pinto-Prades et al., 2014), budget allocation (Linley and Hughes, 2013) and willingness to pay (WTP) (Pennington et al., 2015; Pinto-Prades et al., 2014). The results of these studies have been remarkably mixed. In a recent literature review, Shah (2017) identifies 20 papers reporting empirical studies of societal values and EoL. Seven papers find a positive premium for EoL, nine negative and four report mixed findings (see Shah (2017) for a detailed summary of these papers). Of these studies only three examined preferences for different types of health benefit at the EoL; Pinto-Prades et al. (2014) and Shah et al. (2014) found a preference for quality-of-life improvements and Shah et al. (2015b) a preference for life extensions. The reason for such mixed findings is not clear (Shah, 2017) but it is difficult to explain wholly on the basis of study design, sampling or elicitation methods.

One possible explanation is that such mixed findings reflect substantial moral disagreement. This hypothesis is supported by the findings of the first phase of a two-phase study (funded by the Medical Research Council (MRC) Methodology Panel: project ID number G1002324) that used Q methodology to understand the nature of UK societal perspectives around the relative value of life extensions for people with a terminal illness (McHugh et al., 2015). Q methodology combines qualitative and quantitative methods to study 'subjectivity' – opinions, beliefs or values (Stephenson, 1953; Watts and Stenner, 2012). Data collection is via a card sort, and by-person factor analysis enables shared views around a given topic to be identified and then described; this methodology has previously been applied to the field of health (Baker et al., 2006; van Exel et al., 2015). Using this methodology we identified three viewpoints: i) 'A population perspective – value for money, no special cases', ii) 'Life is precious – valuing life-extension and patient choice', iii) 'Valuing wider benefits and opportunity cost – the quality of life and death'. These viewpoints (described in detail in the original paper) highlight the plurality of views that exist in society around this topic and indicate that current NICE EoL policy may find little support. The viewpoints in this first phase of work are based around statements of opinion, principles and values relating to the provision of life-extending treatments at the EoL. As such, they are more abstract than most preference elicitation tasks, which tend to describe specific (albeit hypothetical) choices and trade-offs. A clear strength of preference elicitation studies is that opportunity cost is presented in terms of the choice foregone or through WTP (both imply budget constraints). However, preference elicitation scenarios are often attribute-based, can be brief or unrealistic and support for policy tends to be inferred by aggregating responses to these tasks. In the context of EoL, preference elicitation studies have resulted in such mixed findings that simple aggregation and measures of central tendency likely conceal heterogeneity. Combining preference elicitation with other approaches might shed light on both the mixed findings in the existing literature and whether respondents are consistent between their viewpoints and stated preferences.

On the rare occasions that different approaches have been combined to examine societal values and EoL, inconsistent results have been found. Rowen et al. (2014) presented attitudinal questions to respondents, following a series of choice-based questions designed as a Discrete Choice Experiment (DCE). Despite their DCE results indicating some support for an EoL premium, responses to attitudinal questions suggested limited support for life-extending treatments and patients at the EoL. Shah et al. (2015b) explored whether respondents agreed with the policy implications of their responses to stated preference tasks. Respondents were first asked to make choices between pairs of scenarios that were either abstract or 'real-world' resource allocation decisions (the latter included qualitative descriptions of patients' quality-of-life and information about the ages of patients instead of conceptual diagrams depicting information about patients, medical conditions and treatments as used in the former), and then were asked to state their agreement (or not) with the implied policy implication of their choice. Results suggested that some respondents struggled to align their views with the need to make specific trade-offs around prioritisation decisions and that disagreement with the policy implications of their choice could result from respondents differing interpretation of policies. These results imply that responses to specific choices and trade-offs may not align with more general beliefs or views around life-extending EoL treatments and that further exploration of this could help us understand the mixed, empirical EoL findings.

In this paper we examine responses to specific choices as well as agreement with more abstract viewpoints in relation to the provision of life-extending treatments for people with a terminal illness ('terminal illness' and 'EoL' are used interchangeably as the NICE supplementary guidance uses the term 'EoL' (NICE, 2009) and their definition implies 'terminal illness'). Respondents were asked to make choices framed with respect to policies at a national level ('Decision Rule') and treatment provision at a regional level ('Treatment Choice'). One scenario in each case is designed to mirror NICE EoL guidance. We elicit respondents' support for the societal viewpoints identified in our earlier Q methodological work (McHugh et al., 2015). We then examine how choices between Decision Rules and Treatment Choices correspond to each other and to the wider societal viewpoints.

2. Methods

2.1. Survey design

The survey was split into different versions, one of which incorporated the Decision Rule and Treatment Choice questions. In addition to these policy choice questions (described in more detail below) respondents were asked to give Likert scale responses (Viewpoint Questions) to indicate (dis)agreement with the three viewpoints identified in McHugh et al. (2015). The questionnaire concluded with socio-demographic questions. Appendix 1 shows the script used in the introductory animation and Appendices 2-4 detail the text of each question (accessed online at: http://www.gcu.ac.uk/endoflife/onlinesurvey/).

2.2. Decision rule design

The Decision Rule (D) question (see Appendix 2) was designed to represent the types of high-level rules applied to coverage decisions, at a national level, by bodies like NICE and the Scottish Medicines Consortium (SMC) in the UK. Specifically, respondents were asked to select how a health system should assess drugs for terminally ill patients that would not pass a standard 'value for money' (VFM) test (used as a lay term for cost effectiveness – see 'Notes' in Appendix 2 for definition). Respondents were then presented with a choice between three mutually exclusive policies: DA – a standard VFM test applied to all new health technologies ('DA – standard VFM test'); DB – permitting 'special consideration' (i.e. provision of treatments even if the VFM is not passed)