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Preferences for end-of-life care among community-dwelling older adults and patients with advanced cancer: A discrete choice experiment



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ABSTRACT

Singapore is in the midst of several healthcare reforms in efforts to finance and deliver health services for a rapidly aging population. The primary focus of these reforms is to make healthcare services, including those at the end of life (EOL), affordable. Given the increasingly high health care costs at the EOL, policy makers need to consider how best to allocate resources. One strategy is to allocate resources based on the preferences of sub-populations most likely to be affected. This paper thus aims to quantify preferences for EOL care both among community dwelling older adults (CDOAs) and among patients with a life-limiting illness. A discrete choice experiment was administered to CDOAs and advanced cancer patients in Singapore and willingness to pay (WTP) for specific EOL improvements was estimated. We find that patients have a higher WTP for nearly all EOL attributes compared with CDOAs. We also show that, for both groups, moderate life extension is not the most important consideration; WTP for one additional life year is lower than common thresholds for cost-effectiveness. Irrespective of whose preference are considered, the results highlight the importance of pain management and supporting home deaths at the EOL, perhaps at the expense of public funding for costly but only marginally effective treatments.

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1. Introduction

Singapore's life expectancy, currently 82 years, is one of the highest in the world and the number of citizens aged 65 years and older are expected to triple to 900,000 by 2030 [1]. With rising rates of chronic disease, most

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Singaporeans die at an advanced age following a period of prolonged illness. This is partly due to the availability of modern life extending treatments; treatments which are in many cases only moderately effective at extending life but that come at significant cost. This is cause for concern for both patients and policymakers because, despite the disproportionate costs, many patients spend this period in significant pain, and do not die in their preferred location. Previous reports from Singapore reveal pain to be present in 82% of patients referred to hospice care services [2]. Further, only about 30% of all cancer patients die at home [3]. This is largely due to the institutional focus on extending life, with less emphasis paid to other factors that may be important at the end of life (EOL) [4].

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Due to a focus on individual and family responsibility, health services in Singapore have historically been financed out of pocket or via an individual or family member's health savings account (termed Medisave). Yet, the aging population has forced Singapore to revisit how best to finance health services at the EOL. In 2012, the government committed to doubling its yearly healthcare expenditure from \$4 billion to \$8 billion over the next 5 years. The focus of the planned healthcare reforms are to make health services, including those at the EOL, more affordable and accessible, especially for older Singaporeans [5]. One of the components of these reforms is to extend Medishield coverage (a low-cost catastrophic health insurance plan offered by the government) for older adults from 85 years to include lifetime coverage by end-2015, and to expand benefits. Though the entire benefit package has yet to be fully articulated, it is expected that under the reformed Medishield (termed Medishield Life), subsidies for life-extending treatments. such as chemotherapy, will be increased [6]. At the same time, the government plans to increase spending in palliative care in the coming years, which should provide greater access to quality EOL care.

In making coverage decisions, many governments consider preferences of its relevant constituents [7,8]. In Singapore, for EOL care, the largest constituents consist of older adults and those with life limiting illnesses as they are the ones most immediately affected by any health care reform concerning coverage for EOL treatments [9]. Yet, it is likely that preferences and willingness to pay for life extending treatments among these two groups differ. This is partly because a community dwelling older adult with years or decades of expected life remaining will discount the value of additional months or years lived in poor health at the EOL. In contrast, a patient with a limited prognosis is likely to see any life prolongation as immediate (i.e., no discounting) and large by comparison [10-12]. As a consequence, patients are expected to have a much greater willingness to pay (WTP) for life prolonging treatments even if there is a minimal chance of success. For analogous reasons, and because of diminishing alternative spending options, patients are also likely to have a greater willingness to pay for all factors associated with a quality EOL experience.

The objectives of this paper are, thus, to (1) quantify preferences for EOL care and (2) compare WTP for specific EOL improvements between community dwelling older adults (CDOAs) and patients with a life-limiting illness as well as to (3) discuss the implications of our findings for Singapore policy makers. Specifically, we use a Discrete Choice Experiment (DCE) to measure preferences for EOL care among CDOA aged 50+ and advanced cancer patients in Singapore (Table 1). EOL aspects considered include extending life by another year, being free of pain, being able to die at home, not being a burden on family/friends, and receiving quality health care services.

Discrete Choice Experiments (DCE) are a powerful method for examing EOL preferences. They are increasingly being applied to the analysis of medical decision making for a wide variety of medical treatments and outcomes [13–23]. Not only will these results allow for comparing preferences between CDOA and patients, they

will allow policy makers to consider preferences and WTP among both groups when making coverage decisions for EOL care in the ongoing health system reforms. Moreover, Singapore presents an ideal testing ground for such a study because to date roughly three-fourths of all health expenditures are financed through direct cash payments or through patient's or family member's health savings accounts (termed Medisave) [24,25]. As a result, cost is a significant factor when considering treatment options and patients are used to taking into account the financial implications of various treatments.

2. Materials and methods

2.1. Sampling design for CDOAs and the advanced cancer patients

The sampling frame was a list of 5000 households (based on a target sample size of 1500, assuming 60% response rate and eligible respondents in 50% households) drawn from the Singapore national database of dwellings using a 2-stage sampling strategy. The primary sampling units for the first stage of sample selection comprised sampling divisions demarcated based on the Urban Redevelopment Authority planning areas. Households were the sampling units in the second stage of sample selection. Of the 5000 households, respondent eligibility could not be determined in 1196 households (mainly due to households being locked or inaccessible); 1696 were found to have at least one eligible respondent (>50 years and Singapore permanent resident or citizen). For households with multiple eligible respondents, one was randomly selected to take the survey. Of those selected, 1067 participants consented (response rate: 63%). 542 of these participants were randomly selected to receive the DCE that is the focus of this analysis; the remaining 525 participants received another survey. Each participant had an equal probability of receiving the DCE or the other survey. The DCE administered to the 542 participants also consisted of an internal validity test which consisted of a task in which respondents were asked to choose between two scenarios where one was superior to the other in all attribute levels. Those who chose the inferior alternative (3.7% of the sample) were excluded out of concerns that their data may be invalid. This left a total sample of 522 respondents for the current analysis (Appendix, Fig. 1).

Between February 2012 and April 2013, 332 advanced cancer patients were interviewed in outpatient clinics at a national cancer center that receives about 70% of all cancer patients in Singapore [26]. The inclusion criteria for selection of patients were age ≥ 21 years, diagnosis of a stage IV cancer and Singapore permanent resident or citizen. Patients too sick to answer the survey, cognitively impaired and not aware of own diagnosis were excluded. As many advanced cancer patients in Singapore are expected to be unaware of their diagnosis [27], patients were selected either through referrals from treating physicians or approached directly at the outpatient clinic by trained interviewers after confirming the patient's diagnosis from medical records and that the patient is aware of their condition. The surveys were approved by the

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