Social preferences for prioritizing the treatment of severely ill patients: The relevance of severity, expected benefit, past health and lifetime health

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ABSTRACT

The study examined the preferences of a sample of the Australian public and health professionals regarding the relative importance of four different criteria for prioritizing between patients: the severity of the condition, the size of the benefit from the intervention, past health losses and expected lifetime health. A discussion-group methodology was adopted to elicit social preferences. This allowed participants time to consider all of the alternatives fully, to seek clarification of the task, and to engage in open debate about the issues raised. Participants traded-off cost-effectiveness for priority to the more severely ill. They placed less importance on past health and the lifetime allocation of health in deciding priority for treatment, and more importance on improving the condition of those who will be left more severely ill or disabled in the absence of treatment. The results pose a challenge to studies reporting support for the "fair innings argument". They also support the Norwegian government's decision not to pursue a life-time health loss criterion as recommended by the Norheim Commission. The study question is important given current debate both in the health economics literature and at the policy level in several jurisdictions

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1. Introduction

A number of studies have reported that members of the public, when asked to adopt a social perspective, judge health benefits to be more important when they are received by more severely ill patients, even if this implies reducing health benefits overall [1–5]. A smaller number of studies have reported a social preference for giving lower priority to the more severely ill if this will maximise health [6–9] but the evidence in these cases has been challenged [10,11]. In the case of Dolan and Tsuchiya [7], for example, Nord speculated that the results may have stemmed from a "fatal misunderstanding" on the part of respondents: they may have mistaken health scenarios referring to prospects without treatment for effects of treatment [10]. In the case of Dolan and Green, the authors themselves describe the results as "puzzling" [6]. In a review of the evidence in 2009 Shah [12] concluded that, on balance, the weight of evidence in support of the severity hypothesis far outweighs the evidence against. Support for severity can also be found in official government guidelines in several countries, and in reports of government-appointed commissions [13–17].

Implicitly entering into this debate, a recent Norwegian commission chaired by Professor Ole Frithjof Norheim (hereafter the Norheim Commission) recommended a number of controversial changes to guidelines for priority setting in health care for Norway [18]. Compared with previous Norwegian guidelines [16,17] the Norheim Commission report placed less emphasis on severity of illness and more emphasis on lifetime health. This implies that, all else equal, patients who have had worse health in the past should be given higher priority for treatment and, more generally, that people facing the prospect of less than their "fair share" of health over the course of their lifetime should be prioritised more highly than others. An implication of these recommendations is that severity of illness – defined as health-related quality of life in the absence of treatment [12] – is only considered to be of secondary importance.

Supporting the position taken by the Norheim Commission, a number of recent preference studies have detected support for the "fair innings argument" [19–22]. But again, the validity of these studies has been questioned. For example, in the public consultation process following release of the Norheim Commission report, the study by Ottersen, Maestad et al. [19] was criticized for failing to clearly distinguish the life-time health loss criterion from the severity criterion. In particular, given the way the questions were framed, it is possible subjects thought they were being asked to compare scenarios starting at birth. If so, there would be no way of distinguishing between support for the "worst off" in terms of their

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expected lifetime allocation of QALYs (the "fair innings argument"), and the "worst off" in terms of their health status after treatment (severity as conventionally understood). The results, therefore, cannot be unambiguously attributed to support for the "fair innings argument".

In response to criticisms of the Norheim Commission recommendations, the Ministry of Health and Care Services in Norway decided not to pursue a lifetime health-loss criterion, and set up a working group to investigate alternative ways of incorporating societal concerns for severity of illness. The working group recommended that absolute shortfall of QALYs (quality-adjusted life years) be used as a measure of severity at the group level [23]. Absolute shortfall is defined as $QALE_N – QALE_D$, where $QALE_D$ is the expected number of remaining QALYs for the patients in question and $QALE_N$ is the normal (average) number of remaining QALYs for people of the same age and gender [24]. Unlike the lifetime health-loss criterion, which includes past health losses in the assessment of severity, the absolute shortfall criterion focuses on the reduction in future QALYs from illness or injury.

