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Priority to End of Life Treatments? Views of the Public in the Netherlands

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ABSTRACT

Objectives: Recent debates in the Netherlands on health care priority setting have focused on the relative value of gains generated by life-extending medicines for people with a terminal illness, mostly new cancer drugs. These treatments are generally expensive, provide relatively small health gains, and therefore usually do not meet common cost per QALY thresholds. Nevertheless, these drugs may be provided under the assumption that there is public support for making a special case for treatments for people with a terminal illness. This study investigated the views of the public in the Netherlands on a range of equity and efficiency considerations relevant to priority setting and examines whether there is public support for making such a special case. **Methods:** Using Q methodology, three viewpoints on important principles for priority setting were identified. Data were collected through ranking exercises conducted by 46 members of the general public in the Netherlands, including 11 respondents with personal experience with cancer. **Results:** Viewpoint 1 emphasized that people have equal rights to healthcare and opposed priority setting on any ground. Viewpoint 2 emphasized that the care for terminal patients should at all times respect the patients' quality of life, which sometimes means refraining from invasive treatments. Viewpoint 3 had a strong focus on effective and efficient care and had no moral objection against priority setting under certain circumstances. **Conclusions:** Overall, we found little public support for the assumption that health gains in terminally ill patients are more valuable than those in other patients. This implies that the assumption that society is prepared to pay more for health gains in people who have only a short period of lifetime left does not correspond with societal preferences in the Netherlands.

Introduction

Health care systems face an enormous challenge due to rapidly increasing demand for health care, beyond a level supported by available resources. Priority setting is essential to keep the health care system viable, which requires decision makers to make difficult choices regarding the treatments and technologies to fund within the health care system. Increasingly economic evaluations are used to inform such decisions, and in many countries, formal Health Technology Assessment (HTA) agencies have been established to inform health care decision making at the national level [1–3].

Economic evaluations inform decision makers about the costs and benefits of an intervention and help them to identify those interventions that represent the best value for money, generally expressed in terms of costs per gained quality adjusted life year (QALY). Such studies traditionally treat all costs and all effects equally [4,5]. That is, health gains receive equal value regardless of how they are generated or who benefits, and equal costs per QALY ratios are considered to be equally 'good'. However, an increasing body of literature suggests that valuing all health gains equally may not reflect societal preferences. Different studies have shown that people care, for example, about the nature and cause of illness and characteristics of the beneficiaries of health gains [6–16]. The social value of health gains apparently varies and depends on contextual information.

Many recent debates in this area have focused on the relative value of health gains generated by life-extending medicines for people with a terminal illness, mostly new cancer drugs [1,17–20]. These newly developed cancer drugs are generally expensive and often provide relatively small health gains, resulting in poor cost-effectiveness ratios. Because such small health gains may still be considered to be very significant to terminally ill patients and society, it may be appropriate to evaluate the cost-effectiveness of such interventions with greater flexibility. In England, for example, the National Institute for Health and Care Excellence (NICE) has made the decision to allow a higher cost-effectiveness threshold for treatments that provide short life extensions to terminally ill patients [21]. However, this has raised the question whether the implied higher social value of a QALY for end of life treatments is indeed in line with societal preferences.

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The empirical evidence for the relative value of end of life treatments is limited [1] and provides mixed guidance. None of these studies are from the Netherlands. Some studies find support for a higher value for treating people with a terminal illness [22–25], but others do not [26–28]. A recent study in the UK identified three viewpoints in a sample of people with professional expertise or personal experience in end of life issues in the context of priority setting and the value of life extending treatments. Only one of the three viewpoints was found to support the decision by NICE to raise the cost-effectiveness threshold for life-extending end-of-life treatments – contingent on there being significant benefit from treatments, value for money and good quality of life [1].

In the Netherlands, cost-effectiveness is an explicit appraisal criterion in drug reimbursement decisions, and guidelines for pharmacoeconomic evaluations recommend that such evaluations take a societal perspective [29]. Still, there is lack of transparency about how the outcomes of an evaluation study are weighted against other aspects in subsequent reimbursement recommendations and decisions [14,30]. First, although several explicit appraisal criteria are applied in reimbursement decisions, such as cost-effectiveness, added therapeutic value, medical need, severity and feasibility, ‘other’ (less explicit) criteria can also be considered. Second, there is no explicit guidance about the relative value of each of these criteria for reimbursement recommendations. Third, a bandwidth of acceptable cost-effectiveness ratios was recommended, from €10,000 for low severity to €80,000 for high severity [31,32]. However, although ‘proportional shortfall’ [14,33] is nowadays systematically used as criterion for severity taking into account the severity of shortfall in both quality and length of life, low and high severity of illness have not been formally defined, and there is no formal maximum on cost-effectiveness ratios either [30,34].