The absolute shortfall criterion also has controversial implications. For example, it implies that, other things being equal, one health state is more severe than another if it affects younger people – since younger people have more remaining life years, which increases their QALY shortfall if they become sick or die. That is, age enters into the absolute shortfall criterion indirectly. While the evidence suggests widespread social support for the severity criterion, there is less support for age as a priority-setting criterion, at least in the way implied by absolute shortfall [25,26]. By combining age and severity into the one criterion absolute shortfall conflates two notions that arguably should be kept separate. An alternative would be to use proportional shortfall and age as separate criteria, where proportional shortfall is defined as $((QALE_N – QALE_D)/QALE_N) \times 100$. This would allow greater flexibility [24].

The present study examined the preferences of a sample of the Australian public and health professionals regarding the relative importance of the severity of illness, expected benefit, past health and lifetime health for priority setting. It differs from the studies cited above in adopting a discussion group methodology. In-depth, small-group discussions allow participants time to consider alternative principles and arguments carefully, to seek clarification of the task, hear alternative views, and to construct "deliberative" rather than "spontaneous" preferences [27,28]. The approach can provide greater insights into the reasons for participant's choices and thus provide a basis for determining whether preferences for "inefficient" health services – services where conventionally measured benefits are less than costs – are justified or not: whether they are based on defensible ethical views or, alternatively, on irrelevant or mistaken assumptions, framing effects, or a misunderstanding of the survey questions.

In part 2 we describe the survey and outline the study design. Part 3 details the research questions. Part 4 presents results, which are discussed in part 5. Conclusions are presented in part 6.

2. Survey and study design

The study took place in Victoria, Australia, and involved eight semi-structured, small-group discussions; six with the general public and two with health professionals. Overall, 61 people participated, with the size of groups varying between four and ten people. Sessions ran for 2 h which included a short break. Informed consent was obtained from all participants. The study received institutional ethics committee approval (MUHREC No. CF12/1521).

The study was based on a sequence of questions (13 in total) each of which asked participants to divide a fixed budget between two

groups of patients, A and B. Questions were divided into three sections in which groups A and B differed with respect to the following pairs of attributes:

Part 1: Severity and health maximization (5 questions)

Part 2: Severity and past health (4 questions)

Part 3: Severity and expected lifetime health (4 questions)

Each of the eight sessions followed a similar format. They began with a general introduction to the topic. This was followed by a preliminary question designed to provide information about the pre-deliberative preferences of respondents. Respondents then discussed and answered the budget allocation questions. One question in each part was singled out for an in-depth discussion. For these three questions respondents were asked to indicate on a Likert-type item their support for a number of arguments in favour of allocating the budget to group A, to group B, or equally.

Discussions were recorded and loaded directly into NVivo 9 software program for analysis. Codes were developed and modified to reflect the main themes that arose in the course of the discussions. These were subsequently analysed for intra- and inter-group variation.

3. Research questions

3.1. Preliminary question

After a general introduction each session began with a question used by Nord in an earlier study. This required participants to choose between giving priority to those who will benefit most from treatment, those who are more severely ill, or treating both groups equally [29,p. 32]. The purpose of this question was to determine whether the small sample in the present study had similar views to the larger, more representative sample in the Nord study. Similar results would increase confidence that our participants were not atypical. It also introduced the main topic of the survey.

3.2. Budget allocation questions

After this preliminary question each session was divided into the three parts described above. Respondents were asked to adopt the perspective of a health service administrator and allocate a budget of $1 million between two groups of patients. In each part groups A and B were described as experiencing a loss of quality of life in the age range 20–40, which was chosen due to the importance of the social and economic contribution of people in this range.

Visual aids adapted from Lancsar, Wildman et al. [8] were used to illustrate the patient health profiles. The level of health depicted in the diagrams was given a numerical value – a percentage of health where 0% represents death and 100% represents full health – and a corresponding health state description derived from the EQ-5D-5L multi-attribute utility instrument (www.Euroqol.org). In Fig. 1 below, percentages are used to illustrate the different levels of health and severity experienced by groups A and B. This is the information participants received. In later figures, which present results, the EQ-5D-5L crosswalk values are also included.

There were two reasons for using health state descriptions from the EQ-5D-5L. First, respondents could be thinking of very different health states when the only information provided is a percentage of full health. With the additional use of descriptions there was a greater chance that respondents would be associating similar health states with the diagrams, which is a prerequisite for valid interpersonal comparisons both within and between groups. Second, thinking abstractly is more difficult for some people than others. Using descriptions catered for those who think verbally,