Recent policy recommendations imply that, based on severity of illness arguments, end of life treatments have a relatively high social value. Busschbach and Delwel, for instance, argued that “… if a patient for example has only few life years left (the life-threatening situation), we are prepared to pay more” [34]. Although this suggests that there is societal support for the provision of costly end of life treatments in the Netherlands, there actually is little empirical evidence for this.

Therefore, this study aimed to investigate the heterogeneity in views of the public on a range of equity and efficiency considerations that were shown to be relevant for health care decision-making, and to examine whether any of these views express support for making a special case for reimbursing costly end of life treatments.

Methods

Q methodology

We used Q methodology [35–37] to explore the diversity of views on health care priority setting in the Netherlands, and our work builds on methods and findings from three recent studies with similar aims [1,12,15]. This study differs from two of these studies [12,15] by its particular interest in the relative value of costly end of life treatments, and from the third study [1] by exploring end-of-life considerations within a broader context of societal preferences and by including a sample of people with personal experience with cancer. It differs from all three studies by focusing on the decision-making context in the Netherlands.

Q techniques are systematic methods designed to identify and describe the *nature* of subjective views. Respondent sampling has much in common with qualitative methods in the sense that a Q methodology study uses a purposive sample of respondents. These respondents are asked to rank a comprehensive set of statements about some topic, and to explain their ranking. The ranking is known as a “Q sort” and Q sort data are subjected to by-person factor analysis [35,38] in order to identify patterns in the ranking of statements. These patterns are then described and interpreted with each distinct ranking representing a different shared viewpoint on the topic of study in the population that was sampled.

Development of the research instrument

We followed several steps in order to arrive at a comprehensive set of statements that are relevant and representative for the decision-making context in the Netherlands regarding health care priority setting in general and in the end of life context in particular. Figure 1 presents a flow diagram of the process.

First, we gathered materials from three previous, related Q methodology studies: the Social Value of a QALY (SVQ) project from the UK [15], the European Value of a Quality Adjusted Life Year (EuroVaQ; http://research.ncl.ac.uk/eurovaq/) project which was conducted in 10 countries and an MRC Methodology Panel funded study on societal values and life extension for people with terminal illnesses (MRC EoL; http://www.gcu.ac.uk/endoflife/), also from the UK [1]. The SVQ and EuroVaQ projects focussed on principles for health care resource allocation in general and not specifically on end of life issues. The MRC EoL project was more similar to this study and aimed to examine values in relation to resource allocation, with a particular focus on the provision of end of life treatments. There were 46 statements developed for SVQ, 34 for EuroVaQ and 49 for MRC EoL.

Secondly, two researchers [SW, JE] used the conceptual framework dividing statements into different characteristics and dimension developed in the EuroVaQ project [12] to evaluate the pooled set of statements. This conceptual framework contained 23 characteristics potentially relevant for prioritisation of health care extracted from literature, in five domains: characteristics of the patient, characteristics of the illness, characteristics of the treatment, health effects of treatment and non-health effects of treatment. In an iterative process, the two researchers placed all 129 statements in the existing conceptual framework. During this process, one domain[1] was relabelled and a sixth domain added to the conceptual framework[2]. In addition, they combined[3] and added[4] some characteristics, and moved[5] several characteristics between domains. Finally, they placed one statement under a different characteristic[6] and disregarded several statements[7]. The

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[1] ‘Non-health effects of treatment’ was relabelled into a more general label ‘broader effects of treatment’.

[2] The sixth domain was labelled ‘moral principles’.

[3] The characteristics ‘socio-economic status’ and ‘payment/contribution’ were combined into ‘income/contribution’.

[4] The following characteristics were added: ‘availability’ (characteristics of the treatment), ‘side-effects/invasiveness’ (characteristics of thetreatment), ‘dignified end-of-life’ (broader effects of treatment), ‘patient choice’ (moral principles) and ‘values’ (moral principles).

[5] The following characteristics were placed under a different domain: the characteristic ‘having dependents/family effect’ was placed under the domain ‘broader effects of treatment and the characteristics ‘income/contribution’ and ‘equality’ were placed under the domain ‘moral principles’.

[6] The statement placed under the characteristic ‘waiting lists/waiting time’ was moved to the characteristic ‘equality’ and therefore the now empty characteristic ‘waiting lists/waiting time was removed from the conceptual framework.

[7] EuroVaQ statement #12 (and therefore the corresponding characteristic ‘health effects should be leading’) and SVQ statements #35 and #37 were disregarded because they were deemed irrelevant for the purpose of the current study.